

**WE WERE
RELENTLESS**

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A Family's Journey
to Overcome Disability

Martin J. Levin

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Library of Congress Control Number:	2008909567
ISBN: Hardcover	978-1-4363-7927-4
Softcover	978-1-4363-7926-7

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I want to thank my wife Mollene—whose calm, rational, but assertive approach to the world was the force that kept us going in the face of adversity.

To Brian—for surviving and thriving during our journey.

To Helen and Sid Kraizman—for leading us down the right path.

To Karen Pawlick—for being a fabulous tutor and providing much needed advice.

And most of all to Jordan—whose “never say die” personality made his success a reality.

“Don’t look back. Something might be gaining on you.”

Satchel Paige

Chapter 1

The high pitched scream broke the silence. The tiny collection of skin, bones, and blood that moments before we thought to be a miscarriage, cried. The baby that wasn't to be, was born three months premature.

Although Mollene had been spotting a bit, we were assured that we shouldn't be concerned. She had an appointment with the ob-gyn at ten o'clock on the following morning.

But then I received an unexpected, hysterical call at my office.

"Marty, the doctor didn't get a heartbeat and has scheduled me for an ultrasound prior to having a D & C," Mollene sputtered faster than her normal rate of speech, which at its slowest rivaled the speed of sound.

"Slow down and say it a little slower." I urged her.

She repeated herself, but the message remained the same. We had been cruising along enjoying one of the happiest times of our lives when this tragic situation befriended us. However, the procedure couldn't be scheduled for a few days. The horror of walking around with a dead fetus was almost too much for her to bear.

The weekend was the longest two days that ever existed for us. Minute by minute, hour by hour, time ticked off the clock, until Monday came and a resolution to our agony appeared before us. Finally, the time of the afternoon appointment came, and we hesitantly made our way to the hospital with the impending feeling of doom. After an eternity passed, the technician called Mollene, and my vigil for her began.

Within a half hour, she emerged with a glowing smile.

"What's with the grin?" I asked?

"The ultrasound was normal. The baby is slightly small for this point of development, but all seems well."

Digesting this news—going from the end of the earth to celebration—was hard, but something I could handle. The doctor told Mollene to rest for the

week because she had been spotting. We immediately went home and called our parents to share the good news, and proceeded with our lives.

The rest of the summer continued uneventfully and Mollene's newly-revived pregnancy went well. Most of her energy was devoted to building our new house which seemed necessary since the apartment we lived in didn't allow children. The project was even more monumental, since neither one of us knew anything about new construction, and Mollene was someone who languished over every detail, making the task that much more difficult.

Summer faded into fall and we were in the homestretch of Mollene's pregnancy. The house was coming along well, and the builder had promised that it would be ready to move in by mid-December, long before the anticipated arrival of the baby in January of 1977. Everything was going well and the world looked bright.

On the evening of October 6, while in the bathroom, Mollene noticed a large piece of bloody mucous, the size of a silver dollar in the toilet. We were not too concerned about it because she had an appointment with her ObGyn the next morning.

Upon completion of her examination, her physician assured her all was well and that he would see her in one month for the next scheduled visit.

That night I went to play hockey with my friend, Bill Kohen, who was an orthopedic resident. Bill had lived upstairs from me, but moved into a condo project down the road, when he found out his wife was pregnant. When we left to play hockey, Mollene went out to dinner with friends.

When I arrived home at about 11:00 p.m., I found Mollene sitting on the bed.

"I'm feeling kind of crummy, with a little bit of pressure," she said.

She decided to get up and go to the bathroom. No sooner had she sat down when she hollered hysterically. "My water just broke!"

I leaped up and guided her back to the bed. Within seconds, the baby was ejected from her uterus. In a panic I called EMS, and the next call went to Bill Kohen who had just dropped me off. Somehow in the midst of all this confusion, Mollene remembered her ObGyn's phone number, whose answering service had him paged.

Looking down hesitantly, I glanced toward the baby which I was sure was a miscarriage. All of a sudden, he began to cry, which startled both of us to a degree that words cannot describe.

I had left the door open, so Bill just came into the bedroom, looked down, saw that the baby was breathing and said, "Cover him up, and tell me where your turkey baster is, so I can suction him."

"I don't have a turkey baster. I never even made a turkey before!" Mollene screamed.

Just then, the phone rang. It was the doctor, wondering what was happening.

I explained to him that Mollene had the baby three months early, that the baby was breathing, and that we were waiting for the arrival of EMS. He said that there wasn't much else to do if we couldn't suction him, except try to pull any mucous out of his throat with a finger.

Just then the EMS crew burst into the apartment. They took one look at the baby, and began to suction him and administer oxygen. One of the men called the hospital, and the other listened to the heart.

It's almost impossible to describe my feelings, looking at that tiny living being, struggling to breathe. The paramedic's hand was much larger than the head of my son. His tiny hands, about the size of one of my fingernails, flailed in the air. We hadn't even come up with a name yet, because of the early date of arrival.

Frantically speaking on the radio, pausing to check something on the baby, the paramedic suddenly stopped talking and said we were going to Beaumont Hospital because they had an excellent neonatal unit. I truthfully had never heard the term *neonatal* before, but it was a word I would become well acquainted with in the following days. He then cut the cord, tied it off, checked Mollene out, and asked if she could walk. Not having any labor, she felt fine. She threw on her coat and walked out of the apartment unaided.

Mollene and I both boarded the ambulance and were whisked off to Beaumont Hospital, which was to be our home for the next four torturous months.

Upon arrival at the hospital, we were greeted by a doctor who turned out to be one of the neonatologists, who took the baby into the neonatology unit. We followed closely, not having the slightest inclination of what we were up against.

The baby was put on an examination table, and the doctor began his preliminary exam. Within moments, a technician placed a plastic bubble over the baby's head, which we were informed, delivered oxygen to help him breathe.

It was at this point that I first got a good look at this miniature creature that was my son. This surely was not what I had pictured. Covering his skin was a fine down, going from head to toe. His skin was quite wrinkled, and the entire facial area was bruised. The limbs were not much wider than a pencil, and the feet were about the size of the first digit of your middle finger.

The doctor paused momentarily and introduced himself.

"My name is Dr. Harm and I am a neonatologist. We have to check the baby out now, so you'll have to leave the room for a while."

I asked, "Can you give us any information on the condition of the baby?"

"I have to do a few procedures. I can speak to you in a few moments."

We left the room and walked out into the hall. A nurse brought Mollene a wheelchair and told her that they would have to take her to a room. We went

to another floor and someone from the hospital met us at the nurse's station to get all our medical insurance information.

We went through the usual red tape, before getting a room assignment. We suddenly realized we were going to a maternity floor, and knew that the babies would soon be brought to their mothers. The thought of seeing all the babies and smiling parents, while the fate of our child was so tenuous, was horrible, and too much to handle. I asked if my wife could be placed on another floor, but was denied because of hospital procedure.

An orderly pushed her to the room, and I proceeded back to the nursery. I had to knock on the window, wait for a nurse to recognize me, and then proceed inside. I was then told that I had to scrub with sterile, pre-packaged kits with an extremely abrasive plastic brush. Subsequently, I had to put on a yellow hospital gown. I eventually looked at the whole procedure as a monumental task.

Hesitantly I proceeded in and glanced around. What I saw was ten or eleven miniscule babies lying naked except for a diaper, on tables with a hood above them. The infants were on their backs, attached to ventilators which hissed as they breathed for the babies. The beeping of the heart monitors, which all the babies were attached to, further added to the continual noise.

The doctor who had introduced himself to me as Dr. Harm spoke.

"Don't be alarmed when you see your baby, but we had to intubate him."

"Why?"

"His oxygen levels were too low, and he was having trouble breathing. The ventilator helps him breathe. We have ordered some x-rays to evaluate his lungs."

I began to ask all the questions that were going through my mind and were tearing my heart out.

"What's the prognosis? What are his chances?"

Dr. Harm had a warm, kind face. In his most fatherly manner, he replied.

"With babies who are this small and premature, there are a million problems that can occur which makes it hard to tell how they are going to do. Your baby was born at home, and we truthfully don't know how well he was breathing, or if he suffered from any oxygen deprivation."

I pressed him. "Can you give me an educated opinion, at least?"

The doctor realized I wasn't going to let this alone.

"I suppose if you want a number, his survival chances are about ten percent. The other question is how well he will do if he survives."

After digesting his answer, I swallowed hard and said. "What kind of time table are we talking about? How soon will we have any idea?"

"That's the hardest question to answer with these preemies. You really can't judge anything until they get off the vents. It's a race against time, because the vent actually hurts the lung tissue. The baby must build up and strengthen the lungs faster than the vent breaks them down."

He continued to explain that some babies in the unit have been on ventilators for almost a year, and probably won't get off and subsequently die.

A nurse came over and said the baby was all set up and it was okay to look at him. We walked over to a table and I was overcome with emotion. As hard as I tried, I couldn't control myself. After I gained my composure, I looked him over carefully, and realized he didn't have any nipples. The nurse explained that it was due to the fact that he was born before the period that the nipples formed.

His tiny chest heaved up and down with each forced breath. The entire circumference of the chest cavity was not much larger than a banana. There was not one ounce of fat on his entire body and each rib was visible to the naked eye. It was explained that the bruising was caused by his traumatic birth.

"You can touch him if you want," the nurse said.

I reached out and rubbed his miniscule hand. Feeling a little more confident, I forced my index finger under the fingers of his tightly clenched fist, and felt him squeeze. Once again I had to fight back the tears. Suddenly a piercing alarm went off somewhere else in the room, and I looked up to see the nurse reach over and flick a baby on the heel. The alarm ceased ringing and the nurse pointed to the monitor, showed me how to read the heart monitor, and explained that preemies forget to breathe sometimes. Flicking them on their foot starts the process again. After the nurse walked away, I just stood and stared at our unnamed baby, his tiny wrist band read, *Boy Levin*.

After an hour of staring at the baby and wrestling with my emotions, I went to the desk where the nurse explained to me that the unit was open twenty-four hours a day, and that I could come in as often as I wished. I thanked her for the information and proceeded down to see Mollene.

As I shuffled through the corridor, the distinct smell of the hospital filled my nostrils. It is an odor, to this day, that brings back the horrible memories of those traumatic moments.

It was probably close to 6 a.m. by the time I got to Mollene's room. She was still wide awake, so I put my arms around her and held her tightly. We spoke about what the doctor had told me, and it was then she truly realized the gravity of the situation. Not having any control over his fate gave us a feeling of such despair. All our hopes and dreams were riding on this thirty-one ounce, eleven-inch baby.

We had waited until we had been married four years to have a baby. At that time we felt children were right for us. Once we were positive, we dove in with both feet, and having a baby was our only passion.

I kissed her and told her that I would go home, call our parents, and be back in a couple hours.

I called my sister who lived nearby, to pick me up.

An unseasonably cold early October wind knifed through my sweatshirt as I waited for her to arrive. It was an ominous-looking sky, with the clouds appearing a mucky shade of gray with occasional white puffs anterior to them. Somehow the day matched my feelings.

Shortly thereafter, my sister picked me up and listened attentively as I relayed my night of horror. We discussed the best way to tell my parents, and decided facing them in person would be best.

Seeing both of us at eight o'clock in the morning sent up an immediate red flag to my mother. I gave her the condensed story and started fielding the obvious questions. They didn't quite comprehend the complexity of the situation, nor did anyone else including me, as we would find out soon enough.

I returned to the hospital a few hours later and I went through the ritualistic scrubbing, and entered the unit. A nurse greeted me and introduced herself.

"My name is Jean," she said.

"Pleased to meet you," I answered. "How is he?"

"He seems to be holding his own. We haven't had to increase his oxygen levels or the rate and pressure it is delivered."

It was at that point, my education of neonatology began.

She carefully explained everything that was involved with maintaining the baby, which I was most appreciative.

She told me that many people put religious articles on the face of the table, and to feel free to do so. Not really having any religious articles left me feeling empty, and I felt I should be do something. I reached into my pocket and took the metal tennis racket that was on my key chain and affixed it to the table. To this day, in periods of extreme crisis, we superstitiously pull out the tennis racket.

Everyday brought a new crisis. The babies were fed by a tube which went directly into the stomach, because the ventilator tube was inserted in the mouth. In order to see the proper placement of the tube, an x-ray had to be taken, and in the baby's wild flailing, he would sometimes pull the tube out. The nurses eventually taped it to his side where it was out of reach. Babies this premature, have very immature nervous systems, and wildly jerk their limbs, and twitch all the time. The staff was constantly on guard for seizures, which were difficult to distinguish from the routine twitches.

We became accustomed to all the hustle and bustle of the unit, which included numerous emergency situations when the doctors had to perform various procedures on any baby. We always had to leave the unit during these procedures and any time they took x-rays.

Chapter 2

As the weeks drifted by, *Boy Levin* seemed to improve one day and then be much worse the next. One day he was jaundiced, the next day the feeding tube was out. For us, improvement was typically gauged by how much oxygen was needed and at what rate the ventilator delivered it—if one of the other many catastrophes didn't take priority.

For some superstitious reason, we still hadn't named him. I suppose we couldn't name him until we felt confident he would live, but it kept nagging at us, that it was the right thing to do.

About three weeks after his birth, he started to become very dusky and the oxygen levels started to decrease. After extensive testing was done, it was finally determined that he was suffering from patent ductus arteriosus. When the fetus is in the womb, the baby gets oxygen from the mother. The fetus does not have to use his lungs. The ductus allows the blood to bypass the lungs and go to the rest of the body. However, after birth the ductus narrows and closes off in a few hours. In preemies who are in respiratory distress, the vessel may stay open. If it stays open, too much blood will stay in the lungs, causing an increase in fluid, making it harder for the baby to breathe. If there is a great deal of blood flowing through the patent ductus, the baby can go into heart failure, which seemed to be happening. The only treatment at the time was to surgically tie the patent ductus arteriosus off.

Since we didn't really have any choice in the matter, surgery was the only option. It was hard to fathom how such a serious procedure could be done on a baby who weighed under 30 ounces. The procedure was explained to us and we were told the risks. We understood that the chances of a baby so sick surviving major surgery were minimal.

After they took the baby, we walked aimlessly out into the hall, dazed. We had no place to go. We leaned up against a wall, hugged each other and began to cry. A kind cleaning lady, who had seen us before, offered us the privacy of her cleaning closet, which we gladly accepted.

Mollene gazed up with tears flowing down her cheeks and said. “What now? What do we do?”

Neither one of us were very religious, so a serious prayer was not the answer. I looked at her, not knowing what to say, and just began to hug her again.

“Let’s get out of this closet and walk up to the surgical lounge,” I said.

The doctor had told us that the procedure would probably take 3 hours, and not to expect results any sooner.

We went up to the lounge and paced nervously back and forth, not having the concentration to read, nor the strength or inclination to make small talk. The time ticked off the clock and every hour felt like a decade.

Sitting and waiting, knowing that my child’s life was in the hands of another person other than mine was painful. Admittedly, not having control of a critical situation was extremely hard for me to accept at any point let alone this one. Although my son was being operated on by an extremely competent pediatric cardiac surgeon, I knew little about the surgery, and it was almost too much for my mind to comprehend.

Exactly three hours later, the surgeon appeared. He said, “The surgery was a success. We were able to tie the patent ductus off. We are cautiously optimistic because he made it through the operation, but with infants this small the procedure takes a great deal out of them, so we have to see what the next twenty-six hours will bring.”

Mollene and I just looked at each other, and the tears began to flow again. After hearing that news, even I who usually had a million questions, didn’t know what to ask, and was tongue tied.

Mollene asked, “When can we see him?”

“Actually, since the neonatal unit is best equipped to take care of him, he’ll be taken down there, and as soon as they have him situated, you can see him.”

We thanked him and headed back to the unit to wait for our yet unnamed baby, to return.

We were standing there as they wheeled him in. He was on his familiar table, bundled up, with the usual assortment of tubes sticking out of his now twenty-six ounce body, down five ounces from his birth weight.

The nurse told us it would take about fifteen minutes to get him properly hooked up in his permanent corner.

When we finally got to see him, we were quite surprised at how pink he looked, since we had become so accustomed to seeing him look so pale. A new tube was sticking out of his groin area, and it was explained that it was an arteriole line used during the surgery.

We each held one of his tiny hands, and just stood there for ages without uttering a word or moving a muscle. Suddenly our solitude was broken by the unmistakable sound of the heart monitor. With the nonchalance that we had

become accustomed to, I flicked the baby's foot and the monitor alarm ceased its ear piercing ring, as our son started to breathe again.

My parents had just come back from Las Vegas, and had brought us a very tiny slot machine. I taped it up next to the tennis racket.

Now we had two good luck pieces.

We stayed at the hospital for about four hours until we couldn't stand anymore, and then we went and had something to eat. This had been our daily routine for the previous three weeks. I had reduced my work schedule so I could come a few times a day, and Mollene spent much of the day at the hospital. In her few spare moments, she was still trying to coordinate the remaining details on our house which was still under construction.

When we returned the next morning we were shocked to find our baby gray and listless again. The respirator was pumping full out and he was once again receiving one hundred percent oxygen. We asked to speak to the doctor. The chief neonatology resident was Dr. Williams who was a young energetic man who always made himself available to answer our barrage of questions.

Dr. Williams spoke, "Everything is fine from the surgery. The heart sounds fine which tells us the patent ductus is closed, but he continues to get more ill."

"So what do you think is wrong?" I asked.

"We are running every test possible to determine the problem, but frankly we don't have an answer yet." he explained.

"I guess there isn't too much more to ask now." I said.

"We'll keep you updated."

We sat there all day as nurses and doctors ran back and forth, constantly pushing, prodding, and checking something different almost every minute. We had been there so much during the previous three weeks, that we had gotten to know every nurse on every shift. It seemed someone was always stopping to offer us a kind word or two.

At around eleven o'clock that night, one of the nurses, Pauline, who we had become friendly with, sat down on a stool and said, "The doctors think they have found the problem. The IV was not functioning right and he is not getting the right amount of fluids. They have rectified that and they feel he should start perking up soon."

I looked at her. "How come it took so long to figure that out?"

She explained, "There are so many things in these preemies that can be off by such a tiny amount that can cause monumental problems, that it is hard to diagnose what's wrong."

"You know we really appreciate all you've done for us here, and how kind and caring you are," my wife said beside me.

"It's a pleasure to have parents to speak to, who are so interested and involved with their baby's care. As you have seen in this unit, some people are not here very often and really don't know what is happening with their baby."

Relieved at this news, I said, “We’re going to sit outside for a few minutes and wait until the shift change. We’ll see you tomorrow.”

As we had come to learn, during shift change, the nurses went through report to discuss the care of each baby, and all visitors had to leave the unit. There really wasn’t any place to sit, so we went down to the vending machines and had some soda with caffeine to stay awake.

Mollene said to me. “You know, we really should name the baby. It’s becoming awkward not having a name.”

I really hadn’t thought about it that much, but just blurted out, “How about Jordan?”

How about Jordan?

My wife stared at me and said, “How’d you come up with that?”

“I don’t know. It just popped into my head.” I said.

“Okay, Jordan it is.” she said.

So at that moment, twenty-six ounce, eleven-inch-long, three-week-old Baby Levin became *Jordan Levin*. We didn’t give him a middle name, because it just took too much effort. It didn’t matter. Mollene didn’t have a middle name either.

Mollene said, “Do you realize we have never held the baby—I mean—Jordan.”

We both laughed at how good calling him by his name, Jordan, sounded.

“I spoke to one of the nurses, and she said as soon as he’s a little stronger, even if he’s still on the ventilator, we can hold him.” I said.

“That sounds great. I can’t believe it’s really going to happen,” Mollene said rather loudly.

We were trying as hard as we could to be positive, but we knew he wasn’t out of the woods yet. He had to be able to breathe on his own, unassisted. There also were so many unanswered questions about Jordan’s physical and mental condition. No one knew how much damage he may have suffered during birth, with the lack of oxygen. He also had been on one hundred percent oxygen many times, which can cause severe retinal damage and possible blindness. Another concern were the ototoxic drugs, which he was given that could cause deafness.

At that point we had no idea what was in store for us, and could only hope for the best.

It was also very tough, because both of us are private people, and we didn’t have much interest in answering questions from friends and family, regardless of their good intentions. I went to work, and to the hospital, and that was it. Fortunately, Mollene was a better communicator and kept the people who needed to know informed.

We went back into the unit and Jordan already was looking better. They had reduced the amount of oxygen he was getting. We had learned that with very low birth weight babies, their conditions improve or worsen very quickly. It was about one o’ clock in the morning, so we decided to head home on a good note, which we had come to understand was not always possible.

Chapter 3

The next few weeks brought more of the same. Although Jordan made it through the surgery, his condition vacillated continually. They tried to take him off the ventilator, he would last a couple hours, and they would put him back on.

Our new house, which had been such a priority, had been placed on the backburner. It was finally finished the first week in December. We were working on moving that day and had not yet gone to the hospital. The phone rang and I picked it up, which was something I almost never did anymore, because I didn't want to talk. It was one of the doctors from the neonatal unit.

She said, "Jordan has been off the ventilator all night, and is just under an oxygen hood with very little assistance. He's doing well and we are very encouraged that he is strong enough to breathe on his own."

I could barely get a word out, I was so excited.

I said, "Thanks for the great news. We are on our way."

I hollered the news to Mollene, and proceeded to cut the phone cord. It was the last call I wanted to take on that phone.

By the time we arrived at the hospital, the oxygen hood was off, and Jordan was breathing room air. The difference between having an oxygen hood and being on the ventilator is that the ventilator delivers the air with pressure, and the oxygen hood just gives the baby oxygen without forcing it into the lungs.

As soon as we arrived, one of the nurses wrapped Jordan up and handed him to Mollene.

"I can't believe we're finally holding him," she said.

Having trouble controlling her shaking from crying, she handed Jordan to me. I didn't do much better.

"It's like holding an empty paper bag," I responded. "He still only weighs two pounds."

The nurse and Mollene both laughed and believe it or not, Jordan looked up and for the first time in his two-month life, smiled too. Moments later, I took

a picture and actually captured a smile. We alternated holding him for hours, to make up for the minimal contact we had with him for the past two months.

Now that the major hurdle of breathing had been jumped, we had to wait until Jordan gained weight in order to take him home. We actually thought we were home free, until one day when we came in and were told by one of the doctors, that a nurse saw Jordan have a couple seizures. She told me that a neurologist came in and wanted to put Jordan on Phenobarbital.

I asked her if any tests were done that would confirm the diagnosis. She answered that all the tests were inconclusive. I told them not to put him on the medication, that I had spent hundreds of hours with Jordan and had never witnessed a seizure. I was sure that the nurse who saw the seizures was unfamiliar with the jerky motions related to his immature nervous system. Subsequently, I asked to speak with the neurologist, whose name I don't remember.

Later that afternoon, the neurologist came in.

After introducing myself, I said, "I'd like some information about Jordan's condition which makes you want to put him on Phenobarbital."

"The nurse said he had two documented seizures, and it is standard procedure to medicate *those type of kids*," he explained.

"Is there any other proof to substantiate this? I was told that the tests were inconclusive."

He said in a rather arrogant manner that I didn't like, "What's your expertise that allows you to question my decision? Here's what's done. He's put on Phenobarbital until he's about five. You take him off, give him a chance. If there's another seizure, he's on for life."

"Until I see a seizure myself, Jordan is not going on Phenobarbital." I responded.

With nothing short of disdain he said, "Your choice, but I won't treat him."

"That's the best news I've heard." I retorted.

He stormed off and told the nurse to have me sign the paper that said I refused treatment.

It appears that I made the proper decision, since Jordan never had another *alleged seizure*.

Laboriously, the weeks dragged on as we waited for Jordan to achieve the magical five pounds, which was supposed to be fighting weight. We made our usual two-or three-times-a-day hike to the hospital, and just continued to wait for Jordan to gain some more weight.

One frigid afternoon in mid-January, fourteen grueling, torturous weeks after Jordan's traumatic birth, the staff concluded that he could go home the next day, at four and a half pounds! They felt, since we had spent so much time with him, that we are able to take care of our still underweight baby.

We were overjoyed and overcome, not knowing which emotion was more powerful. It was almost impossible to leave the hospital, knowing

that Jordan would be home with us the next day. However, we decided to celebrate and go out to eat. We knew we weren't leaving the house for a long time once he came home.

The next morning, we arrived just past the seven-thirty report, already loaded with supplies and a camera with lots of film.

After we scrubbed and walked over to Jordan, who was on the other side of the unit where well babies were, we were greeted by a glum-looking Dr. Williams.

"We had some complications during the night. Jordan started throwing up and he's gotten worse. He's been constipated, so we gave him an enema, but to no avail."

"Now what?" I asked.

"He has had a couple of incidents of projectile vomiting, which leads me to think he may have pyloric stenosis," Dr. Williams said.

I knew what the *pylorus* was, but really didn't know what happened with pyloric stenosis.

"Could you explain it to us?" I asked.

"The area where the stomach empties into the intestine is controlled by the contractions of the pylorus. The pylorus becomes thick, narrowing the opening, so the contents of the stomach can't pass into the intestine, and are subsequently thrown up violently," he explained.

Mollene asked, "How do you diagnose it for sure?"

"There are a couple of ways. One is the continued projectile vomiting. The other is upon physical exam, feeling a little olive—like area above the naval. The olive is the thickened pylorus," Dr. Williams further explained.

"So, what do you do to solve the problem?" I asked.

"You have to surgically cut the pylorus muscle and spread it apart to increase the size of the opening. The muscle thickening decreases and then heals by itself. The operation takes about thirty minutes and the baby can go home in about 48 hours."

"Here we go again," Mollene said.

Dr. Williams responded, "After all he's been through, this is a piece of cake. We'll bring him through this and you'll have him home in a couple days."

The surgery was performed later that day and proceeded without incident. We were told that Jordan would begin eating small quantities more often than normal feedings. He did fine with that schedule, and they began increasing the amount of formula the next day. Later that day, we were informed that it was a *go* to take him home.

We arrived at the hospital the next morning with our fingers, toes, and anything else that could be, crossed. Jordan was in his plastic basket wheeled right up by the nurses station, ready for our arrival. Mollene dressed him in a red t-shirt with white overalls. She had bought the clothes in the toy store,

because doll clothes were the only clothes that were not too large for him. One of the nurses sat him up and I snapped as many pictures as I could in various poses.

Everyone from the staff who was on duty that shift was gathered around us, bidding farewell and wishing us luck.

Dr. Williams came over and said, “This has been a long roller coaster ride, but your son is one tough character and made it through. I want to wish you the best of luck and hope all goes well with Jordan.”

Mollene said, “We can’t thank you enough for all the kindness and compassion you have shown us these past four months. I know we’ve pestered you with a barrage of questions, but your patience never wavered.”

“Thank you. Working with you has been a pleasure,” Dr. Williams responded.

He held up Jordan, gave him a hug, and walked off.

I went to the lobby to check him out and receive a copy of the bill. The grand total was fifty-seven thousand dollars for the hospital, and twelve thousand dollars in professional fees. This was totally covered entirely by our insurance plan. I am sure a four-month hospital stay in current dollars would be well over a million.

When I got into the car, I cranked up the heat to combat the bitter January cold. This was to make sure Jordan, in his delicate state, wasn’t exposed to the cold. I pulled up to the curb and Mollene ran out of the hospital with Jordan, tightly bundled in his yellow snow suit, fit for a doll.

All I wanted right then was to drive away and see Beaumont Hospital in my rear view mirror.

While driving it was almost impossible to keep my eyes off of him. We kept up a continual chatter, although he was sound asleep and oblivious to his first outing into the big world.

After arriving home, we put him in a small cradle in the living room and turned on the gas fireplace for added warmth. We spent most of the afternoon alternating between watching him and dozing off. Just laying on the floor, knowing Jordan was finally safe and sound, was one of the most secure feelings I have ever experienced.

Later that day, the tranquility was shattered by our parents’ exuberance as they joyously entered the house to see their grandson. The ground rules for being in the house were no smoking and everyone had to wash their hands before they picked him up. We had pizza for dinner, and everyone took turns doting over Jordan.

The first day ended uneventfully. We took the little cradle into our room and slept fitfully. We strained to listen and to see if Jordan was breathing, which was made easier by the slight rattling sound that remained in his lungs. We had been told that the noisiness would disappear as he grew stronger and his lungs improved.

Chapter 4

Jordan progressed by leaps and bounds, accomplishing something new every day. He was still very far behind other babies of the same age, because of his pre-maturity. We were informed to treat his development in accordance with his projected birth date, which was supposed to be around January 10, which made him about one month developmentally.

Being so concerned with his development, considering all Jordan had gone through, we watched every action and reaction he made. I have to admit that I was unbelievably nervous about there being some disability popping up. It was on my mind all the time, and I was always comparing him to other babies.

This was one of the things I never should have done.

Mollene was more reserved about each movement, but deep down she was as worried as I.

Sleeping had become a word only used in the past tense, as in—before Jordan came home. The kid did not sleep at all. I had agreed to get up and do the middle of the night feedings. These were very important, since he needed to gain weight.

Our normal night involved attempting to feed him at about eleven o' clock, which was a real chore because he was colicky. When he was fed, we had to keep moving. If we stayed still, he wouldn't keep the nipple of the bottle in his mouth. At certain times, he wouldn't eat unless he was on his stomach, which entailed laying him on my arm, turning his head sideways, and trying to aim the bottle into his mouth. Since he had to be fed every three hours, one prolonged feeding ran right into the next one.

After the attempted feeding, Jordan and I would usually hit the couch with him lying on my chest, watching *The Ghoul*. *The Ghoul* was a local celebrity from the dead, who showed Q-grade horror movies. These movies looked like they had been produced in someone's garage. *The Ghoul* spent the rest of the hour, fighting with *Froggy the Gremlin*, who was his arch enemy. Froggy usually ended up on the wrong side of a stick of dynamite, which only Jordan

probably saw, because I was asleep. After the intensity of the feeding, I was exhausted and out of it.

When he wasn't eating or sleeping, Jordan had a little mischievous grin on his face, that usually meant something was about to happen. He was in constant motion. As soon as he could turn himself over, he was rolling around the house getting into everything. *Search and destroy* became his mission in life. We had to remove everything that sat on counters or tables. All stairwells had to be blocked off, and all doors had to be locked. Hooks were put on every door, at the top, so Jordan couldn't get to them.

The New Years Eve when he was one year old, I came back home to pick something up and I found him throwing records into the fireplace while the babysitter napped. It was lucky there wasn't a fire in the fireplace. The next day, I taped up a large piece of cardboard in front of the fireplace.

We still had to be careful with Jordan's exposure to germs. All who handled him had to wash their hands, and we tried to keep him away from obviously ill people. Actually, one of the positive ramifications of being so careful was dealing with smoking. Although no one told us to keep him away from smoke, because of his lung development, we told a little white lie to my parents. Both of them were pretty heavy smokers, and we informed them that Jordan could not be near smoke. For the first time ever, I saw them pay attention to any situation involving smoking, and noticed when the urge arose, they closed themselves in the laundry room or went outside.

Chapter 5

By spring we were feeling pretty cooped up in the house.

Usually one of us was always home with Jordan, since we really didn't take him out much during that first winter. We decided that Jordan was strong enough and needed to see the world, so we planned a trip to see our friends, the Mecklenborgs, in San Diego.

The trip turned out to be just what we needed. Other than the exhausting task of flying across the country, with Jordan, cooped up in a plane, the trip was great.

Ted and Pam lived in a little house just a block from the ocean. The area was alive with people enjoying the near perfect San Diego climate.

Our friends Ted and Pam had a son, Justin, who was just a few months younger than Jordan. Every morning we put the kids in strollers and walked them down to the beach—or should I say—Jordan walked the stroller down to the beach, because he couldn't sit still that long.

Arriving at the ocean was always a great thrill for me. I loved the sound of the waves crashing into the shore, and I loved the salty air that permeated everything. The entire experience brought back a certain serenity that I had been deprived of since Jordan was born.

The couple weeks we spent in San Diego consisted of a daily bike ride that I took with Jordan. Although putting him in the plastic child's seat on the back of the bike was like leading a high strung race horse into the starting gate, he enjoyed the ride after we eventually started going. His arms flew around wildly as we cruised down the street.

During our first ride, I discovered a drive-in restaurant, "Der Wienerschnitzel." The restaurant was a small, red, A-framed building with a drive-up window. Driving the bike up to the window created a sense of adventure. Being a junk food junkie at that time, I couldn't resist the temptation of trying a specialty hot dog. It didn't matter that I had just finished breakfast

twenty minutes before. The dog was probably nothing exceptional, but eating it out in the fresh salty air made it taste exquisite.

Since he didn't care much about eating, an occasional tiny bite satisfied Jordan's curiosity of the food. It was easy to tell Jordan's lack of concern for food by his rather skinny build.

After consuming my hot dog, we would continue our fifteen-minute journey, usually resulting in Jordan nodding off. I hated when we got back to Ted's house, because the lack of motion would usually wake Jordan up.

The vacation started out fine, but after a few days, my own personal demons began to surface. The underlying fears about Jordan being really okay in all respects were back nagging at me. I was still comparing him to every kid I saw. Was he walking as well? Was he as coordinated? Was his speech on par?—after all, he barely made a sound.

I tried to console myself, but it didn't work. Comparisons between kids drove me crazy. I was usually better off if I wasn't near any other kids.

Chapter 6

After the vacation, the months passed quickly and Jordan seemed to be progressing quite well developmentally. His fine motor control and balance were excellent. These were two of the skills which we were told might be poor in someone born so prematurely. He had a retinal evaluation, which was surprisingly normal for being on such high concentrations of oxygen for such an extended period of time.

However, it was around that time, that we began to question Jordan's speech and language development. He really didn't vocalize very much, but we and the pediatrician blamed it on the fact that he was so comfortable pointing at objects. The doctor felt as soon as Jordan felt the need to speak, he would. We also questioned his hearing, but nothing was ever pursued by the pediatrician, so we started doing some small tests ourselves.

When I went to get him in the morning, if he hadn't climbed out of his crib by himself, I would lightly tap on the door. He was always up, and waiting for me to come in. Being totally ignorant about hearing, I figured hearing loss was out of the question if someone could hear such a quiet tap. Jordan also always responded when the door—one level below my parent's apartment—opened.

Still having some doubt in our minds, we had my neighbor, Sid Beck, an ear, nose, and throat specialist, examine Jordan. He felt Jordan had a great deal of fluid in his middle ear that should be removed, but said he didn't think that it, in itself, was the entire problem. Sid recommended that we get tubes put in Jordan's ears and then have his hearing re-evaluated.

Although it was necessary, another operation seemed incomprehensible. But we knew it had to be done.

The day of the surgery came and both Mollene and I were nervous wrecks. Somehow, already having Jordan home, and having to go back to a hospital, seemed to increase the magnitude of the situation.

When it came time for Jordan to enter the operating room, Sid came and carried him in himself. The total time that had elapsed, from start to finish, was only about thirty minutes, but seemed much longer. All went well, and two exhausted parents went home with a fully alert child.

We went home and laid down with Jordan between us. We fell asleep, only to be awoken by the sleepless wonder crawling over us to escape. He wasn't the slightest bit tired, so we decided to take turns sleeping. I drew guard duty first.

Although we knew in our hearts that the tubes were not going to solve the problem, we pretended for a couple weeks that he seemed to be hearing better. Once we could no longer postpone the inevitable, we made an appointment to check Jordan's hearing.

Chapter 7

After the realization set in that Jordan really must have a hearing loss, we were told that Oakland Schools had a department for hearing evaluation. Knowing the time had come to seek the truth, Mollene set up an appointment.

The day of the appointment I had to work, so Mollene took two-and-a-half-year-old Jordan. I suppose I could have gone, but in my mind I knew I couldn't face the music. After all that had transpired in the hospital, I had tried to shut out the possibility that something could be wrong with Jordan, who had achieved Superman status in my head. Since coming home from the hospital, he actually was an extremely healthy baby.

I received the dreaded call at work. Mollene was crying hysterically.

"Marty, the doctor said he's profoundly deaf," Mollene exclaimed.

"What's that mean?" I asked.

She said, "The doctor didn't really explain things very well. He said Jordan doesn't hear much of anything."

"I don't get it. Is he deaf or doesn't he hear very well?" I asked.

"I am telling you what he said," she answered, trying to talk between sobs.

"What do we do now?"

"He said that Jordan has to go into a program at Oakland Schools and learn sign language."

At that point I was so overcome with a combination of fear of the unknown, and being horrified, that I just couldn't talk. I couldn't believe anything could be wrong with my perfect child.

It was an intense struggle trying to make it through the rest of the day at work. I had spent four months nervously at work waiting for hospital updates and this seemed to bring back all those unwelcome, haunting feelings. My emotions raced back and forth between anger—*how could this happen after all we have been through?*—and total despair. Knowing my personality, I didn't know how I could cope with this devastating news.

We spent the next entire night discussing our new dilemma. Sid came in and explained what it meant to be profoundly deaf. Basically a person who is profoundly deaf can hear a few sounds at certain frequencies. That's why Jordan could hear a tap on a door, but couldn't hear anything when you spoke to him.

Banging and tapping were very low frequency sounds, which fell in a range which he could hear. Human speech was a much higher frequency, so he couldn't hear it.

The results of a hearing test are called the *audiogram*, and Jordan had what was called a *corner audiogram*. An audiogram is a written map showing all the different frequencies and the amount of decibels it takes for a sound to be heard. He had a small amount of residual hearing in the very low frequencies if the sound was amplified a great amount. We also found out that some of his responses may have been to the vibration, and not to the sound.

The most baffling part of the whole situation was how he followed directions and knew what was going on. What we didn't realize was that he had taught himself to read lips, and that's how he learned everything. It was an even more amazing accomplishment after understanding how difficult lip reading is. Many sounds totally look the same on the lips, and it is virtually impossible to tell the difference. Mall and ball are perfect examples of difficult words. Most deaf people do not become accomplished lip readers, but Jordan had mastered it as an infant.

The next day, Mollene called Oakland Schools, and made an appointment to speak to someone about programs that were available for the hearing impaired.

She met with a woman who had a more optimistic view of the prognosis of profoundly deaf children. The woman explained that with the proper teaching techniques, many hearing impaired children, along with sign, could learn to speak quite well.

Mollene was taken to a classroom of fifth grade hearing impaired students, where she observed them. After watching them go through their lessons for a while, the administrator had a few of the children speak to her.

Mollene could barely contain her disappointment in the speech quality of the children. None of the kids had understandable speech. According to the teacher, these were examples of some of the kids with better speech.

As soon as I arrived home from work, Mollene greeted me in tears.

"It was horrible. You couldn't understand a word these kids were saying, and they were supposed to be the best," she cried.

A huge lump descended into my throat, making it virtually impossible to talk. Mollene threw her arms around me and just sobbed. Not feeling very comforting, I squeezed her tight and said nothing.

After a while, I gained my composure and said, “There has to be something more to do. We just can’t take one opinion and accept it.”

Mollene offered, “Why don’t I call Children’s Hospital and find out what they have in the way of audiological services?”

The following day Mollene set up an appointment with the audiologist at Children’s Hospital.

After the examination was completed, Dr. Eldes spoke with us.

“Jordan definitely is profoundly deaf, as previously diagnosed.”

I asked, “What can be done for him?”

She said, “With intensive speech therapy he could learn to speak, but it’s a very difficult job. Many people today use total communication, which combines the ability to speak with sign language.”

“How effective are hearing aids?” Mollene asked.

Dr. Eldes answered, “Unlike glasses, which somewhat restores normal vision, hearing aids amplify only so much. In Jordan’s case, his loss is so great it will only give him about thirty percent hearing, but that is not necessarily the same kind of quality you and I enjoy. We really don’t know how much distortion there is in the sound being amplified. So we may be increasing the loudness of the distorted sound. Hearing aids help but do not fix the whole problem.”

I asked, “What should be done next?”

“He has to be fitted with hearing aids and put in a nursery school program for the hearing impaired,” she responded.

“Let me ask you a question. If I were Henry Ford and had all the money in the world, what would I do with my kid?” I asked.

Dr. Eldes laughed, and said, “There are residential schools for deaf children that do wonderful jobs, but with your help and sending him to Oakland Schools, he should do pretty well locally.”

I thanked her for the help and with an audiogram in hand, the three of us marched off to face the world.

The next situation that had to be dealt with was informing our parents about Jordan. Both sets of our parents were very close and involved with him, and had suffered through his lengthy hospital stay. The thought of giving this new round of bad news had us tied up in knots. We tried our best to break it to them gently, but how do you tell someone gently that their cherished grandson is deaf? It’s not that deafness was the end of the world, but the previous generations’ view of deafness was completely jaded. The common expression previously was “deaf and dumb,” and most people had very limited contact with the deaf population, including our family.

Chapter 8

We went back to Oakland Schools, and Jordan was fit with what was called a *body aid*. It was a box that was about six by four inches, and fit in a little pouch on his tiny chest. A speaker cord connected to each ear. One of the drawbacks of a body aid is, as the child moved around, his clothing would brush against the speaker, and a great deal of static would be created. We were told that Jordan's loss was so great that ear level aids would not give him enough amplification.

The body aid was large, cumbersome, and horrible looking. Everyone stared as Jordan went by. He was totally undaunted by the situation, except he periodically stopped to remove the earphones.

We were informed that just because you put a hearing aid on a person doesn't mean that he or she starts hearing. There is a learning curve, where the person has to be educated to what he is hearing. Babies learn those things automatically, but older children have to be taught to hear sounds they never really heard before.

Trying to familiarize ourselves with hearing impairment, we called Oakland Schools, and requested some literature, which they told us they didn't have much and that we should consult the library.

The only book the library had on the subject was a book titled *Deaf Like Me*, which was more of a horror story to us rather than an aid. The content of that book included information we didn't want to be told. It didn't contain one sentence that was positive or uplifting, and the tears began to flow again. We decided that the book wasn't going to lead us in the direction we wanted to head, although we weren't sure where we were headed.

Not being prone to easy defeat, Mollene decided that a bookstore was the place to find the information we needed to educate ourselves on the task ahead.

While asking the sales lady about books on hearing impairment, a woman turned to her and said, "I couldn't help but overhear you. I hope this isn't

intruding, but my sister-in-law has two profoundly deaf children who speak quite well.”

“Where’d they go to school?” Mollene asked.

“They went to Country Day,” she answered.

Detroit Country Day is a very well-thought-of private school in a suburb of Detroit.

“How’d they do there?” Mollene continued.

The woman answered, “Quite well, to my knowledge, but my sister-in-law is really a great lady and would be happy to talk to you. Why don’t you call her?”

She gave Mollene the phone number and Mollene put it in her pocket, where it stayed for the next few weeks. Finally she got the courage to call the woman.

The woman, Nancy Shapiro, was extremely cordial and helpful. She explained in general everything that had been done with her kids. After talking for quite awhile, Nancy told Mollene that her children were older teenagers, and that she really wasn’t current on all the techniques that were being used at that time. She suggested that Mollene contact Helen Kraizman, who had an eight-year-old hearing impaired daughter, and that Helen was very active in all the current groups. Mollene thanked Nancy and decided that contacting Helen was a necessity.

Chapter 9

An entire new world opened up after Mollene spoke to Helen Kraizman. She was informative and most of all optimistic about Jordan's chances in a hearing world.

Helen told Mollene about her daughter Lisa.

"Lisa is eight years old and is severely deaf. We have taught her to speak, which she does extremely well. She uses speech as her only means of communication."

Mollene asked, "What about total communication?" We were told that total was the best way to go."

"The philosophy of being totally oral is the program we follow. This program states that using sign inhibits the development of speech. You must also realize, if a person uses sign as a way of communicating, the only people who can speak with the deaf person, are those who also know sign. It can severely limit the amount of people who can be spoken to," Helen explained.

"How do you teach a person without sign if you're in an Oakland Schools program which is advocating total communication?"

"You must find a program that fits your needs. Lisa goes to the Detroit School for the Deaf. It has worked very well for her," Helen said.

Mollene and Helen spoke for over an hour, with Helen telling her everything she could to help satisfy Mollene's curiosity.

Helen put Lisa on the phone to speak and Mollene's eyes lit up. She couldn't believe what she was hearing. Lisa was extremely articulate and just the medicine that was needed to lift up our spirits.

"Marty!" She called to me, "You have to listen to this little girl. She speaks great."

I picked up the phone and said, "Hello Lisa, how are you? I'm Marty, Mollene's husband. We have a little boy who is hearing impaired like you."

She asked, "What's his name?"

I answered, "Jordan. We'd love to meet you."

We spoke for a minute but I was so overcome with emotion, I had to stop. I gave the phone back to Mollene who had been writing verbatim everything Helen had told her.

Helen said, “If at all possible, there is a conference in Toronto this weekend called “The Voice Conference,” that you should attend. It is all about teaching deaf children to speak. My husband, Sid, and I are going. The conference has renowned speakers from all over North America speaking about all topics including hearing aids—of which there are huge differences.”

Knowing that we would do anything that could possibly be done to help Jordan, Mollene told Helen we would attend, and made the arrangements to meet the Kraizmans in Toronto.

Chapter 10

When we arrived at the conference in Toronto, dozens of kids were running around wearing hearing aids. Most of the children ranged in age from one to twelve or thirteen. I had never seen so many hearing impaired children before, and felt comforted. I suppose the secure emotions emanated from being comfortable among other people who were experiencing the same problems I was.

The first part of the conference was a discussion with six children with severe to profound losses, children who were strictly oral. The children ranged in age from seven to ten years old. After a short biographical introduction, each child spoke.

We were amazed at each child's ability to speak, which was far different from the expectations we had after hearing the children we had been exposed to at Oakland Schools. Although the children did not articulate perfectly by normal standards, they were understandable and used speech as their method of communication. We were thrilled that the possibility existed for Jordan to speak, but began to realize that an enormous task lay ahead of us.

After the discussion had been completed, experts on hearing impairment from around the country, began to speak. There was Doreen Pollock from Denver, Helen Beebe from the Helen Beebe Center, Dr. Dan Ling from McGill University in Montreal, and a woman who impressed us and ended up being our mentor; Dr. Ciwa Griffiths, from the Hear Center in Pasadena.

She took us by storm when one of her first statements was, "If someone tells you your hearing impaired child cannot do something, don't you believe it."

Secondly, she spoke about hearing aids, making us aware that ear level aids were available for any hearing loss. This news was a great relief. The cumbersome body aid attracted unwanted attention, and we also noticed when people spoke to Jordan, they spoke differently than to other children. If we wanted strangers to talk naturally to our son, the obvious signs of deafness had to disappear.

Dr. Griffiths shared that parents are the most important element in how successful a hearing impaired child would be in learning to speak and acquiring language. Although schools played a role, parental intervention was necessary to ensure success. The parents had to be devoted to a program of auditory training, which systematically trains the child to listen.

For parents, although there were formal lesson times, every minute spent with a child was a lesson. If you are eating dinner, for instance, every utensil or morsel of food is talked about and dissected.

She said that these axioms had to be followed for success. The children had to wear the hearing aids on a full-time basis. The aids had to be chosen relative to the degree and curve of loss. Each child must be taught to listen to sound and to interpret those sounds cognitively. The therapy had to build listening skills, vocabulary, and concepts of daily life situations. A deaf child must be in an environment where there are normal speaking people, because one repeats what one hears. Children who are only around deaf people will speak like deaf people. Children must go to regular schools and hear normal hearing people.

Another speaker we heard was Dr. Dan Ling who was known as the guru of speech. He asked for hearing impaired children from the audience who were having trouble with certain sounds, and used them to demonstrate.

First he asked the teachers what specific sound was difficult, and then he proceeded to help the child produce the troublesome sound. For example if the child could not produce “t” properly at the beginning of a word, Ling may have the child try a combination like *ahtom, ahtom, ahtom, tom, tom, tom*. The *t* may be easier to produce in the middle of the word at first, and then secondarily, he was able to get the child to say it in the front of the word.

Seemingly, he had a million tricks in aiding sound production and seemed like a magician. His knowledge of speech development and his charisma inspired both the children and teachers alike.

Another point that Dr. Ling made was the importance of proper hearing aids and proper amplification. He chose a child who was profoundly deaf and had him stand about five feet away, with his hearing aids removed and back turned. He called to the child softly without a response. He continued to increase the volume until Dr. Ling was shouting. The child failed to answer at any level.

The child then put his hearing aids on, and the process was repeated. At a volume slightly louder than a whisper, the child responded to the voice, but was unable to determine what was being said. As the level of loudness increased a little, the child answered the question.

He then repeated the process by moving the child further away from him in increments of five feet. This demonstrated how dramatically the child’s ability to understand speech decreased as the distance increased.

At the conclusion of the program, we didn't know what to think. Our heads were filled with days of information, but we didn't know how to process it or what to do next.

Mollene said, "Obviously all the information we have learned up to this point is so different from what the people are saying here. At least there seems to be some hope."

"We need some direction," I said. "We have to connect with some of these people here."

"Why don't we go speak with Dr. Griffiths from the Hear Center? She seemed so positive and I loved what she said," Mollene offered.

We approached Dr. Griffiths. She was being mobbed by people throwing questions simultaneously at her from all directions. She calmly waded through the multitude of inquisitive people and sat down for a break.

"Dr. Griffiths, my name is Mollene Levin, and this is my husband, Marty." She responded, "Pleased to meet you."

Mollene began to tell her about Jordan. "We have a two-and-a-half-year-old, profoundly deaf son who was recently diagnosed. He is wearing a body aid and has minimal speech or language. We have been painted a very poor picture of his future, as far as learning to speak. All the hearing impaired children we have been exposed to don't compare in speech and language development to the ones we've seen today. I guess all I can say is, *help*."

"You heard what I said. If someone tells you your child can't do something, don't you believe it," she responded.

"That's why we came to talk to you. All we have heard is what he can't do, and you focus on what can be done," I said.

Dr. Griffiths said, "You must believe in yourselves and your child, and what you believe can be achieved."

Mollene said, "Where do we start?"

"If the facilities that you have locally are not up to your standards, you can visit our center in Pasadena. We have a three-week out-of-town program where we assess the hearing, fit the aids, and teach the child and parents in therapy. We send the parents home with an idea of a program to begin with the children."

I said, "I cannot begin to thank you. Just listening to your speech had inspired us and given us hope that was not there."

"Come see me in Pasadena and really find out what you can accomplish with your child," Dr. Griffiths offered.

Another interesting person we met was Judy Simser, who spoke. However, it was not her speech that significantly changed our lives as a family.

Mollene was in one of the lounges after a long day when she saw Judy Simser. "I really enjoyed your lecture today. It really inspired me."

Judy responded, “Thanks for telling me. It’s a good feeling when I can lead parents in a positive direction. Teaching a hearing impaired child can be so frustrating, that any positive sign can be a blessing.”

“Do you have a hearing impaired child?” Mollene inquired.

“I have a hearing impaired son who we have trained auditorily. It was because of him that I first became interested in the field,” Judy said.

Judy continued to speak about her family and other children.

“I can’t imagine how you can have other children and still devote the time it sounds like is needed to properly teach your child,” Mollene said. “We’ve talked about having another child, but we are afraid. My son is a wild man who requires continual care, without working on speech and language development.” Mollene commented.

“On the contrary, another child adds a whole new dimension to the life of your son. It gets the total focus off of him. It’ll make him a much more well rounded-person.” Judy responded.

“I still can’t fathom it.”

“It’ll help Jordan realize that there is more in the world than him. He’ll learn from the experience of having a baby. Every single event that happens in his life is a chance to expand his knowledge, and his vocabulary,” said Judy. “You’ll never regret what it will do for your son.”

When we met up later in the day, Mollene shared with me the advice she received from Judy Simser. We both wanted another child, and loved her advice, but it still needed some consideration.

Chapter 11

We left the Voice Conference with our heads held high for the first time in quite awhile. We had renewed hope that the sun was going to shine tomorrow and could actually hear the birds sing and had hopes for blue skies.

Totally undaunted by what we were getting into, we had a feeling in our hearts that Jordan could be a normal speaking person. The battle was just beginning, but Dr. Griffiths made believers out of us with her statement, which we have repeated in our heads a million times since then, “If someone says your hearing impaired child cannot do something, don’t you believe it.”

We decided that going to Pasadena was a necessity, and we began to make arrangements immediately after arriving home. We wanted to have time to go to Disneyland, so we planned to be in California for a total of three weeks.

We arrived in Pasadena after a typical *Jordan flight*. Always being in motion did not change on a flight. We had flown across the country numerous times with Jordan before, but this flight seemed to be his worst. We were unable to keep him in the seat even for a moment, since he could unfasten his seat belt. We spent the entire first leg of the flight chasing him up and down the aisle, as Jordan tried to visit with the other passengers.

Since we made the arrangements on such short notice, this particular flight or flights as they were, had two stops and a change of planes. To further complicate matters, the departure time was 10 p.m., when most people would sleep, except for Jordan, who fell asleep only when he was totally exhausted.

We had a layover in Chicago for about two hours, and while Mollene and I wanted to sleep in the airport chairs, Jordan had other ideas. We spent our nap time chasing him around the airport into areas that no one even knew existed. Shortly before it was time to board the plane, he fell asleep in a chair with both hands up in the air. Falling asleep from exhaustion in mid-movement was a normal Jordan experience. We would say that he *slept fast*.

About ten minutes later, our flight began to board and Jordan awoke from the short nap, fully refreshed and ready to rock and roll, however, we

were exhausted and dreaded another session of chase up and down the aisle. Remarkably, for some unexplainable reason, Jordan crashed in his seat and slept most of the way to Phoenix.

While laying over in Phoenix, Jordan decided he was hungry and couldn't be convinced that there was nothing open at three o'clock in the morning. So we played chase up and down the concourses of the airport. Traveling, or going anywhere with Jordan, usually gave us an in-depth tour of wherever we were. He finally gave up in frustration and decided to accept the graham crackers Mollene had brought for such an occasion.

We arrived in Los Angeles after a relatively uneventful flight at five o'clock in the in the morning. Following a ten-hour flight, Mollene and I couldn't focus our eyes from exhaustion, however Jordan was rested and ready to seek out new trouble. After checking into the motel which was to be home for the next few weeks, we unsuccessfully tried to sleep before heading to The Hear Center for our appointment.

Knowing the importance in getting down to business with young children after short introductions, Jordan was put in a room to be evaluated. He was taught to play the *go game*, where upon hearing a sound, he was to put a ring on a spindle. Each ear was tested separately to determine if one ear was better than the other.

First the sounds presented were very soft, and when it became obvious that he was not hearing them, the volume increased varying in frequency from low to high-pitched sounds. Jordan eventually started to respond to some of the stimuli, and put the rings on the spindles. The process was fairly slow and laborious, due to the fact Jordan wasn't used to hearing anything, and he was so easily distracted.

When the testing was completed, the audiologist explained to us the significance of his audiogram, which is a display of how Jordan heard at each frequency. It showed that he heard sounds only that were very low in frequency and loud in volume. He had hearing only in the left hand corner of the graph, and was called a corner audiogram. That indicated, that he could not hear any normal speech in the range we talk. The sounds he could hear were like a door closing, a drum banging, or a jet taking off close to him.

Although we had him previously tested and had seen the audiogram, it had never been explained to the degree it had been now. Having it spelled out in a simplistic manner was shocking. I realized how handicapped Jordan was, and an immediate wave of sadness came over me, followed by tremendous guilt. How was it possible that we didn't know all along how deaf Jordan was? Were we that oblivious, or worse yet, that stupid? This was an issue I would wrestle with for a long time.

Having completed the evaluation, we went into a room for Jordan to be fitted with ear molds.

The audiologist said, “I’m going to put a piece of cotton in his ear, followed by this pink material which will harden, and will be a pattern for an ear mold.”

We had seen it done before when they made the molds for the body aid.

As we watched the audiologist explained, “It’s a very soft material, which just flows into the ear.”

The audiologist put a swab of baby oil in his ear, followed by a piece of cotton on a string, to pull it out. As she attempted to pour the waxy liquid into his ear, Jordan began to pull away from the audiologist’s grip and then escaped. Keeping with his *modus operandi* of disappearing like Houdini, he was gone in a flash.

Although he couldn’t hear me, I hollered out of habit for him to come back. If it weren’t so frustrating, it might have been a comical sight as I chased him through the hall into the next office. I came to a sudden halt as Jordan ran behind the desk. I looked up and realized the woman laughing was Dr. Griffiths.

“I’m sorry,” I said.

“Don’t be sorry,” she replied, “I’m used to little kids running around. I love it.”

I made a desperate leap and managed to grab Jordan by the arm, as he started to climb onto the desk. I picked him up, and cradled him tightly in my arms as I had done millions of times before. He squirmed, but my strength prevailed, and I was able to convince him that I was going to win this battle, at least momentarily.

Dr. Griffiths said, “It’s alright. Put him down. I have something for him.”

I turned Jordan’s face towards mine. “Calm down. This is Dr. Griffiths and she has something for you.”

Jordan smiled and leaped from my arms as I eased up on my grip. Dr. Griffiths opened her desk drawer, and pulled out a red balloon and said, “Jordan, I’m going to blow this up for you.”

She proceeded to blow it up as Jordan waited semi-peacefully in anticipation. As soon as she had tied the string around it, Jordan reached for it, and immediately began to swing it around ferociously.

She said, “I see that Jordan has been evaluated and that he is going to be fit for some new aids. We will try to get these as soon as the molds are finished so that the beginning training will be most effective. In the meantime, he’ll continue to use the body aid he currently has.”

I began to say something, but Jordan waved the balloon in my face, causing me to hold it with him, so he couldn’t do any harm with his new weapon. Anything Jordan had in his hand represented a weapon of potential destruction.

Dr. Griffiths just chuckled and said, “I think when he acquires some language and can express himself better, he’ll probably calm down a bit.”

“I sure hope so. We were in the middle of making ear molds when he decided he had enough. I better take him back and finish the ear molds.”

She replied, “Go ahead. We’ll speak later.”

After much clawing and grabbing, the task of making ear molds was completed. Jordan was free to explore the room as he desired. We spoke with the audiologist about the process of producing ear molds, which involved taking the impression and then creating the actual mold that fit in the ear and was attached to the aid. She explained that it was of the utmost importance that the ear mold fit perfectly so that the hearing aid didn’t produce feedback. Feedback caused a high pitched noise that was annoying to other people, and can disrupt the sound the patient hears. She felt that the molds would be ready in about three days.

Knowing that Jordan had probably reached his limit for the day, we were sent off to enjoy the California sun. We spent the day at the pool of the motel, and were totally exhausted from jet lag, but as usual, Jordan was going strong long after we faded.

Chapter 12

The next morning we arrived bright and early to begin therapy. The therapist had Jordan sit in a little chair and we sat in the back and out of the way, so that we didn't distract him. Mollene had a red spiral notebook to record the drills that were being done.

It had been explained that auditory training was teaching the child to use and develop the residual hearing that remained. Just because a child had a hearing aid on didn't mean he could hear a sound. Children had to learn to listen to each sound. A hearing newborn hears the sounds from birth and naturally learns what they are, or represent. The longer a hearing impaired baby goes without sound, the harder it is to teach him what he is hearing.

The lessons began with Jordan listening to sounds and pointing to his ear, when he heard the sound. She hit the drum behind him, to make sure he heard the sound, rather than responding because he saw the drum being hit. The trainer banged a drum, pointed to her ear, and said "I heard that."

She tried it four or five times, before Jordan got the hang of it. Next she shook a bell, and he did not respond. It was difficult to determine if he didn't hear the sound or if his limited attention span had reached its limit. She gave him the bell and let him shake it for a while, and then tried again. On the first try, a huge smile came across his face, and he pointed to his ear.

After trying a few more listening exercises, she began to combine a listening exercise with an attempt to get Jordan to verbalize. She took a balloon and said, "Up, up, up," as she pushed it up. Next she did the same thing, but covered her mouth as she said it numerous times.

She explained, "It is critical that you cover your mouth when you speak in order for Jordan to develop listening skills. Don't be discouraged if you don't get much verbal response at first. You must remember that his hearing age is newborn, and newborns do not talk. They take in a great deal of information for months before they even start babbling."

“So are we going to teach Jordan to actually babble before he speaks?” I asked.

“Actually that is exactly what you are going to do. He will follow that order of producing sounds just as if he were a newborn. There is a definite order of how sounds are produced. Let’s do a little more of this lesson before we lose him.”

While we were talking, Jordan slipped off his chair and was headed for the door. I jumped up and with one swift motion, picked him up and took him back to the seat. “I think that he is reaching the end of the line and that I’ll have him sit in my lap.”

The teacher nodded in agreement. “It is very important at this point that he recognizes his name.”

She covered her mouth and pointed at him and said, “Your name is Jordan. Jordan is your name.”

She then pointed to Mollene and said, “Momma. This is your momma, ma, ma, ma.”

Jordan began to use all his strength to pull from my grip, swinging his body from side to side. Realizing I was fighting a losing battle, I proceeded to let go, and he jumped to the ground. Expecting him to last more than twenty minutes would be a minor miracle. The teacher gave Jordan the balloon, took him by the hand, and started to lead him into the next room.

“I’ll have someone watch him while we talk,” she said.

When she returned she pulled up a stool and sat down in front of us.

“The more you understand about the speech process, the easier it will be for you to help Jordan. Although he will have a tutor, and be aided in school, the two of you are the quarterbacks of his education. You are going to have to orchestrate everything. His success will revolve around how much time and effort you put in. Teaching a profoundly deaf child all that he needs for success is a full-time job.”

She explained that learning to listen was the first option, and although Jordan had a profound loss, he could still be taught to use his residual hearing. “Language is auditorally-based, and even children who are profoundly deaf can learn by using hearing if it is properly done. They must be amplified with binaural hearing aids, which will allow them to use their residual hearing to the best of their abilities. Hearing aids will not make Jordan hear perfectly, but will allow him to hear speech.”

We were totally engrossed in what she was saying. Our minds were like sponges, absorbing every word. Mollene was furiously writing in her notebook, making sure she didn’t miss a syllable.

“Another very important factor with hearing aids is considering how far you are away from the child. Sound is measured in decibels, or *db*s. Hearing

aids drop off about six db's for every yard. Therefore the loudness of the sound is diminished significantly as you get further away. It is very important that you stay very close when you work with Jordan." she explained.

I asked, "How does his ability to read lips play into this?"

"Obviously he has acquired uncanny lip reading abilities which will definitely be used to his advantage. In situations where he can't hear because there is too much background noise, or the speaker is too far away, lip reading will be very advantageous."

"Should we encourage lip reading?" I asked.

"I would not encourage or discourage it. At this particular time, it is very important to cover your mouth and encourage audition. Lip reading, for him, just comes naturally. The key to natural sounding speech is listening. Normal speech has to have good rhythm, rate, and intonation. It must not be flat, slow, or without melody. This cannot be picked up by lip reading. Also some sounds cannot be distinguished on the lips. For example, say *call* and *hall*. See how the *c* and *h* look on the lips. They are identical, and can only be differentiated by listening. When he is aided he will be able to tell the difference between *c* and *h*." she explained.

"This information, with most of it being so foreign, is hard to comprehend, let alone pass on. Just hearing all this makes the task of teaching Jordan almost insurmountable," Mollene said.

"All of this will fall into place as your understanding increases. Every day more and more pieces of the puzzle will be put together. I know this seems tough, but your hard work will be rewarded. You're going to hit plateaus, when it seems like you're not making any progress. All of a sudden a breakthrough will happen. This is only the first step, so don't get too overwhelmed. We'll talk more tomorrow."

Each lesson began with a repeat of the previous lessons. Repetition was the key to improvement. Every skill had to be mastered in an orderly manner. For example an "s" is produced very late in a child's oral development, long after many sounds are mastered.

The first skill that really had to be mastered was just vocalization in any form. It really didn't matter at first what sounds came out. Then while playing, the teacher tried to convince Jordan to make twelve sounds in a one minute period. Then he tried to hold one vocalization for three seconds, such as *ahhhhhhhh*.

Breath control is very important, and is a major fault with deaf children who tend not to use enough breath when speaking. Many times the child's tongue is not in the proper position, letting the air go into the nose, producing a very nasal sound.

The early progressions went from the long vowels, diphthongs like *ow* in *wow* to consonants. The first consonants that were worked on were the plosives, *b* and *p*, which required a great deal of breath. Plosives were demonstrated

by the movement of air on a flame, or paper. If the paper or flame didn't move when you said a word with *p* or *b*, not enough breath was being used.

Each lesson began back at the beginning with vocalizations, the production of many sounds and so forth. This continued until a new concept was introduced. Every lesson was done while playing with toys, and Jordan would try to simulate the sounds. A cow goes *moo*, and a ghost goes *boo*. Although every method was used to keep Jordan's attention, he would only last for a limited time. However it was encouraging to see that he was making progress and hopefully would continue to improve.

We were at the Hear Center for seventeen days, and we had taken in a wealth of knowledge, but surely not enough to tackle the huge task on our own. Some of the choices we were considering included looking for a tutor trained in the auditory approach, or even moving to Pasadena. Although moving wasn't our first choice, I had a California Optometry license, which would make it possible.

We were ready to leave but couldn't without seeing Dr. Griffiths. When we went into her office, she was sitting behind her desk, with her ever-present smile beaming across her face. She radiated optimism every time I saw her.

"Hi Jordan, how are you?" she asked.

He waved and said his version of *hi*. We sat down and Jordan made an immediate leap off my lap to check out Dr. Griffiths's drawer, where she always had some little toy to play with. He grabbed a toy car and started rolling it on the floor, with the approximation of the car sound babbling from his mouth. What a wonderful sound! Only a few short weeks before, nothing would have come out of his mouth.

"I understand that you are leaving for home today. In my opinion, it has been a largely successful visit," she said.

"We learned so much and even though there is so much to do, we now have hope and a direction," Mollene replied.

"Jordan has made huge strides and I am sure he can succeed with much speech and language development. I've said this before, but it is worth repeating. He must be placed among his hearing peers, in everything he does. Regular school is a must, so he can imitate the normal hearing kids. There is no substitute for good role models," Dr. Griffiths explained.

"We realize that and plan to enroll him in a regular nursery school as soon as we get home. We cannot express our thanks enough for all you have done for Jordan," I said.

"It gives me so much pleasure to see all my hearing impaired kids talking up a storm. It looks like Jordan is well on his way. Please keep us advised on his progress, and if there is any advice or help you need, call us. Good luck." she said.

Mollene and I smiled, said our good-byes, while Jordan ran up and gave Dr. Griffiths a huge hug.

On the way to the airport, Mollene read me the letter that Dr. Griffiths had handed her. The relevant parts of the letters are as follows.

The recommendations following the initial testing were: 1) use of binaural hearing aids, 2) enrollment in individual therapy one hour per day with emphasis on auditory training, and 3) evaluation of binaural ear level hearing aids.

Jordan was seen for eleven hours of individual therapy. One or both parents were present during each therapy session. Jordan started localizing sound immediately after he was fitted with binaural hearing aids. He was conditioned for play audiometry, utilizing both voice and tones within the first therapy sessions. During his stay at the Hear Center his verbal responses changed from vowel and guttural sounds of one and two syllables to three and four word responses with good rhythm and tones within the first few therapy sessions. Some phrases were acquired such as, "I want; don't fall down; help me, etc." His approximations are improving. He started generalizing simple question forms. He has good short and long auditory memory.

Some sensory integration problems were noted, visual spatial insecurity, poor defense mechanisms, constant physical activity, poor sleeping and eating habits.

Jordan's prognosis for the development of speech and language is excellent based on the progress demonstrated here during the past three weeks. Continued use of binaural amplification, individual auditory training, enrollment in a pre-school program with normal hearing peers, and a sensory integration therapy program are recommended.

Chapter 13

Once we arrived home, our entire focus was on what to do next. Mollene began an exhaustive search to find a tutor who followed the auditory program. Most programs in the area believed in total communication, which was a combination of speech and sign.

We had been given a few names in Michigan, but since the people in California didn't know where they were, none of the locations were close. The first people that she spoke to were in Berrien Springs which was on the western side of the state, about a three-hour drive from us. She spoke about tutoring, but said that you had to be in the Berrien Springs School District to receive services.

If nothing else came up, we considered moving there, but if push came to shove, we probably would have preferred Pasadena.

Mary Campbell in Ida, Michigan, was next on our list, and she was about an hour south of us. That would have been possible to either go for tutoring, or to move. Mary was extremely helpful and gave us a great deal of information on oral programs, but informed us that students had to be in the Ida District.

She did tell us that she knew of a teacher who used to work for her and lived in Bloomfield Hills, a few miles from us. Mary thought she might be tutoring. Her name was Karen Pawlick.

Mollene immediately called Karen. "Hello, my name is Mollene Levin, and I was given your name from Mary Campbell. I have a two-and-a-half-year-old profoundly deaf child and am interested in having you tutor him."

Karen responded, "To tell you the truth, I have tutored a few children, and am not really interested right now."

"We really need help." Mollene exclaimed.

"My training is oral, but most of the parents around here want total," Karen said.

Mollene said, "We want strictly oral for Jordan. Mary Campbell gave you the highest recommendation with your knowledge of training kids orally."

“That makes the idea a lot more appealing, but the other problem is that I have two young children. I would have to take the kids to a babysitter, and by the time I pay the babysitter, it won’t be worth my time.”

Always pretty quick, Mollene replied, “If you tutored Jordan at your house, I could watch the kids for you.”

Karen thought for a minute, and said, “I’m not saying that I will tutor your son, but why don’t both of you come over tomorrow afternoon so I can meet you and talk.”

Karen told Mollene to come over at three o’ clock, and gave her directions. This would be the most important call Mollene ever made concerning Jordan’s oral education.

Taking Jordan anywhere was always an experience, because where ever he went, he wanted to check it all out. Hopefully Karen’s kids and their toys would keep Jordan’s interest long enough to talk a while.

Jordan was a skinny child with a mop of sandy hair and an impish grin with dimples. Karen almost immediately fell in love with him.

Mollene filled Karen in on our saga, beginning with his prematurity to our most recent journey to the Hear Center. For someone as young as Jordan, there was a great deal to tell.

The story wound down and Mollene asked, “So, what do you think?”

“My aversion to tutoring is that it hasn’t been very rewarding for me with the kids I’ve taught. The other problem is that the kids I have taught come a few days a week, and nothing else is done the rest of the week. You seem to comprehend that speech and language development for a hearing impaired child is a full-time job.” Karen stated.

“My husband has very flexible hours, and between us, we plan to devote our entire attention to teaching Jordan. We know he can succeed, and we plan to do everything possible to insure this.” Mollene replied.

Karen answered, “Since you have already solved my babysitting problems, I’m willing to give it a shot.”

“That’s great. I can’t tell you what this means to us. We don’t have to move now, and I’m confident you’re the person Jordan needs.”

Mollene and Karen decided that three sessions a week would work, along with Jordan going to nursery school. They would begin the next week, and during the summer Jordan would come in the morning, and then in the afternoon during the school year.

Chapter 14

It finally felt like Jordan's hearing impairment had sunk in for us, and we felt momentarily that we had the situation under control. Since the time of his birth nearly three years before, our world had been in a constant state of mental and emotional turmoil. At first we were concerned with him just surviving, and after that, we were anguishing over Jordan not having any disabilities. Due to his traumatic birth, the length of time he was on a ventilator, and the many procedures that were performed on him, the chances of him not having problems were remote.

So far the only apparent problem was the hearing loss. Not that being deaf is minor, but I suppose compared to the multitude of physical disabilities that he could have had, the deafness could be dealt with.

Coping with a child with a disability was a huge responsibility, which was something that no one could tell us how difficult it could be. We did not know anyone, except Lisa Kraizman, who was deaf. However, Lisa was much older than Jordan, and although she was extremely successful orally, she had attended schools for the deaf.

It really created a very lonely feeling, which made us feel at times like it was us against the world. Every day brought a new crisis, which could have been another ear infection, noisy hearing aid, sores in the ears from the molds, or my own paranoia that Jordan's hearing seemed to be getting worse.

Every morning began with checking the hearing aids, since Jordan was too young to inform us if they did not sound right. We would listen to them with a modified stethoscope which had a rubber end with a neck that the hearing aid fit into. We would do a five sound test, including *ay*, *eee*, *I*, *sss*, and *sh*. After a few days, I became quite proficient in determining if the aids sounded right.

Then we would wrestle with Jordan to get the aids in his ears. Since the mold was a fairly hard plastic, it took a bit of shoving to get it in properly. After awhile we learned some tricks and realized a slight coating of baby oil made the task easier.

After working up a good sweat, it was time to check how well he was hearing with the aids. This was another fun part of getting ready in the morning. One of us would sit Jordan down approximately ten feet away from the speaker with the rings. One of us literally held him down while the other one said the five sounds. When he heard the sound, he put a ring on the spindle, if he was so inclined. This made it extremely difficult to tell if he heard a sound or just didn't care to tell us.

That routine went on every morning. Probably testing the aids and hearing could have been checked every other day, but do to my compulsivity, it had to be done every day or Jordan's progress would have been slowed down. My own demons drove me to make sure every variable was ideal, or it would raise havoc with my everyday existence.

Broken aids were another serious problem, which required immediate attention. Since we were told that wearing two aids was extremely important, in my mind, a poor sounding aid was going to cause irreparable harm to the daily learning process. If we found an aid to be damaged, Mollene or I had to race to the hearing aid dealer and get a loaner aid to use while the main aid was in repair.

Another common cause for hearing aid downtime was sores or cuts in the outer ear canal. These occurred for a variety of reasons including pushing too hard on insertion of the mold, or getting bumped in the ear. Once a sore occurred, it either had to heal, which took many days, or I had to come up with a way to make the mold not press too hard on the irritated area. The best solution I came up with was, placing a dab of Vaseline on a q-tip, and putting it on the sore. Sometimes this worked, and other times, I found an ear canal full of blood when I took the mold out at night.

This daily routine took its toll on all three of us. Some mornings we literally had to chase Jordan all over the house to catch him to get his aids in. As soon as that task was accomplished, he'd disappear before we could check his hearing. All of this proceeded breakfast, which was a major chore in itself, leaving us many times aggravated and frustrated before the day even began.

Chapter 15

The next step in Jordan's saga was finding a nursery school that would offer the appropriate setting and secondly, accept him in their program. It was important that the director, and subsequently the teacher, understand what we were trying to achieve.

Mollene and I had talked in great detail about what we expected out of a nursery school, and realized what an added burden Jordan could present to a teacher. Since he couldn't hear most of what was said, the teacher had to be conscience if Jordan was paying attention, so that he could read the teacher's lips.

One of the other major problems that existed was Jordan's limited speech and more critical, little of what he said was understandable. His ability for receptive language outshone his communication skills. Many people feel if a child cannot speak, he cannot comprehend what is being said.

Our search for the appropriate nursery school ended with one that was highly recommended—Bloomfield Nursery School. Mollene set up an appointment to meet the director, Shelley Moss.

Shelley impressed Mollene immediately with her willingness to tackle a challenge.

“Shelley, you're going to be dealing with a very rare situation with Jordan.”

“Can you give me some background on Jordan?” she asked.

Mollene responded, “Essentially Jordan was three months premature and weighed 31 ounces. He beat all the odds by surviving, and through countless medical problems, he overcame the residual problem and is profoundly deaf.”

“What does *profoundly deaf* mean? Does he hear at all?” Shelley inquired.

“Jordan has about 5% residual hearing remaining. With hearing aids, he hears at about a 30% level. The work we're doing with him teaches him to listen and allows him to function at a much higher level.”

“Does he sign?”

Mollene explained, “We are teaching him to speak, so he uses speech as his only means of communicating.”

“Why don’t you teach him to sign? Isn’t it much easier for him to learn?” she asked.

“We felt, since the majority of the world is hearing and speaking, we wanted Jordan to be able to speak. Teaching someone with Jordan’s loss to speak is no easy task, but we feel that this is the best situation for him. There is a huge separation between the oral deaf and the deaf community. The deaf community believes all deaf people should use American Sign Language, and that wearing hearing aids and speaking is denying one’s deafness.”

“How do you think we can help Jordan function at Bloomfield Nursery?”

“Jordan has limited understandable speech right now,” Mollene answered, “but he understands what is said. However the teacher has to be aware that she is looking at him when she speaks. I realize that this could be a burden, but it is necessary.”

“I’m sure we can do it with a bit of practice. My staff has accommodated many kids with a variety of disabilities and look at it as a challenge rather than a burden.”

“There is one other issue that needs addressing. Jordan is in continual motion, and is unbelievably curious, and into everything. Don’t treat him any different than any other child. The firmer you are with him the better.”

“We’ll do our best to help him fit in. I’m sure it’ll all work out.”

This was reassuring.

Chapter 16

The first day of nursery school rapidly approached, and we planned our strategy, armed with ideas that would help Jordan succeed. The unknown factors worried us sick. There was not a textbook to read or study which could give us the answers to make this situation work.

The first hurdle to overcome was Jordan himself. We had no idea how he would respond to being in a controlled environment, where he wasn't the center of attention. He had been in a babysitting service where Mollene exercised, and did fine. However, in that situation, he was not required to sit still and pay attention.

The first day, true to form, when Mollene dropped him off, he leaped out of the car, and was ready for action. Mollene, however, wasn't.

Shelley looked at her tear-filled eyes and asked, "Are you okay?"

Mollene responded, "I can't believe someone else is going to be responsible for Jordan for three hours. I almost don't know what to do with myself."

Jordan was generally up for a new situation, and obviously leaving him at the school did not present a problem for him. The teacher had already been briefed by Shelley Moss on Jordan's needs. Mollene and I had come up with the idea of giving the teacher a notebook, to briefly write down the activities that were covered that day. Having that information would allow us to review the material and help Jordan comprehend what had been covered that day.

It is so hard to explain how much Jordan missed in a normal classroom. When the teacher spoke to another student, Jordan had to keep moving his head back and forth in attempt to keep up with the conversation. By the time he turned to the voice, part of the first sentence was already spoken, causing him to have to pick up the idea of the conversation in mid-stream. Being an extremely active child, not hearing anything but mumbles at that distance, trying to pay attention to a conversation that he is lip reading twenty feet away, caused him to miss much of what was being said. However, with our help, we were expecting Jordan to be able to do it.

Lip reading threw another variable into the education of Jordan.

Lip reading is an art, and not something that every person can pick up or be taught. It is extremely hard to do and even an experienced lip reader may only be able to lip read 40% of the words in a conversation with total accuracy. However, the rest of the missing words are filled in by understanding the content of the conversation.

Imagine how difficult it was for a three-year-old who was prelingually deaf and didn't have any knowledge of the syntax of the language to understand what a teacher was explaining.

Trying to lip read in a mirror can give you a good idea of how hard it is. Look at the words *fan* and *pan*. On the lips, they look almost identical. *Man* and *band* are virtually impossible to tell the difference. All the short vowels look the same on the lips. *Pack*, *peck*, *puck*, *pick* look the same.

How much a person moves his or her lips also has a huge effect on understandability. People who have minimal movement make lip reading much harder. Good lip readers can tell the difference between words by tongue movement, which is visually absent through a narrow mouth opening.

Many people have a tendency to over exaggerate mouth movements when they are speaking to a deaf or hard of hearing person. This significantly decreases understandability, because the already typical hard words are virtually impossible since the exaggerated movement changes how a word looks on the lips.

Lip readers are foiled by men with mustaches, especially if the hair hangs over the lip. Beards, as well, cover the cheek movement, which can relay facial movement. This is also a visible clue to discerning what a word is. As hard as it is to believe, an accomplished lip reader can distinguish between different accents of people from different regions and countries.

What is important to successful comprehension is the key word of a sentence. Many times not knowing a few words in a sentence isn't critical to understanding what is going on. However, if you miss the main word of the sentence you have no clue as to the meaning of the conversation.

Chapter 17

Having found a tutor was a huge step, but we were totally unprepared for what it was going to take to turn Jordan into to a speaking person.

Upon arriving at Karen's to begin his first lesson, she took him upstairs so he wouldn't be distracted by her kids whom Mollene was taking care of.

As she explained to Mollene later, Karen put Jordan in a small chair, which she expected he might sit in. Sitting in a chair was not one of Jordan's strong points, so he proceeded to get up. Determined to demonstrate who was in charge, Karen told him to get back in the chair. With a little assistance, Jordan resumed his position in the chair. Having assumed she had won the battle, Karen proceeded with the lesson.

Within seconds Jordan decided that he had enough and got up again. Realizing that Karen was up against a formidable opponent, she resorted to a stronger game plan. Seating herself on the floor, she grabbed Jordan and placed him between her legs. Realizing struggling was going to be fruitless, Jordan succumbed to Karen's strength.

When the half-hour lesson was completed, Karen carefully explained step by step what was done, as Mollene feverishly wrote in her notebook.

Jordan's speech and language development began back at the beginning to make sure the entire process was orderly. All the sounds that a baby would produce were introduced in the exact order that they would be learned naturally. Babies could not produce a sound that they were not ready to make, and the same situation held true for Jordan.

Although the first steps were done at the Hear Center, Karen started at the beginning to make sure Jordan's foundation was right. The first sounds to be made were just vocalizations that followed the vowels. She would demonstrate with a ball and move it up saying the ball is going up, up, up. It was important to raise the pitch of the voice to correspond to the movement of the ball. Understanding the speech of a hearing impaired person depends just as much on the speech patterns, as the pronunciation of the words. The rate, rhythm,

and intonation had to be the same as that of a normal hearing person, so that the speech was understandable.

Everything had to be said in full sentences so that Jordan got used to hearing the patterns of speech properly. Karen explained that every conceivable event and happening during a day had to be described to Jordan in painstaking detail in order to make up for all he missed auditorily.

When you analyze how much is said in the course of a dinner conversation, you may realize how much Jordan could miss in that short period.

The next lesson was slightly more civil, but after half an hour Jordan had more than reached his limit, and was surely ready for the road. Jordan and Karen spent quite a bit of the time jockeying for position as to who was going to run the show. Jordan was not to be denied the dominant position he had attained in our household. Karen was not going to be held at bay by a toddler. Her sheer strength was a deterrent, but she could not totally conquer him. Dominance wasn't established and the battle would go on for a long time.

Just so Karen wouldn't feel defeated, Mollene relayed a story about Jordan's will and perseverance.

"A couple months ago, we were having our neighbors, the Becks, over for a casual pizza dinner. We had told them we couldn't establish an exact time for dinner because it was impossible to eat with Jordan and you never could be sure of when he would go to sleep. We told them we'd try for about eight o'clock."

After twenty minutes of chasing, Jordan was finally in his crib, and actually seemed calmed down enough that he might go to sleep.

The Becks came over with the pizza about nine, and everything seemed like a go.

No sooner had we sat down than in walked Jordan carrying his little sleep pal, Benji. Benji was a little flat cloth Detroit Tiger figure that was named after the Tiger outfielder, Ben Oglivie.

I told Jordan nicely to go upstairs and back to bed. He smiled with his impish grin and shook his head *no*. Knowing that pleading and cajoling was fruitless, I picked him up and put him back in bed.

To make a very long and frustrating story short, Jordan came back down ten times that evening, figuring that we would give in and let him stay. We probably would have, except you couldn't eat when he was around, because you had to watch him every second.

Needless to say, the pizza got cold, as Sid and Sharlene looked on in bewilderment.

Around eleven o'clock, Jordan finally succumbed to sleep. In total frustration, after leaving his room, I slammed my butt into the wall. The dent I created remains in the drywall today.

Karen listened to the tale and realized she had her work cut out for her, and was to face the largest challenge of her teaching career.

Chapter 18

Jordan began making progress, creating a more uplifting atmosphere around the house, but the struggle was just at an incipient stage. Every minute of every hour was lesson time for Jordan. There was much time to be made up for, and I wanted to do it in just one day. I'm not sure if I was driven by guilt or the need for instant results. Always having the need to view immediate results, the tiny victories that came on a daily basis were not enough. I always strived for too much, and my thirst for success could not be quenched.

From the second Jordan awoke, which was usually at the rather late hour of six o' clock in the morning, the informal lessons began. Hearing aids were put on and checked, as the process was explained to Jordan. Every task, chore, pain or pleasure was relayed in incredible detail.

Breaking every sentence down into sub-sentences had to be done. Brushing his teeth became a major production. First we had to describe taking the toothpaste out of the drawer. The drawer pulls in and out and makes a squeaky sound. Then, the art of squeezing the Crest toothpaste onto the green brush with the plastic, clear bristles was described.

"Now you have to brush your front teeth up and down and your back teeth side to side."

Then describing how the toothpaste is aqua colored and tastes minty, came next. "Then you must rinse your mouth with cold water from the tap. The cup is made of hard, blue plastic. Tap on the cup so you can see how hard it is. On the left side is the faucet for the hot water and on the right side is the cold water faucet. Hot water is very dangerous because you can burn yourself."

All this had to be done while you were covering your mouth with one hand to encourage listening, and holding down a three-year-old who had much more interesting plans than teeth brushing.

Getting dressed was done with a long, drawn-out, one-sided conversation. We described every article of clothing including size, color, what it's used for

and how it goes on the body. Each body part had to be described, and what the body part was used for.

This was all coupled with, “Jordan, stand still. Don’t move. Get up. Come back here. We’re almost done.”

Holding him with both hands, legs wrapped around him didn’t guarantee he wasn’t going to slip away. The nickname *Houdini* had stuck because of his uncanny ability to release himself from his shackles. Getting out of high chairs and car seats was child’s play for such an accomplished escape artist.

The day was broken down into one informal lesson after another. All meals were eaten at the same temperature because the descriptive conversation prevailed, leaving so little time for actually eating. I had learned to eat all foods at room temperature, which worked for most foods except for ice cream, which became a modified milkshake. For Jordan, the soupy ice cream was a bonanza, because it could be slurped down, which was much less time consuming than chewing.

Most of the time Jordan consumed his usual two bites and the chase would begin. He would always slip out of his high chair which we had rigged with a child proof strap.

In order to take advantage of his constant motion, we invented *drive-by eating*. Jordan had a favorite little white truck that he logged on hundreds of miles around the house. As he cruised through the kitchen, we would hold a bite out of food. and he would drive by as we put the food in his mouth on the fly. Drive-by eating had its drawback as most of the time the floor received more nutrition than Jordan, but at the time we were thankful for whatever morsel landed in his mouth.

It was around that time that Jordan developed a chronic case of diarrhea. Modifying his food consumption was tough, because his already limited diet was down to nothing. Numerous times a day the flood gates would open, and poor Jordan was faced with an uncontrollable mess, which was quite devastating for a recently toilet-trained child.

After a week, when the problem didn’t rectify itself, we took him to the pediatrician for an evaluation. Blood work, stool samples, and all the other diagnostic tests yielded nothing. The conclusion was that some kids had chronic diarrhea, and had to live with it.

Not being overly accepting in nature for defeat, we ran numerous food elimination experiments on our own until we found the culprit—milk in larger quantities. Finally the problem was eliminated after a few messy months.

Although devastating, not to mention the inconvenience of the situation, a few rather funny situations rose out of the diarrhea days.

One story that stands out most in my mind was the time we had gone out to dinner and my parents babysat for Jordan. After they made a frustrated attempt

to feed him, which must have bordered on impossible, they took Jordan for ice cream. If my mother admitted to frustration, the ordeal must have been hair raising because my mother wasn't one to admit defeat, which begrudgingly she did.

Just as my parents went to put Jordan in the car after his two licks on the ice cream cone, which my dad finished, a massive bout of diarrhea attacked. Massive quantities of the ugly demon poured down, covering his bare legs and white gym shoes.

My father immediately freaked out and set him on the hood of the car, holding him gingerly by the hand for support. Medical emergencies were not my dad's strong point.

"Hey, Florence come here and help me," he yelled in a panic.

She answered, "Just hold him and I'll see if there are any rags in the trunk."

She opened the trunk and found nothing that resembled a rag. Being a clean and neat freak, there was no way that the now covered and screaming kid was going in her car.

Being ever resourceful, she found a plastic garbage bag in the trunk, which became her solution to transporting Jordan.

"Harold pick him up, and put him feet first in the bag," she cried.

My mother held the bag, and my dad placed the bewildered toddler into the bag. My dad held Jordan on his lap, while my mom drove, taking each turn much more carefully than normal for fear of dumping Jordan and his oozy mess.

And that is how Jordan got home without trashing the precious interior of my parents' new car.

We arrived home just in time to see my mom placing Jordan into the laundry room tub to remove the bag. The expression, "A picture's worth a thousand words," is true!

Chapter 19

On the days that we didn't see Karen, we worked on speech, listening and language skills at home. Whenever Jordan opened his mouth, every single word was analyzed. We followed an orderly pattern that was established by Daniel Ling, PhD.

Each sub skill had to be mastered. By this time Jordan was able to produce all short vowels pretty well. It wasn't just the production of the sound but being able to use it in every situation that arose in normal speech.

For example if you took the vowel *i* which is the phonetic symbol for a long *e*, the orderly progression went like this.

First *i* had to be produced without exaggeration or nasality. This involved making sure that the sound was being produced without the lips forming the sound without exaggeration, so that the face appeared normal. In order to do that, there had to be enough breath support to get the sound produced naturally.

Hearing impaired people have a difficult time using enough breath, so consequently the sound travels through the nose, making it sound nasal.

Next you must maintain the *i* for at least three seconds with good voice quality. This involves making sure that there is a sufficient amount of breath to last the three seconds. Normal hearing people automatically have enough breath to support their sounds. This has to be taught to hearing impaired people.

Each sound required a strategy in teaching it. To improve breath control, we had Jordan blowing out a candle. To learn the tongue placement for an *L*, we would put chocolate or peanut butter on the roof of his mouth. Then he would lick it off and try to say a syllable with *L* in it, such as *la,la,la*.

Next a syllable such as *ba* would be repeated 12 times with a rate of 3 per second.

After perfecting this 12 times with the same syllable, we would switch to 12 times with different vowels, such as *bi, ba, bi ba*.

As laborious as the sequence was, this process didn't go smoothly. Many times, it would take weeks to get one segment of this progression right. However more frustrating than the time element was having worked two weeks on a sound, and having it disappear the following week.

There were many nights that Mollene and I just shook our heads and questioned what we were doing. The level of frustration became monumental at times, and it felt like it was impossible to continue.

I remember many nights after Jordan went to sleep, that I would just lie on the floor, not being able to move or speak in a state of suspended animation, just trying to shut everything out of my mind.

Mollene would say that she had to talk so excessively during the day, explaining so much to Jordan, that she couldn't say one more word by night time.

There have been numerous studies which show the high rate of divorce among parents of hearing impaired children, and most of these people were not following the strictly regimented program we were following. Most parents were teaching sign to such profoundly deaf children which was less pressure than following the oral method.

In terms of sound production, the sound had to be produced at a high, low, and medium pitch, followed by saying the sound in a loud voice, quiet voice, and a whisper. Before successfully completing a sound, it had to be used in a phrase, and then correctly in fluent speech.

It is important to remember that the process was being done with a three-year-old, who had many more ideas rolling around in his head, which he preferred to do, rather than boring speech lessons.

In order to keep Jordan's attention, we tried a multitude of ideas. We would sing, dance, crawl on the floor, or jump up and down. We always tried to make the lesson interesting, although it wasn't interesting enough for Jordan. Many lessons ended in yelling and frustration from both parties. Other times a mad chase would develop, which would end up with me dripping sweat and questioning myself—*Why in the world was I doing this?*

This is not to say there wasn't a euphoric high that would follow after he was able to successfully produce a sound that we were working on for weeks.

One of the killer sounds was *s*, because *s* was such a high frequency sound, it was almost impossible to hear. The *s* had to be taught by showing Jordan how to place his lips and tongue and the amount of breath it took to produce it.

Speech was not the only skill that had to be perfected during lessons. Listening skills had to be developed as well.

One of the first skills in the *learning to listen* process was hearing and identifying a telephone ring. The normal hearing baby hears the phone from birth and learns to identify the ring with the phone and someone answering

it. Hearing impaired people do not automatically hear just because a hearing aid is thrown on them. They only hear a conglomeration of noises that have no meaning. Teaching the significance of the phone was a process in itself. Mollene would sit Jordan down in front of the telephone and call my mother or her mother and tell them to call her. She would then point to her ear and say, “Listen Jordan, do you hear that?”

She then would point to the phone and say. “That’s a telephone. Do you hear it?”

She would do this five or six times. It probably took a week before he made the connection from the sound to the phone.

Every single sound had to be detailed as to what it was and what it related to. This was done in lessons and all the time that was spent with Jordan. Bells, birds, horns, hammers, rain, thunder, instruments and thousands of other sounds had to be pointed out dozens of times before he would make a correlation between the object and its correlating sound.

The other part of the lesson was language development. Being almost three years old before any formal language was introduced put him three years behind the average child. The hearing child has all the receptive language experience long before they utter a word. How can you expect an infant to speak words when they have never heard words?

We made a list of five words that we knew Jordan had to learn, and put them on the refrigerator. We would go over them many times during the day, after being introduced during the lesson. Five new words were attempted to be learned every day, along with an idiom.

Hearing impaired people tend to take everything very literally. One of the first idioms we taught Jordan was “*It’s raining cats and dogs.*”

That idiom sure took a lot of explanation.

Friday was review day and we went over the skills of the week, including all twenty-five words and the five idioms.

Chapter 20

Our goal was to raise Jordan as a hearing person who lived a totally normal life. Between tutoring with Karen, nursery school, formal and informal lessons, it was not an easy task. However, we made sure to squeeze in play time every day. Making arrangements for him to play with the kids from nursery school was no problem, since moms called up and made the arrangements.

Mollene was also able to find time for mother-toddler classes, ice skating lessons, gymnastics, and even found time to drop him off at the babysitting service at the community center, so she could take aerobic classes there.

Somehow, he was able to control his wild and uncontrollable antics at the babysitting service, because they always reported what a well-behaved and charming child he was. Charming I could buy, but well-behaved gave me reason to pause.

It would be unfair to say Jordan was a bad kid, but rather was a curious and mischievous child, who would stop at nothing to fulfill his needs. He was lacking skills in self-preservation, which eventually made emergency room visits for stitches commonplace.

One of the events that occurred in the annals of Jordan's history of curiosity and potential disaster is particularly worth mentioning.

At the age of three-and-a-half, it was still in everyone's best interest if Jordan's whereabouts were known. One morning while I was doing a lesson with him, I had to take a bathroom break.

I said, "Jordan, sit here and play with the toys for a few minutes while I go to the bathroom."

He nodded yes, so I left the room. I came back a few minutes later to find the room deserted, which, truthfully, I half-expected. Jordan could now hear me throughout most of the house if I hollered. He could not understand what was being said, but he knew the yelling was for him. I hollered for him, but got no response. I looked throughout the main level of the house, but didn't see him, so I went upstairs.

Mollene was in the bedroom, so I asked her.

“Where’s Jordan?”

She replied, “I heard you holler before, but I assumed you found him.”

“No way.”

We looked at each other, having already performed the drill dozens of times, we started to check all the rooms in the house.

We barely had checked his room, when we heard a loud crash and felt the vibrations. Realizing it came from the garage, we raced down the stairs, and flung the inner door to the garage open. There was Mollene’s silver car crashed right into the shelving unit against the garage wall. Sitting proudly in the driver’s seat unscathed, with an ear to ear grin radiating over his entire face, was Jordan. I yanked him out of the car, gave him a precursory once over to determine if he was okay and then proceeded with a mouthful of expletives, which are not supposed to be said to children. Whoever gave advice on raising children obviously never lived with Jordan.

We asked him what he did, and to the best of our understanding, he crawled up on the dryer and took the keys from the hook. He then went into the garage and got into the car. After putting the key in the ignition and turning the car on, the car leaped forward, over the cement barrier and crashed into the metal shelves. Obviously, this was possible because the car had a manual transmission, which allowed it to move forward without placing the lever into gear.

If it weren’t for the shelves, the car probably would have wound up in the kitchen.

Daily lessons were supposed contain speech, language and life experiences. So I suppose his first driving lesson fell under life experiences.

Chapter 21

Jordan seemed to have the uncanny ability to blend in with the other kids although at that period, he had minimal speech. What he did say was largely unintelligible by the casual listener. This created a much higher frustration level for us, rather than for him. He seemed relatively untroubled by his limited vocabulary and poor speech quality. Getting his point across didn't seem to pose a problem for Jordan with the other kids.

It was hard for us to listen to him speak to other people knowing all too well they didn't understand him. During lessons, his speech seemed clear to us, but out in the world, it sounded like gibberish. Many times I felt the need to speak for him, but I tried my hardest not to do it. I knew that if he was going to survive in the hearing world, he'd have to make it alone. However, it did become necessary to fill in some thoughts for him when he spoke to adults.

Our quest for knowledge concerning speech and the hearing impaired child next took us to Montreal, which was the home of McGill University.

We had seen Dan Ling at the Voice Conference in Toronto and were fascinated by his ability to coax sounds out of the kids he worked with. So along with Karen, Jordan's tutor who was quickly becoming a new family member, we took off for Montreal. McGill had just started a new program to accommodate out of town children visiting the facility.

We arrived in Montreal on a blustery November day and, as usual, with my questionable sense of direction, we wound up lost. I had to jump in and out of the car at gas stations to seek directions. Never dressing appropriately for the weather, I was chilled to the bone as the fierce wind penetrated my t-shirt. After the tedious drive, with Jordan revved up to maximum output, running around looking for directions wasn't in my game plan. However, after an hours worth of missed turns and assorted expletives, we arrived at our destination.

The address was an older charming looking building that appeared to be built in the 1930's. The grey brick seemed to blend in with the ominous

November sky that was dotted with darker gray clouds. Fighting against the fierce wind, we climbed the few stairs to the entrance. I rang the buzzer and was greeted by a thin woman with dark hair, who introduced herself.

“Welcome, I’m Muriel, and I will be your guide and tutor for the week. The program of having people from other areas is new, so bear with us as we work out some of the bugs.”

We all acknowledged our pleasure at being there.

I said, “Can you give us an idea of what’s planned for the week?”

She answered, “Sure,” as she began showing us around the apartment.

“Since it’s already mid-afternoon, today will be a free day, which you can just do what you want. If you’re hungry you might try the deli just down the street. The food is excellent.”

As expected, Jordan tore through the minimally-furnished apartment. We hurried after him to keep damage to a minimum. I hollered for him to stop, but curiosity beat obedience two out of three times. I ran ahead and caught him, and picked him up just before he got to the bedroom. Fortunately, he was still pretty light for his age, which made it possible to grab him on the fly.

He gave me a questioning look as to why I would possibly want to stop his exploration of unknown territories.

“Put me down,” he said emphatically.

“Not a chance right now, Jordan.”

Returning my comment with an impish grin, he knew I had won this round, and would wait for his next opportunity.

The rest of the group caught up with us and Muriel continued her interrupted itinerary for the week.

“Tomorrow Jordan will start off with an audiological evaluation. I know he has had many evaluations, but we like our own to see exactly where he is at this time. He’ll have a short break, and then after the audiogram is looked at, his speech will be evaluated for all our very specific criteria.”

“How long does that take?” I questioned.

“Probably in the neighborhood of two hours, but I will break it up, so he doesn’t get too burned out.”

Karen said, “Would you mind if I was in with you? I feel I could help you keep Jordan focused on what you need accomplished. After all, I’ve been through this before.”

Muriel had an idea of what she was up against since Mollene had spoken to Muriel on the phone, prior to our visit. We were finding Jordan always functioned best when he came with a list of instructions.

“Glad to have the help,” Muriel answered. “I’ll let you guys get settled. I’ve compiled a list of restaurants, malls, and events in Montreal to keep you busy in your spare time.”

I blurted out, “Are the Canadiens in town?”

She said, “Actually they are. They play at the Forum tomorrow night.”

“I know they sell out every night. Do you know any way we could get tickets?”

Muriel said, “I have a friend who can get tickets. We also have access to a babysitter, so the three of you could go.”

Mollene made a face because she had been dragged to every stadium and arena in every city we had visited.

“Come on Mollene, you’re going have a chance to see the Montreal Canadiens at the Forum. It’s almost like a religious experience,” I begged her.

She said, “Save the sell job. I know how much you want to go. I’ll go, but you owe me. How about you, Karen?”

“I like hockey, so count me in,” Karen replied.

Muriel said, “I’ll arrange everything for the game. Tomorrow morning, someone will be over at nine to walk you over to the University for the testing. See you in the morning.”

That night we decided to try an Italian restaurant, around the corner. Mollene called, and they said the restaurant was kid-friendly. The real question was if it were Jordan—friendly.

The wind had died down, but it was still rather bitter as the four of us made our short trek down the street to Vince’s Italian Restaurant. Upon entering, the restaurant reminded me of the typical North American imitation of the classic trattoria which I had seen in numerous plazas throughout Italy. Vince’s had dim, romantic lighting, red and white checked table cloths, and empty wine bottles hanging from trellises strategically placed as room dividers around the restaurant. Traveling among the diners was a group of elderly musicians seeking requests to play their favorite songs played in the old world Italian style.

“I’m not sure this is the place for Jordan. It looks like a slow service place to me. The music isn’t going to mean anything to him. However, grabbing the bottles and flinging them would be right up his alley,” said Mollene.

I responded, “I really agree with you, but I’m too lazy and tired to look for another place. So keeping in tradition of having Jordan experience so many new things, tonight is fine dining.”

“I don’t know why I let you talk me into things, but okay,” Mollene responded.

“Look at it as an adventure,” I replied.

Mollene shrugged and said, “Yeah, adventure.”

Forgoing the ambiance and choosing speed, we decided to skip the wine and appetizers, and go right to the main meal. We expressed our need for expediting the meal to the waiter, and hoped he got the picture.

I placed Jordan on a booster, and told him nicely that I would appreciate it if he were to stay in the seat and eat his meal. According to all the child

psychologists who stressed the importance of asking a child to do something versus demanding, I was playing it right.

In order to keep Jordan occupied, during the wait for service, we immediately began to talk to him about his trip to Montreal. Having him in a somewhat controlled environment was a real opportunity which didn't present itself too often.

Although he was chronologically three years old, his hearing age was only four months. He was absorbing concepts like a sponge but was still way behind the average child his age. Not having to go through the ritual of describing every object on the table, and every movement, allowed the time for more advanced conversations.

I told Jordan that Montreal was in Canada, which was a country north of the United States. He knew that we lived in Michigan, and the city of Detroit, what ever that was, but the United States and Canada was a new concept.

Objects and concrete things which he could see and, better yet, touch, were easy to explain. Abstract ideas created a greater problem which many times required a great deal of creativity to explain.

I said, "Michigan, where we live, is called a *state*, which is in a country named the *United States*. The *United States* is a group or a lot of states combined together."

"Where are we now?" he asked.

I responded, "This is the city of Montreal which is in the country of Canada."

I didn't want to explain that Montreal was also in a province that was like a state. I figured that idea might be a bit confusing, and to tell the truth I didn't remember what province Montreal was in.

We tried not to gesture, but rather use words for descriptions, but sometimes a bit of hand movement made the difference in understanding. Along with few gestures I described what North meant and showed what direction we went to get to Montreal, Canada.

"Mollene, do you have a pen and your pad?" I asked.

Mollene reached in her purse and brought out the mandatory pad she carried to keep notes about Jordan. I began a rudimentary drawing of the U.S. and Canada. By the time I finished, it was obvious Jordan had used up all his patience and began to try to squirm out of the booster.

Luckily, the waiter came with our soup, and the prospect of playing with food detained Jordan from leaving the table. The excitement of eating didn't really interest him much like the rest of us since Jordan never seemed to be hungry or have a favorite food.

Karen took her turn and explained to Jordan that he was eating minestrone soup, which had many vegetables in it. She pointed out and described each vegetable including what color and shape it was. She described that he had

ripped open a cellophane package and was crushing the crackers. She took the cellophane package in her hand and crinkled it.

Karen said, “Listen to the sound of the cellophane crinkling.”

Obviously liking the sound, Jordan picked it up and began rustling the cellophane himself. Already having enough training, he moved the cellophane closer to his ear, realizing the closer an object was to him, the louder the sound was. The restaurant was rather noisy which made the importance of being close to his ear even more relevant than usual.

Wearing a hearing aid, created its own set of problems, which meant background noise was the most troublesome. As well as amplifying speech, hearing aids also increased the volume of any noise in the vicinity. If something is said from five feet away, and a corresponding noise is produced at approximately the same distance, the noise will drown out the speech. The low frequency noise sounds such as tapping, pounding, or even paper rustling can be very annoying to someone wearing a hearing aid.

We had become very conscious of what the surrounding environment was like when we took Jordan somewhere. Many restaurants had flat drywall ceilings where the sound bounced off creating an incredible amount of noise. Although we were aware of the problem, choosing a restaurant with acoustical sound absorbing tiles was not always possible.

When encountering noisy situations, we became conscious of the situation and tried to be very close to him when we spoke. Also in noisy places, Jordan’s lip reading skills kicked in and made it possible for him to know what was going on.

The rest of the meal went quickly and was mostly uneventful until we made the mistake of trying to stretch our luck and go for dessert. Pushing Jordan’s ability to sit, usually wound up in disaster, but since he appeared a bit subdued, we went for it.

By the time dessert came, Jordan decided he had enough sitting, and was trying to slip out of the booster chair. However, on his way down to the floor, he grabbed on to the edge of the tablecloth, pulled it, similar to the magicians who remove the cloth, and leave the dishes. Not perfecting the trick well enough, caused a few plates to crash to the floor, silencing the tumult of the restaurant. As inconspicuously as we could, we placed the broken plates back on the table, asked for the check, and left quickly.

Normally not concerned about dessert, Jordan complained voraciously about not getting his ice cream, but to no avail.

So much for another life experience.



Jordan at 2 months old



Jordan at 4 months old—The day Jordan came home



Jordan at 5 months old—Firemen that saved Jordan's life



A rare moment—sleeping



At hotel in Pasadena, during our 3 week stay



The infamous “go” game at 3 years old



At 4 years old, Jordan holding his baby brother Brian



Jordan's first pair of skis at 5 years old
He ended up sleeping with them that night



Classic Jordan



Jordan's favorite superman outfit—5 years old



Jordan loved to clown around—5 years old



Jordan and Brian—a rare relaxing moment



Jordan, Brian and Marty skiing in Vail. Jordan is 9 years old



Jordan and Brian having fun at Grandma's pool in Florida.
Jordan is 9 years old



Jordan speaking at his Bar Mitzvah. 13 years old



Jordan, Marty, Mollene and Brian at Jordan's Bar Mitzvah



Happy Jordan as he always is. 15 years old



Jordan horsing around with Brian. 15 years old



Andover High School hockey.
16 years old



Jordan's high school graduation.
One of my proudest moments as a parent.
18 years old



Trip to Mexico. 20 years old



After water skiing. 21 years old



A trip to Venice. 21 years old



Jordan's MSU graduation. 22 years old



Hillary and Jordan. 31 years old

Chapter 22

The next morning the audiological evaluation went well, since Jordan had done it before, and actually enjoyed the procedure. The audiologist evaluated the results, which were pretty similar to the most recent ones we had brought with us. The audiogram was used by many traditional teachers to measure how well the child should be expected to speak, because it showed the limits of their hearing.

Teachers who believed in auditory training and using speech as the only method of communicating did not believe an audiogram to be a limiting factor in expectations.

We still always followed Dr. Griffiths's words—not to believe that a young impaired child's progress should be limited. Jordan was already exceeding the expectations that his audiogram would lead someone to expect.

Following the evaluation, we were ushered in to meet the guru of speech, Dr. Dan Ling. He was an impressive man with gray hair, and the aura of a mythological god, because of his reputation.

The audiologist introduced us.

Dr. Ling responded with a rather formal, "How do you do? I assume this is Jordan."

I took Jordan over to him, and not being briefed in formality, Jordan responded when Dr. Ling offered his hand, with a hand slap, or a modified high five. I suppose that is not the way Dr. Ling was usually greeted, but he chuckled none the less.

"Well let's have a look at this audiogram. I see that Jordan is profoundly deaf. How old was he when you began training?"

Being a bit ashamed that it took so long to discover Jordan's deafness, I quietly answered, "We began about three months ago."

He responded with, "Well let's listen to what he sounds like. Jordan, why don't you have a seat over here."

Dr. Ling showed him where to sit and immediately began to rattle off a few syllables. “Bee, bah, boo. Now Jordan repeat that for me.”

Knowing this drill very well, Jordan immediately repeated what he had heard.

Dr. Ling smiled and said, “Very good.”

He then began to run through a series of drills, which Jordan eagerly repeated. After about ten minutes, Dr. Ling said, “Pretty impressive for just a couple months of speech therapy. We need to have a therapist go through a complete evaluation so we can make the proper recommendations to improve Jordan’s speech.”

Jordan got up from his seat and began to race for the door. We quickly bid Dr. Ling adieu and took off after Jordan. I swooped him up in one motion when I caught up to him. Used to being grabbed from behind, he didn’t resist.

A very detailed evaluation followed, which took up the better part of the afternoon. Every facet of speech was analyzed to determine exactly where Jordan was and what work had to be done to turn him into a normal-speaking person.

Most people think speech consists of teaching a person all the letters in a language. However it is a much more detailed and complicated process.

The complex evaluation began with just basic use of the voice. Next it proceeded to voice patterns which included duration, intensity, and pitch. Long vowels and diphthongs were evaluated next. The evaluation was designed to follow the order in which an infant learns speech. Next came beginning consonants which included such items as plosive *b* and *p*, and fricatives *h*, *f*, and *v*. Short vowels are evaluated next which include more plosives, fricatives, and the liquid *l*. Consonant blends which include *gr* and *bl*, *tw* and *sc*, just to name a few of the dozens of two-letter combinations. Consonant blends also occur at the ends of words; such as *trouble*, *gargle* and *spades*.

We were then told that we would discuss the evaluation and future strategies the following morning.

That evening we went to the Forum and saw the most revered—the Montreal Canadiens. Definitely not the purpose of the trip, however it added another dimension to the success of the venture.

The next morning, one of the students came over to entertain Jordan, while Muriel discussed the evaluation with us. Breaking down Jordan’s speech in such detail opened our eyes to how truly complicated the task of successfully turning him into a normal speaker would be. The evaluation of breaking down every component of his speech and having a template to follow made the entire program much easier for me to follow. We also received a copy of Dan Ling’s book *Speech and the Hearing Impaired Child: Theory and Practice*.

Probably the most valuable tool we received was a copy of *Cumulative Record of Speech Skill Acquisition*. This manual was written to trace progress

throughout speech and language development. It set up both short and long-term goals for learning each target and sub-skill. Having such a well-defined course was something that I felt was missing from our approach at the moment.

Slowly all the pieces to the puzzle of speech and language development seemed to be falling into place. What we found was that every lecture and article was worthwhile, because invariably one very useful piece of knowledge would come out of them.

Montreal just happened to be loaded with them.

Chapter 23

Life back home was hectic, to say the least. The morning ritual of chasing Jordan around to get him ready for nursery school was not easy. After the exercise of doing everything with his hearing aids, lengthy descriptive breakfasts and dressing, he was ready to face a new day of learning and speech lessons. While most kids could be dressed and fed in about ten minutes, the process took a minimum of one hour on a good day.

Keeping a balance between academics, speech and language development, and being a three-year-old kid was tough.

Jordan had a schedule which kept him pretty tied up. We weren't really looking to add to his activities, but he began to show an interest in snow skiing. I had skied for years and continued to ski at some of our local resorts on Sundays with a few friends. Jordan was fascinated with the equipment and began to ask questions about the sport. At that point I decided it would be great to teach him to ski.

When Jordan was evaluated before leaving the hospital as an infant, we were cautioned due to his pre-maturity and, not knowing if he had been deprived of oxygen, that he could suffer a myriad of problems. Being told that balance, gross motor, and especially fine motor skills were areas that could present problems, we were keenly aware of his progress. Interestingly enough, his motor skills were exceptionally advanced, and were one of the areas that he was normal, relative to his chronological age. Taking that into consideration, I felt that he could handle skiing at three years old and believed it would be a good outlet for his pent-up energy.

Our neighbors, the Becks, had started their daughter Linsey skiing the year before, and had a pair of 90cm. plastic skis and a pair of boots, which we borrowed. We dressed Jordan in every piece of clothing he had, covered with a one piece snow suit.

Next to the Becks' house was a twenty-foot area that had an incline of about five degrees. A snowfall of about four inches from the previous night

covered the mini-hill. Due to Jordan's light weight, needing a base underneath seemed inconsequential.

The big moment arose and we walked over to the hill, excited with the anticipation of Jordan's first skiing adventure. Although covered by a scarf, his excitement could be seen in his eyes. Before we walked the seventy-five feet to the area, Jordan said, "I have to make a pee-pee."

I rolled my eyes at Mollene. Trying to be a calm and understanding parent, I smiled and said, "Do you think you could wait ten minutes?"

"No, I have to go now, Papa," he said.

At that point Jordan called me *Papa*, because, in the sequence of teaching speech, he couldn't say a *D* for *Daddy*, which I preferred to be called. However at this point, we were thrilled he spoke as well as he did.

After doing his business and getting himself all wrapped up again, we heard the ever-dreaded high pitch sound emitted by the hearing aids' feedback. When something covered the microphone of the hearing aid, or there was not a proper seal of the earmolds, the aids produced a high-pitch, extremely annoying sound. Some people could hear their own feedback, and make the proper adjustments, but we didn't really know if Jordan was aware of it himself. A snowsuit was a very bad offender in causing feedback, because it was not very porous, and when the microphone hit against it, there was a strong seal. Since children have short necks, this caused the ear to almost rest on the shoulder of the suit. Compounding the problem was a hat that covered the ears. We were completely crazy when it came to feedback because we felt, if Jordan walked around buzzing, he would be subject to ridicule. Besides that, feedback was annoying. Everything that was possible was done to minimize the possibility of feedback. New earmolds had to be made every three months due to growth and the increasing size of the ear canal.

Finally after a session of flattening the shoulder on the jacket and adjusting the hat, we were ready to proceed to the top of the Matterhorn.

Putting the skis on turned out to be a trying task. The skis did not have a standard binding where the person just stepped in, but rather had a leather strap, which wrapped around the boot. Every attempt to attach Jordan's foot to the ski resulted in him walking right out of it. Not being endowed with a lot of patience, both Jordan and I were becoming quite frustrated. Finally after about ten attempts, I succeeded in getting the ski firmly attached to his boot.

"Jordan, I am going to push you down this little slope. Keep your feet straight and facing down," I said.

Mollene was at the bottom of the hill, with a video camera that we had borrowed, preparing to capture the future downhill racer on tape for posterity.

Anxiously awaiting the big moment, I said, "One, two, three, go!"

Down the little slope, Jordan slid safely, all of the way to the bottom of the twenty-foot slope, which he sped down, in about two seconds. His face was covered with an ear-to-ear grin.

I knew if I could get him to try skiing, he would love it, because of his love for speed and action. Being doting parents, we were so proud of him, and gave Jordan a huge hug. The accomplishment of skiing down that towering mountain was similar in my mind to the Wright brothers' exhilaration after their first flight. Once he got in the groove, there was no stopping him. We kept going until, I was totally exhausted from carrying him up the hill for about two hours.

Having totally mastered the mountain next door, Jordan graduated to the sledding hill at the elementary school the next day. The school had a real hill that was one hundred feet long and was rather steep, which made carrying Jordan up a tough chore. However *Super Dad*, who wanted his son to experience everything, lugged Jordan up the hill.

After attempting to demonstrate a snow plow stop, I gave him a gentle shove, and down the hill he flew, with me in hot pursuit. All of a sudden I saw the cyclone fence at the bottom of the hill, and I hoped either Jordan would remember how to stop, or the terrain was flat enough to stop him. Through a combination of a long run-off and an attempt to stop, Jordan slid to a gentle stop. By the time I had stumbled down the hill, I found him with a look of confidence and the desire to do it again. We spent the rest of the afternoon with him skiing and me increasingly becoming pooped from dragging him up the hill.

That night Jordan took the skis to bed and slept with them, which became his habit when he got something new.

Chapter 24

We had thought about the subject of more children for awhile and just didn't know to how to decide what to do. We knew we always wanted another child, but there were so many factors that caused concern.

We had learned that Mollene had Jordan prematurely due to an incompetent cervix. The condition caused the weight of the baby to press on the cervix which would just totally open up and the baby would pop out.

In order to keep that from happening, a procedure called a *circolage* would be performed. This procedure laced up the cervix so the baby couldn't escape. That eased our minds from a medical standpoint. We could prevent a repeat of Jordan's birth from happening.

Another area of concern was whether or not the baby would be deaf like Jordan. As much as we wanted another child, we weren't sure we would be able to devote as much time to another deaf child. Even though we were advised to have genetic counseling, we felt confident that Jordan's deafness was due to the combination of his prematurity and ototoxic drugs.

The next issue which loomed over our heads was how realistic it was to have another child with the incredible amount of time that was allotted to Jordan. Would it be fair to a new baby, or would it diminish the time which was available to tutor Jordan?

Jordan was a full-time job for two people. Luckily, Mollene was not working, and I had a very easy schedule, which made me available much of the time to help out. When I would be home for the entire day, Mollene would disappear and not show up until late in the day, getting a well-deserved break.

After considering all the possibilities, we opted to go for it. Mollene became pregnant almost immediately, which obviously clinched the decision.

We told Jordan that Mommy was going to have a baby, which truly seemed to excite him. Jordan was the kind of kid who liked new things and rolled with the punches. So the prospect of a baby sounded like fun to him. We decided to let

Jordan be our spokesperson, to tell my parents the good news. Actually, Mollene wasn't with us when I first went to visit my parents. As soon as we hit the door of their apartment, Jordan, bubbling with excitement, screamed it out.

"Mommy is going to have a baby!"

My mom had a puzzled look on her face, because in Jordan's enthusiastic state, he didn't enunciate his words very well.

I said which I had to do so many times, "Say it again, slower."

Still bursting at the seams, he blurted it out again. "Mommy is going to have a baby."

Although not as well as he spoke in a more calm state, my mom got the message this time. She picked Jordan up and gave him a big hug and kiss, and reached over to me and gave me a kiss on the cheek.

"That's wonderful. I am really happy for you," she said.

Jordan jumped out of her arms, and being still fired up, raced into the den to tell my dad. Not understanding Jordan's speech as well as my mom, it took my dad about three attempts for Jordan to get his point across. Jordan's speech at that point was completely understandable to us, because we regularly had to fill in missing sounds. To someone who knew him, his speech was passable, but to the casual person he encountered, there was a great deal of repeating.

However, as many times as he had to repeat things, he never seemed self-conscious or overly-frustrated. Fortunately for him, his personality allowed him to handle it.

It was Mollene and I who were bearing the weight of Jordan's inability to make himself understood at certain times. Hearing him speak poorly, when we knew he could do much better, would frustrate us and also get us very angry.

When a normal hearing person speaks, he or she can monitor what and how something is being said. When a profoundly deaf person is talking, even with amplification, he or she cannot monitor what is said well. Therefore, deaf people are unaware many times of what their speech may sound like.

We would constantly point to our ears and remind Jordan to listen to what he was saying. Remembering that he was also a four-year-old toddler who had other things on his mind was something that wasn't always in the forefront when it came to him speaking to other people.

It was around this time that we purchased an auditory trainer, which was a machine which aided in teaching listening skills. The trainer was a unit which had settings that could be adjusted for decibel loss in the different frequencies, therefore eliminating the need for the hearing aid. The speaker used a microphone which sent the sound through the unit and was delivered to the headset of the listener. The advantage of the auditory trainer compared to hearing aids, was that the sound could be transmitted directly to the ear of the listener. This would eliminate any background noise, thus producing a more true sound. The trainer was a valuable asset, and helped teach listening

skills, but had its drawbacks. The unit was large and cumbersome which meant the user had to stay in one place. This severely limited the length of the lesson due to Jordan's lack of ability to remain seated in one place very long.

With regard to telling my dad about Mollene being pregnant, he finally got the point and the questions began. Although my dad was extremely excited about the prospect of another grandchild, the trepidation over a repeat of Jordan's traumatic birth caused some serious concerns. Although I had explained many times that Jordan's premature birth was due to the incompetent cervix, my dad needed the reassurance of another explanation. His skepticism of the medical community in general sometimes clouded his judgment, especially on issues relating to his own family.

After filling him in again on the function of the circolage, he seemed as comfortable as possible and immediately changed his attitude from one of concern to elation.

Chapter 25

Jordan was now four years old, and his speech seemed to be progressing at a rapid rate, although never fast enough for me. His quality of speech was improving as well as his command of the language. Although the progress was amazing, the amount of work that remained became more apparent. Comparisons to other kids inevitably caused me great concern. Other kids were already sounding like encyclopedias compared to Jordan's most rudimentary discussions. It made no difference how many times I told myself that he was three years behind, and one day would catch up, the pain was still there. Sometimes I was so disturbed by my making comparisons with other kids, that I found myself avoiding being with Jordan when he was with other children.

After a particularly difficult lesson or frustrating day, I would question if we were doing the best for Jordan by subjecting him and us, to this continuous barrage of teaching. Were we hurting him mentally more that helping him? What are the ramifications of this steady diet of being pestered to improve his speech and vocabulary?

We kept asking ourselves if he would be better off learning sign. Should we be putting the greater part of his education in the hands of the schools, after all they were supposed to be the experts at teaching the hearing impaired.

Mollene would always say, "Our goal is to have him be normal and able to communicate with everyone. By teaching him sign, you are severely limiting his potential. I can't bear the thought of not being able to speak to him verbally."

I'd always answer, "You're right. There's no question about it. I'm just frustrated."

Usually the hour of self doubt quenched the fires in the pit of my stomach until the next episode.

One attribute that we made sure we didn't overlook was that Jordan was a ton of fun. Besides his mischievous behavior, he was a kid who was fun to be with. He loved to be thrown around, wrestled with, and just generally liked to be played with. He was a child with a thousand expressions, who was always

smiling and ready for a good time. One thing I always said was that I hoped his language would develop fast enough to keep up with his sense of humor.

Jordan's physical progress was progressing extremely well. He was agile and had excellent hand-eye coordination. Fine motor skills, which were supposed to be an issue with preemies, were far above the average.

Days could be filled with highs and lows, depending on what happened with Jordan on a particular day. I was probably close to being a manic depressive and may have needed counseling or medicine to keep me from totally fixating on him. My life was totally dependent on Jordan.

Chapter 26

Fortunately, Mollene had the surgery and the circolage was in place. Her activities were curtailed, and she wasn't allowed to travel, which brought up another issue. Her parents had bought a condo in Delray Beach, Florida, and we were going to stay there with Jordan to initiate it. After much discussion, she twisted my arm to go without her. My in-laws were not going to be there yet, so Jordan and I were going to be left to our own ingenuity.

I explained to Jordan that Mommy couldn't go, but being the world traveler he seemed rather undaunted by the news. He was much more interested in going on an airplane, not really remembering some of our monumental flights from the past. For a *Jordan trip*, the flight went rather smoothly, with a minimum of airport chasing due to having a non-stop flight. After past experiences, I learned that it was worth it to pay more, than get the cheaper fare with numerous stops.

We arrived at the condo and were completely surprised at the roominess. Jordan was going to have plenty of room to explore.

"I stay with you, Papa," he said.

Jordan liked to crawl into our bed during the night, which we were trying diligently to discourage, with minimal success.

I responded, "No, you'll have your own room, just like at home."

"No, with you," he demanded.

"Be a big boy, and stay in your own room," I insisted.

The expression on his face told the story. There wasn't a chance in the world that he would stay put. Knowing that his will was much stronger than mine, come nightfall, I was going to be the one who would surrender.

Obviously the discussion was completed, so Jordan tore off to explore the rest of the condo. He managed to open the lock to the screened-in patio, and was already attempting to open the door to the back.

"Hey, hold on. Don't go outside," I hollered.

I ran over, opened the door and grabbed Jordan's hand. Not wanting to be restrained, he attempted to pull away, but my grip was still stronger than his.

I unlocked the door, took his hand, and ventured into the back area. A large well landscaped retention pond was situated no more than forty feet from the back door. The thought that this situation was a disaster waiting to happen raced through my mind as Jordan pulled away to get a better look.

I raced over and said, "This pond is not for swimming. I don't know what's in it, so stay clear."

Although Jordan was an excellent swimmer, I didn't want him being alligator food, since so many ponds in Florida had alligators for residents. Once his curiosity of the pond area was satisfied, we went inside to unpack and attempt to relax.

I began sifting through the bags for shorts and t-shirts for us, because the northern winter clothes we were wearing just weren't going to cut it. I walked into the living room to give Jordan his clothes when I discovered him poking at a pack of rather repulsive-appearing ants.

"Come on, get up, and wash your hands,." I demanded.

"No, I want to play with them," he replied.

It wasn't a question of hearing, but I often had to raise my voice to get my point across.

"Now! Get up and wash your hands."

Grudgingly, he obeyed. I bent down and examined the critters more closely. To the best of my knowledge, I went with my original assessment that they were ants.

Not having, any bug killer, I opted for using a wet piece of paper towel to be my murder weapon. Realizing that the probability of more ants existing, I put bug killer on my shopping list.

The next couple days were great. Our friends, Steve and Sandi Matz, were staying at a complex just a few miles away, so they joined us for most outings. We went to the pool, the beach, a spring training baseball game, and out to eat. Everything was working out well, until the morning of our third day. Jordan came in to my room and said, "Papa, I have these red things all over my tummy and arms."

I examined them and determined that they were probably bites from our little house guests, the ants, who I had unsuccessfully tried to annihilate. I had a small tube of cortisone in my drug bag, and figured it would reduce the itch and inflammation.

We stayed at the pool all day but by the end of the day, Jordan's alleged bug bites had spread to his entire body, including his face. Since we hadn't been in the condo all day, bug bites seemed to be a misdiagnoses.

The Delray Beach hospital was just across the street, so I figured we might as well get the little red welts checked out. After a short wait, we were called in

and the doctor took a short history, asking me about the questionable lesions. He took one quick look and proclaimed, “chicken pox.”

I thought about it for a second and responded, “How is that possible? He already had the chicken pox about six months ago.”

“I can tell you that this is a case of chicken pox. Possibly he really didn’t have it before, or occasionally someone gets such a mild case that they don’t build up enough immunity to prevent another case.”

“So, what should I do with him?” I asked.

“Put some anti-itch medicine on them, keep him from scratching and out of the sun.”

As we left the hospital, Jordan said to me, “He had a big mustache, and I couldn’t tell what he said.”

“Jordan, you have the chicken pox again.” I answered.

Not knowing that chicken pox were supposed to be a one-time event, Jordan didn’t respond

Obviously, since he was to stay out of the sun, I figured we might as well go home. I explained it to Jordan, and after some serious complaining, he realized if he couldn’t be outside, home was probably the best option. I went back to the condo and changed our flight to the next morning, which would get us home mid-afternoon.

I called Mollene and told her about Jordan’s chickenpox.

“But he already had them. Once again Jordan does the impossible by getting them twice.”

I explained to Jordan that I was going to have him wear long sleeves and pants in order to hide his chicken pox. I had him pull his hat over his eyes in an attempt to cover his face. I picked him up so that I could keep him away from other people, as we made our way onto the plane. Everyone had already boarded as I carried him down the aisle and set him into the window seat, which I figured would keep him away from anyone else.

No sooner had we sat down, than Jordan in his loudest, most perfectly-enunciated speech of his life, said, “Papa, these chicken pox itch.”

Enough said about good speech.

Chapter 27

Living on a lake created its own set of problems for dealing with hearing aids. When we took Jordan into the water, something had to be done with his aids. After mulling the situation over, we came up with the idea of devising a durable container, which turned out to be a margarine container. We cut a piece of sponge to fit in the container, put the hearing aids on it, and then put another piece of sponge on top, before replacing the margarine container top.

By sandwiching the aids, they were well-protected from being bounced around with the margarine container also serving as a flotation device, in case Jordan decided to take the container out for a swim.

The other hearing aid issue involved Jordan being without his hearing aids while being in the water. We knew we couldn't call to him if we needed to. Secondly, we hated him to be without his aids for so long, considering how much time he spent in the water.

The situation created a couple of loony parents who immediately ran to put his hearing aids on the second he climbed out of the water. Convinced that not being amplified for two minutes would severely limit his language development caused us to be bouncing up and down every two minutes.

Due to the fact that he continually had tubes in his ears, because he always had fluid, he had to have a waxy tight-fitting ear plug in his ears to prevent water from getting in. Therefore we were always alternating between the hearing aids and the plugs.

The spring of 1981 was unseasonably warm with the mercury hovering around the 80+ degree mark the entire month of May.

Mollene was entering her seventh month, and all was well except her discomfort from the unbearable heat. Her feet would swell. In order to eliminate it, she tried sit down and elevate them, which was not the easiest task with Jordan racing around.

The morning of May 24th brought temperatures in the mid 80's, with humidity around 100%. It was the day before Memorial Day, and I decided to take a six-mile run with a few friends.

Not properly hydrating myself before or during the run left me weak and very light-headed by the time I ran home. The room was spinning around and I began to feel cold and nauseous. With all the strength I could muster, I dragged myself into the kitchen and began to drink water, which didn't seem to ease my burden very much. When I laid down, the room began turning around even faster than before. I forced myself into a sitting position and that's where I sat for the next few hours. I really felt poorly for the rest of the day and just basically lounged around doing nothing. Around nine o'clock, Mollene began complaining about feeling some cramps, and went into the bathroom.

She hollered out, "You're not going to believe this, but my water broke."

I thought to myself that *this* was happening again.

"I'll call my parents and get them to come over so we can get to the hospital," I said frantically.

My mom came by herself in record time, which was no great feat for her because she was well known for her lead foot. We hopped in the car and began our drive to Sinai Hospital in Detroit where Mollene's doctor was on staff. We hardly spoke, not quite knowing what to say to each other.

Although she was already at seven and a half months, the horrible thoughts of another premature baby were racing through our minds. Jordan's ordeal had taken so much out of us that the thought of a repeat was inconceivable.

I said, "I guess we're not having a Memorial Day picnic."

Being quite used to my nonsense, she ignored me as usual.

Although ignoring speed limits, the ride took an eternity before we finally pulled up to the emergency entrance of the hospital. After the usual red tape at admissions, Mollene was ushered into a labor room and hooked up to a monitor. After completing the rest of the paperwork, I was allowed to come in. Entering the labor room reminded me of when I had donated time at the Detroit House of Correction. The room was narrow, with a bed, chair, and a table with a monitor on it. Obviously the vomit-colored paint had been leftover from the prison. It's hard to believe that such a happy event as the birth of a child was initiated in such a dreary place.

Although the monitor showed Mollene was in labor, she couldn't feel anything. I tried to explain to the resident that Mollene had a circolage and she had to have the stitches removed before the baby could be delivered, but he kept telling me that we were waiting for her own physician.

Finally Dr. Lakin came and decided it was time to get the show on the road.

He said, "We need to take you, Mollene, and immediately remove the circolage. We'll put you in a twilight sleep for the removal and then probably the baby will follow shortly afterwards."

I was told to wait and that I would be called as soon as the baby was born. I gave her a peck on the forehead, wished her good luck, and said that I'd catch her in a few minutes. Nervously, I sat down and began to watch the replay of the Indianapolis 500, which didn't come close to holding my attention.

About half an hour went by when all of a sudden people started running out of the delivery room. Then a couple of doctors went into the room and suddenly a blue baby, attached to a multitude of tubes and wires, was wheeled out on a small cart.

I kept trying to ask what was going on, but to no avail. Finally Dr. Lakin emerged, and said, "The baby was born in a great deal of respiratory distress. We have him breathing okay with the aid of a ventilator, but we can't really determine what the problem is."

"What are you going to do now?" I asked.

"They are sending him up to be evaluated. More than likely we'll have to send him to New Grace which has a neonatology unit."

I asked, "How's Mollene?"

He answered, "She's fine. I did an episiotomy, but that's about the only discomfort she'll have. She really didn't have any labor. As soon as they know anything, someone will tell you."

About an hour elapsed before a doctor came and told me that the baby was being transferred to the neonatology unit at Grace hospital.

"Can I see him?" I asked.

"Hurry up. I'll take you." He responded.

I was led into a brightly lit examination room, with the baby who was to be named Brian, lying on a warming table attached to the all too familiar array of tubes and wires. He was a dusky shade of black and blue, and appeared as bad as Jordan did at his worst. As much as I had seen before, it somehow did not prepare me for the sight of another helpless baby. Immediately I turned away and began to sob.

The nurse told me that they had to move the baby that minute. I reached over and rubbed his tiny hand. Although he was mammoth compared to Jordan, his condition made him seem much smaller. Watching them wheel him out sent that cold feeling of reality up my spine, and the thought that I wouldn't see him again pierced my brain.

I knew it would take awhile to examine him once he reached Grace, so I figured I would try to find Mollene. I wasn't sure what she knew of the situation yet. After asking a multitude of people and pounding up and down the halls of the hospital, someone was able to track her down. As I entered her room, and looked at her, we both started crying. I couldn't look at her without sobbing, so I turned away and began to speak.

"What do you know?" I asked.

"Really nothing. I don't know if the baby is a boy or girl." she said.

I tried to smile and said, "It's a boy. We have another boy."

“What’s going on?” she asked.

“There isn’t much to tell. He is breathing with the aid of a vent, and they can’t figure out what’s wrong. He really should be developed enough to breathe on his own. They’re moving him to the neonatal unit at Grace,” I said.

Mollene responded, “I just can’t believe this is happening again.”

“I just don’t know what to think or say. I have to get out of here and go see what they are doing. It’s been almost four hours since he was born and no one seems to have any idea what’s wrong.”

I kissed her on the cheek and gave her a half-hearted hug and left to go to the other hospital which was only a mile away.

When I arrived at Grace Hospital I was desperately trying to keep focused and control my emotions, I cruised through the deserted hallways to the neonatal unit. When I arrived at the unit, the nurse told me that they were working on the baby, and it would be a while.

“What’s his condition? Did they figure anything out yet?” I asked.

The nurse was nice enough and tried to be compassionate, but said, “I really can’t help you, because I don’t know anything other than he is on a ventilator and they are trying to evaluate him now.”

I tried to sit down and wait, but found myself pacing back and forth. I kept thinking about Jordan, and what we had gone through with him, and the possibility of doing it again. The horror of the four months waiting for Jordan to improve kept running through my head. I kept repeating that this couldn’t happen to us again. After a long hour, the nurse come out and said it was okay for me to come in. She told me to scrub and put on a gown, a procedure that I was all too familiar with. I went into the unit and was motioned over by a doctor standing over the baby with an oxygen bubble over his head.

“The baby is okay now. He had a pneumothorax, which is a hole in the lung. We had to put a tube, which you see, through the chest into the lung to re-expand it. As soon as we completed the procedure, his lung function improved, and went from that dusky color to bright pink.”

“I can’t believe the difference in him. He looks great!” I exclaimed.

The doctor, whose name tag read, *Dr. Patel* said, “I know you are very excited that the baby has improved so much, but we must be cautious on a long-term prognosis, due to the possibility of hypoxia. He could have had bleeding into his brain and—”

I interrupted, “I don’t want to be rude but I had a very sick preemie and I know all the possible complications and would prefer not hearing them again.”

She paused and gave me a look of surprise and then said, “Okay, I won’t tell you any more details, but you will have to watch his progress very carefully. He will go from this critical side to the regular neonatal nursery in a few hours if all is well.”

I thanked her and squeezed Brian's hand before I made the phone call to Mollene, that all appeared to be well.

Brian progressed well, and was gaining weight like crazy. Everyday the nagging issue of hearing came up in my mind, so I would tap outside the isolate to startle him. He jumped to the most subtle tapping. Although I knew too much about hearing that a low frequency tap did not constitute a hearing evaluation, I was convinced that everything was fine. All we wanted now was the sounds of cries from our back bedroom from Brian when he came home.

Two weeks passed and Brian was allowed to make the trip home.

Chapter 28

Bringing a baby into the house that Jordan ruled had us a bit unnerved, but Jordan was madly in love with his baby brother. He would sit and talk to him, and was totally thrilled when we let him hold Brian.

The next milestone in Jordan's life was rapidly approaching, the beginning of kindergarten. Somehow, the act of following up on our convictions was more intimidating when faced with the prospect of dealing with public school versus a private nursery, which we were paying.

Mollene scheduled an appointment with the principal of the school Jordan was supposed to attend. Karen came with her as an expert to substantiate what Mollene had to say. After exchanging the usual salutations, which Mollene thought was to be an uplifting experience with a principal from a school district known for its progressiveness, the meeting turned into a battleground. Mollene presented a modified version of the *Jordan Levin story*, which had already turned into an epic novel. The principal took it all in without appearing the least bit impressed by a relatively moving story.

"But why should he be in a regular classroom, when Bloomfield Hills has the best programs available for deaf students?" the principal asked.

Mollene answered, "We have chosen a different path for him to follow. Everything we have learned states that placing the child in a regular classroom with hearing peers will give him a better chance to succeed in a hearing world."

The principal countered with, "These programs were designed to teach the children to speak and function with normal children. He will be mainstreamed into certain regular classes when he is able to be competitive with the other children."

Karen said, "Have you ever spoken to any of the deaf students? They can't speak well enough for you and I to communicate with. They're mainstreamed in name only, but really are not part of the class. The other kids can't understand their speech, so they don't really do anything with them."

“Deaf kids hang out with deaf kids. It’s who they are comfortable with,” Mollene said.

The skirmish went on for about an hour, before the principal called in the kindergarten teacher to explain the potential situation. The teacher seemed to have no greater understanding of what we were trying to do than the principal. She seemed to present the same argument that she couldn’t understand why Jordan wouldn’t be better off in a hearing impaired program.

After a few hours of haggling, the outcome of the meeting was most disappointing for Karen and Mollene. They failed to convince the opposition that having Jordan in regular classes was the most advantageous for him. However, due to the disabilities acts that stated children couldn’t be prevented from going to school, Jordan was going to regular school without the blessing of the principal.

When the school semester began, Mollene met with the teacher and explained in detail what we felt was necessary to be done for Jordan in order to succeed in regular school. She explained that she had to be facing him in order for him to tell what she was saying, due to the necessity of Jordan reading lips.

“If you can’t understand him, do not hesitate to ask him to repeat it. You won’t hurt his feelings, because he is used to it. Do not treat him any differently than the rest of the children,” Mollene explained. Without the principal being present, the kindergarten teacher seemed to have softened to our plight.

Mollene then asked, “Would it be possible to come and talk to you for two minutes at dismissal time every day? Jordan misses so much. This would allow us to go over anything done during the day.”

With a bit of reservation, she agreed. No one really got the picture of what Jordan was really about.

As Mollene was about to leave the school, the principal ran up to her and said, “In order to have Jordan in a regular classroom, and not labeled as hearing impaired, you have to sign away all his rights as a handicapped student. He will be unable to receive special assistance or tutoring.”

Obviously, this was going to be us versus them. Mollene signed the paper and left the building without comment.

Chapter 29

Fortunately, Brian's development seemed to be improving, easing our minds about all the potential problems that existed due to his traumatic birth. The question of deafness was not an issue, since he responded well to sounds of all frequencies.

Kindergarten proved to be a challenge far beyond our wildest dreams. For most kids, kindergarten was a fun time with few cares. To Jordan, it was an added burden to his already busy life.

There was morning kindergarten, followed by his lesson with Karen three days a week, along with speech and language tutoring at home the other days. Packed in also were gymnastic classes and also his new conquest of ice skating, so he could play hockey with an assortment of kids from school. His lack of understandable speech didn't seem to present a problem with the other kids.

When Jordan came home after all this, the daily discussion began about what had been done at school that day with Mollene who had diligently written down every word the teacher had told her at their two-minute meetings after school. Jordan wasn't really much help when it came to relaying the events of the day. Mollene would ask him what happened at school, but he really was not capable at that point of describing much in great detail.

Jordan was pretty carefree, and nothing seemed to bother him, but kindergarten was killing me. Most parents wouldn't have been under as much stress if their kids were entering Harvard. Making sure he understood every idea and concept during his half-day at kindergarten was the foremost thought in my mind. I'd call Mollene from work and ask what Jordan did in school that day.

I'd ask, "Is he getting it? Is he understanding what is being done?"

She'd say, "Relax. He's doing okay."

The pressure that was created by the principal being opposed to Jordan was intense in my mind. We had to prove that we had made the right choice in putting him in a regular program. I couldn't stand to think of him failing.

Too much effort had already gone into making him the person he was. He was still my Superman and success was the only option.

When the year ended and kindergarten was just a memory, relief was found in the form of summer vacation for me. We were back to our so-called normal situation of Karen, followed by daily speech and language lessons. However, any time spent with Jordan was speech correction time, and a language development lesson. We still described every single object and concept around him, to make up for lost time and his inability to hear the peripheral conversation.

The summer buzzed by in its usually speedy way, and the prospect of first grade was staring us in the face. Most parents were thrilled when the kids headed back to school, but for us it meant more torture sessions.

Although it may sound like I couldn't stand the work, that wasn't true. We had chosen our path and felt in our hearts we were doing the very best we could for Jordan. I felt bad and sorry for him that he had to endure this amount of continuous work, but we believed that it would improve his quality of life in the long run.

The first grade teacher was an animated young woman with a charming personality, who was very upbeat about teaching Jordan. Mrs. Finnegan seemed to accept the challenge of teaching a hearing impaired child in a regular classroom.

Mollene had a meeting with Mrs. Finnegan prior to the first day of school. Armed with her *Jordan Levin set of directions*, Mollene set down the guidelines of dealing with Jordan.

"Jordan is profoundly deaf and even with his hearing aids, he does not hear very well. He reads lips extremely well, and you must face him when you are speaking to him," Mollene explained.

"What if I'm in front of the class writing on the board?" she asked.

Mollene answered, "I know it's difficult, but you must turn and face the class when speaking. If you are going to give a test in the future, you probably have to tell him individually to make sure he got it."

"I'm sure I can get used to that," she reassured Mollene.

"One of the most important things to know about Jordan is that he must be treated like everyone else. He's not used to being handled gently or shown favoritism. He actually doesn't realize that he is different than the other kids, which makes him quite unique. We have worked very hard to mold him into the kid he is. When he speaks to you and doesn't make himself understood, just ask him to repeat it. He's used to being told to enunciate and speak more clearly," Mollene explained.

Mrs. Finnegan smiled and said, "I'm sure I am up to the task and am looking forward to meeting Jordan."

"I have one more request if it's possible? I'd like to speak to you for two minutes after you dismiss the kids, so that I can get a rough summary of the day's work," Mollene asked.

"No problem. Just come right after the kids leave the building," Mrs. Finnegan replied.

First grade was no less challenging for me than kindergarten. The underlying message that the principal was waiting for him to fail, always hung over us like an impending thunderstorm.

One unseasonably warm October day, the first call came from school. Mrs. Finnegan had called Mollene and had told her that Jordan kept taking his shirt off and wouldn't put it back on. The other issue was a bit more crucial, which concerned Jordan not being able to comprehend phonics.

Mollene felt I was the best person to go and speak to Mrs. Finnegan's concerns. After making an appointment to see her, I discussed the issue with Jordan, who didn't see what the big deal was. He thought he was cooperating and learning phonics.

We knew Jordan could learn to read phonetically, because that was actually part of the method we used in teaching him to speak. I felt that having Jordan at the conference, I could prove my point.

When I arrived at school, Jordan was sitting in the front row, with his shirt off. I tried not to laugh when I walked up, but seeing his naked little skinny chest and arms sticking above the desk made me chuckle out loud. I introduced myself to Mrs. Finnegan, and tried not to smile as she told me her concerns with Jordan's apparent need for being naked.

Turning to Jordan I said, "Jordan, I know it's hot, but could you please put your shirt on and keep it on in class?"

"Yes, Dad," as he now called me instead of Papa, because he could now say the sound for *d*.

Jamming ourselves into the tiny desks, Mrs. Finnegan and I sat on either side of Jordan. She placed a stack of papers of Jordan's past work on the desk and began to show the papers of a person who was clueless concerning phonics. When Jordan didn't feel like doing schoolwork, he would write the same answer for every question, which he did so masterfully on these papers.

I said, "I see your concern that these papers would indicate that Jordan cannot get phonics, but I am confident that I can prove otherwise."

Mrs. Finnegan next asked the question which we always were waiting for. "Do you think he can't do phonics because of his hearing loss?"

I calmly answered my rehearsed answer. “There is nothing Jordan can’t do because of his hearing loss.”

Mrs. Finnegan gave me a quizzical look, but probably figured there was no use questioning a moron.

I said to Jordan, “Please show Mrs. Finnegan that you know phonics.”

He gave me a kind of look that could have meant that I was joking, so I gave him a little hidden squeeze on the elbow to indicate that I was serious. I began to show him his original papers and had him repeat the assignment verbally. He rattled off the sounds that all the letters made almost without effort. I knew that this type of assignment fell right into his wheelhouse, because his speech was taught phonetically. After running through a couple papers in about ten minutes, Mrs. Finnegan said, “Okay, I guess that proves that you know your phonics, Jordan.”

Jordan just grinned knowing he still had the upper hand.

Chapter 30

Trying not to be as assertive as I could be, I had decided not to push Jordan into playing hockey as much as I wanted to. I played in a league a couple nights a week and I figured if he was interested he'd say something. Mollene had taken Jordan to toddler skating lessons, and he seemed to enjoy the skating well enough, but hockey still hadn't been mentioned. When he was younger, Jordan would always say, "Papa, go hock," when I left to play. Well, the idea popped into his head in the early fall just before starting second grade. Unfortunately, it was just after the deadline to sign up for the Southfield Hockey League. However, Mollene with her powers lying somewhere between assertive and desperate, convinced the secretary of the importance of Jordan being able to play. The tryouts, where the kids were rated, happened to be the next day. That night we raced out to the sporting good store and purchased all new equipment. Jordan just beamed as he stood and gazed at himself fully equipped in the mirror. This situation surely had the makings of Jordan sleeping in his bed with the hockey equipment.

That night the usual trepidations began floating through our minds, concerning dealing with Jordan on the ice.

"Mollene said to me, "You're going to have to tell the instructors about Jordan. This is going to be just like the usual beginning of the school year story."

"I guess I'll have to get the coaches together at the beginning of the session, and tell them to try to be conscious of turning in Jordan's direction when they speak. That could be tough with a swarm of kids skating around," I answered.

"You know Jordan has pretty good intuition and probably will just follow what the other kids do," Mollene said.

"Another concern is Jordan hearing a whistle with all the noise on the ice," I said.

"I guess we'll just figure it out like we have everything else so far," Mollene reassured me.

Jordan was all revved up the next morning, running around the house fully dressed in his cherished hockey uniform by seven o'clock. There was no stall, chase, or hassle to get dressed or put on his hearing aids that morning. He had watched quite a bit of hockey on television so he knew the gist of the game, and was practicing all his stick handling moves through the house. Fortunately we convinced him not to use a puck, but rather his imagination, as he roared around scoring goals.

We arrived at the rink early, but there was already a parking lot full of cars, and a swarm of kids racing through the lobby of the rink. There were five tables set up where the kids were supposed to register alphabetically. After lining up behind the table marked *k through o*, I turned around and of course just in the nick of time grabbed Jordan by the hood of his jacket as he attempted to run off.

"Jordan, you have to stand still and wait your turn," I told him.

He glared back at me with the *fat chance* look.

"They need to put a number on your jersey. If you're not here you can't play," I explained.

Already having learned when I was lying, he grinned, but nonetheless, it appeared that he agreed to stand still. After signing in and getting a number, the kids all raced for the benches in the lobby to have their already harried parents, lace up their skates. Jordan could barely keep his feet still, as the electricity of excitement leaped through his body. Like a herd of loose cattle, the kids raced to the door to get on the ice. Many of them not being too steady on their skates, started a chain reaction of kids falling over like dominoes. Not being deterred by their fallen comrades, the remaining standing ones pushed onto their destination.

Many of the kids had very little prior skating experience, and began spinning, and twirling before crashing to the ice. Kids were bumping into each other, falling down and sliding along the ice taking down unsuspecting victims. I was feeling guilty laughing, but nonetheless, the whole scene was hysterical. In the midst of my laughter, a couple of the coaches passed in front of me. I headed them off and introduced myself. I explained Jordan's situation in the thirty seconds the poor guys had, as they were being mobbed by a ton of other parents. They assured me that they would be sensitive to Jordan if he needed special explanations, but most of the drills could be followed just by watching. I really knew that, but sometimes the overly protective parent who emerged in my head forced me to say something to the coaches.

The drills ran on for about an hour, as the coaches had the kids do assorted skills, ranging from skating to attempts at stick handling. Some of the older kids who had played in the league before, had skills head and shoulders above the others. It was fairly obvious who had some prior coaching by the way they carried themselves on the ice. Surprisingly Jordan, handled

the session quite well, and was quite attentive. Having had skating lessons and stick handling in the basement was obviously a contributing factor to his achieving a degree of competency. Fatigue seemed to be taking its toll on most of the kids, but Jordan seemed to get stronger as the time increased. When most people began to tire and lose their edge, Jordan just began to get his second wind.

I said as he left the ice, "Did you have enough for today?"

He responded with a resounding, "No."

"Aren't you tired?" I asked

He shook his head. Knowing my customer well enough, I knew that pushing the issue would be counterproductive, so I took Jordan by the hand and escorted him through the rink lobby to physically remove his skates quickly or I would be chasing him all over the ice in street shoes.

By the end of the week, the coach of the team he had been chosen by, called. Jordan was on the Omaha, in the mite league. All the teams in the Southfield Hockey League were named after Indian tribes. The teams had nine forwards, six defensemen, and a goalie. Telling Jordan the information about the hockey team sent him into a frenzy. He ran downstairs, put on his hockey equipment, and began stick handling with a golf ball, with vigor I had not seen before. He was non-stop until I finally dragged him to bed three hours later.

When he arrived at the first practice, we found out that two teams practiced at the same time, each using half the ice. The coach first had the kids skate around the half ice clockwise and then counter-clockwise. As the whistle blew, Jordan stopped just like everyone else. Either he was hearing the whistle or he responded to the other kids stopping, but at that point all that mattered was that he stopped at the whistle. The practice went on for about an hour, as the kids raced up and down, as the two coaches evaluated their skills. The head coach then divided his team into three lines. The red line was the best, followed by the blue and yellow line. Being a raw rookie, Jordan was on the yellow line with the rest of the ankle benders. Towards the last ten minutes of the hour, the two teams had a short scrimmage. I have to admit that I felt extremely proud when I saw Jordan jump onto the ice for his first time.

The entire first hockey season was great fun, as I watched how much the kids progressed throughout the season. Jordan became more excited every game as his skills improved and his knowledge of the game increased.

I worked every other Saturday morning, so I missed some of the mid-morning games. My biggest disappointment was in the second to last game of the season, when Jordan scored his first goal, and I wasn't there. It made up for it when he called and said, "Daddy, I got a goal."

That was the beginning of his hockey career. Hockey became the love of his life. Jordan's life revolved around hockey as a player or a spectator, keeping tabs on his idol, Wayne Gretzky. Hockey was a great equalizer for him, because he didn't have to talk or listen. He was on the same playing field as everyone else, and it allowed him to be truly competitive.

Playing hockey was Jordan's arena to shine.

Chapter 31

Elementary school was a challenge for a few reasons. Hanging precariously over Jordan's head was the principal's overall attitude towards him, which never seemed to change. Although most of the teachers seemed cooperative, the pervasive feeling that it was inevitable that Jordan wouldn't be able to cut it among his hearing peers, was always lurking in the shadows. Every time Jordan had a problem with a concept, it was blamed on his hearing loss. We tried to tell the teachers that, just like every other student, he could have some difficulty in certain areas.

One of the most challenging areas for Jordan, us, and his teachers was math story problems. He just couldn't seem to get the concept of what was to be done. Although he was reading at grade level, his comprehension skills were sorely lacking. To Mollene and me, it was obvious where the story problem difficulty came from. His teacher, however, blamed it on his hearing, and said story problems would be something he would never be able to do. When Jordan couldn't do something, he helped reinforce the teachers' attitude, by writing absolute gibberish. If he couldn't or didn't feel like doing something, such as math problems, he would write down the same answer for every problem.

Getting used to the same scenario, we sat down and attacked the problem, creating a solution as we went along. Unfortunately there was no template for what we were attempting to achieve with Jordan. We were dealing with a child who was deaf, who had to be on the move, and had a short attention span. Knowing that Jordan did best with things that were done visually, we took a story problem and played it out live. We would take a problem such as—a person has eight oranges and gives away four, and then buys six apples. How many pieces of fruit does he have total?

We actually took the fruit out and went through the procedure

Multiplication was another issue that presented a unique challenge. No matter how many times we went over the tables, Jordan could not seem to get the concept of what multiplication was. We went over all the different ways of presenting it, such as using balls and saying, "you have two groups of two

balls equaling a total of four balls,” and so on. Finally after months of trying every conceivable method, he understood multiplication, but then couldn’t remember many of the tables. We found some flash cards that not only had the factors, but also had pictures to give visual clues, to remember the answers. A card might have an elephant whose eyes were circled for eights and a hockey stick for a seven, multiplied to give you fifty-six hockey playing elephants.

After months and months, Jordan learned his multiplication tables, but to this day we still occasionally ask him, “What is seven times eight?”

Jordan being in school ruled my entire day, many times distracting me from anything else I was attempting to accomplish. When I was working, my mind was occupied, until it came close to three o’clock when Jordan got out of school. I couldn’t wait until I could call Mollene and find out what transpired during Jordan’s day. During my days off, what I did was dictated by needing to be available to greet him at the door or make the 3 three o’clock call. If Jordan had a test the previous day, the chance that he might get the results consumed my mind. A poor test score could destroy my entire day.

If Jordan had a hockey game, Mollene would drive and I would sit in the backseat of the car with Jordan and go over his work, to and from the game. Studying with a child who was pumped up from playing hockey, then on the verge of exhaustion, who had a limited attention span, was no small task.

Since Mollene didn’t attend most spectator sporting events, I was on my own if we went to see the Tigers or Red Wings. Tutoring Jordan on those nights was a one man show. Jordan would hold a word list or review, and during traffic jams or red lights, I would quiz him on the material. While we were at the games we would go over everything between innings or periods. Although this method obviously had its flaws, it allowed Jordan not to miss any event that other kids had the opportunity to attend.

Having to be a friend, father, and tutor created a complex love-hate relationship between Jordan and me. He and I were best buddies when it came to having fun and doing things together, but when homework time came around, he dreaded seeing my face. Realizing that I was relentless in having him succeed, he knew I wouldn’t give up until he learned the material. The combination of what he missed due to his hearing loss and his poor retention skills, made for some unbelievably bad sessions, which usually wound up with me yelling and screaming. Eventually, I would come to my senses and we would begin again, usually followed, by me apologizing.

The frustration levels on each side were very high, as there was a great deal of pressure on him to do well. Fortunately, Jordan had developed an extremely tough outer shell, where nothing bothered him too much. In the middle of me being extremely upset, he would calmly ask me if it was okay for him to go do something.

Chapter 32

Although his schedule was grueling, Jordan managed to have time for fun. He played baseball, hockey, snow skied, and had learned to water ski. Every year we took a couple of skiing trips to northern Michigan, and when Brian was five we started skiing out west.

Elementary school was an infinitely long event looking at it day by day, but actually the years flew by. Mollene and I had numerous discussions during Jordan's time in elementary school about his ability to do work on his own. If it weren't for us helping him every single day, he never could have succeeded on his own.

We always blamed his inability to retain the material on not getting the message transmitted to him auditorily and poor processing. The other reason was he just didn't care to pay attention to the details.

By the time he was reaching middle school, we began questioning that something else might be wrong. Were we so concerned with speech and language development, that we may have missed something else? The idea arose that he wasn't in the proper school situation. We thought it was possible he should be going to a different type of school. We started to discuss the schools in the area that had any possibilities.

Mollene said, "Both Country Day and Cranbrook have the reputation of being extremely academically-oriented." West Hills, where he was going to go, was also rated very high academically, however the other two were supposed to be more difficult."

"That's about the last thing we want—Jordan going to a tougher school," I countered.

The third local school we considered was Roper, which was supposed to be for gifted students. My nephew and niece went there, and my sister was a staunch supporter of their teaching methods. The school environment was considered to be rather loose, with students being somewhat on their own to accomplish what was expected. This sounded totally wrong for Jordan, but

since nothing else seemed to be right, we figured we would check it out. Being rather naïve in what “gifted” really meant, without being too sarcastic, I found out that “gifted” meant what ever you wanted it to mean.

So, we decided Jordan was gifted, and proceeded on with getting more information on Roeper.

Mollene went to talk to some of the administrators of the school. After a lengthy meeting, where everything was explained to her about how the school was run and their philosophy on the emphasis of individualism of the child, Mollene explained it to Jordan. After this discussion, the principal recommended that Jordan see a psychologist who specialized in children with learning problems. She felt that making sure there were no underlying problems was prudent before proceeding with the possible Roeper program.

We went to see the doctor that was recommended by Roeper. Upon meeting her, we went through the usual history of *Jordan Levin*. Upon taking Jordan to her office numerous times with an arsenal of tests and numerous discussions with him, she felt she had amassed enough information to come up with a diagnosis.

“Dr. and Mrs. Levin, I have worked with Jordan for the past few weeks, and have been quite impressed with the success you have had with him. He seems to be an incredibly well-adjusted child, and he is a joy to work with.”

She paused for a long second and I interjected, “You sound like there is a major *but* coming up.”

“No, hardly, but I think there are numerous issues to be addressed. You raised the question of his lack of attention and memory when it comes to school, and also his continual need to be moving. I feel that he has the need to be his own person in school. He is entirely too dependent on you and other students for help with his notes. He needs to possess his own notes, to establish his own identity.”

Mollene and I glanced at each other and tried to remain expressionless as the psychologist continued.

“If he took his own notes, he would be occupied, feel fulfilled, and have a sense of accomplishment you are denying him by having someone taking notes for him.”

Trying not to come off as either stupid or arrogant, I asked, “After all this time, and multiple evaluations, you’ve concluded that Jordan’s problem is having the need to own his notes. Do I have this right?”

Realizing what a fiasco this effort in futility had turned into, Mollene kicked me under the table, signaling that a “let’s get out of here” was in order. The so-called learned doctor had totally blown this diagnosis, by missing one of the most important facets about Jordan—he could not take his own notes. It was impossible for him to hear what the teacher was saying and to write it

down. In order to comprehend a lesson, it was mandatory that he fully face the teacher. Knowing that it was futile to explain anymore, we attempted to thank the doctor, paid our bill unhappily, and left.

After our questionable evaluation, Mollene called Roeper to schedule a visit with Jordan during school hours. She took Jordan out of class, which was breaking our own rules. Missing school usually meant major fever, profuse bleeding, or throwing up. Upon arriving, Jordan was sent into some classrooms to observe and speak to some of the children. Simultaneously, Mollene went around and visited some classrooms to get a feel for the atmosphere of the school. After being in a classroom for five minutes, she knew that this school would never work with Jordan's personality or needs. The students had the freedom to do anything they wanted during their class period. Kids were wandering around as they pleased. For a student like Jordan, who could sharpen twenty pencils at a time to keep from doing work, this freedom and lack of structure would not work.

Upon the completion of the half day, Mollene and Jordan met up, and almost simultaneously said, "This is not going to work."

Chapter 33

Now that Jordan was going to start middle school, a new predicament arose: how would Jordan respond to more social situations? Up until this time, most friend-related situations were handled by the parents. We lived in an area where the kids had to be driven most of the time, so parents had to be involved with all arrangements.

Up until now, Jordan seemed to be able to handle himself appropriately, but a lot changed when kids reach eleven or twelve years. My mind began to work overtime. Would he fall into a group of kids to hang out with? Would he be shunned because of his speech? What about girls?

School, speech, language development, sports, social situations, and Brian was more than I could handle. This was ignoring the situations I had to deal with in my own life. Mollene had the ability to deal with all the pressure much better than I could. At least she could hide her feelings better. In my heart, her coping skills were far superior to mine. If something happened between Jordan and another kid, I was always worried that it had to do with Jordan's deafness. I was never able to separate out the normal problems kids had with each other. Being torn between trying to make Jordan totally self-sufficient and making sure that everything was perfect, was a tall order and required much will power to let him fend for himself.

Speech lessons were two days a week after school, and as much as Jordan disliked making the trek to Karen's house, he was adequately cooperative.

Jordan's speech and language development had developed after eight grueling years. Being totally objective was extremely difficult since my expectations were very high and no one could live up to them. Jordan worked hard and had to endure more than what should have been expected from a young child. However, since he was raised with that way of life, he really didn't know anything different.

To Mollene and me, Jordan's speech quality was excellent. He could produce all the sounds and most people could understand him quite well.

At times when he forgot to enunciate, his speech could become rather poor. Among his friends, speech understanding posed no problem. When middle school began, his speech quality was a bit nasal, which was a proverbial problem with hearing impaired people. The nasal quality was caused by not using enough breath to push the air out of the mouth, thus forcing air to exit the nose. We were constantly working on exercises that emphasized breath control. With the nasal quality to his speech, Jordan was often confused for someone with a foreign accent.

Most hearing impaired people have slow speech, without proper rhythm or intonation. Jordan's rate of speech was excellent, probably due to keeping up with his mom, whose speech was slightly faster than a speeding bullet.

Hearing impaired people usually speak in a monotonous tone, due to their inability to have anything but very flat sounding speech. We worked very hard to make sure Jordan added rhythm and intonation to his speech by practicing scales and singing songs. Mollene would play the piano and Jordan would imitate the sounds going up and down the scale. Following that exercise, she would jump an octave lower and then higher, in order to help with changing intonations

Teaching speech was like going to war, winning battle by battle, hoping for an eventual victory. Not having seen many local children who had met our expectations made it rather difficult sometimes to continue the fight. However, we knew surrender was not a choice. We planned to continue pushing ahead until we achieved what we set out to accomplish.

Evaluating language development was totally another issue, realizing that the normal child hears everything directed at him, as well as extraneous conversations, television, and radio simultaneously. Being barraged with background noise, the normal hearing child cannot help but expand his vocabulary.

Consider one example of a child going shopping with his mother and sitting in a grocery cart. All the possibilities of picking up language are overwhelming. Hearing what his mother says to him, asking the clerk a question directly, hearing the clerk answering someone else's question, his mother speaking to another shopper, another person talking to him, announcements in the store, checkout, and so forth. The hearing impaired child is missing most of the experience of being in a store. Our job as Jordan's tutors was to recreate all those situations. We would have to describe every single event that went on in a grocery store aisle by aisle, shelf by shelf, can by can. Just running into a store for one item turned into serious lesson.

Teaching five new words and one idiom a day, along with vivid descriptions, certainly helped him acquire language. Yet he still lagged behind the average child in middle school. Being able to read and watch television with captioning broadened his opportunities for better language development. By the same

token, the other children still outpaced him. Somewhere during this time, Jordan began expanding his vocabulary to include more words than we had taught him.

At one point, probably around the third grade, Jordan was watching the beginning of a television show, which had a message, “Closed captioning for the hearing-impaired.” Jordan turned to me and said, “If I use this, I must be hearing-impaired.”

Chalk one up for being successful in making him feel that he was the same as everyone else.

Chapter 34

Although Jordan may not have shared my feelings, just seeing the elementary school in my rear view window gave me tremendous satisfaction. Having beaten the dowager empress of a principal who ran the school and never softened on her stance about Jordan, gave me the feeling of a conquering hero. I was the General, and Jordan was the foot-soldier in the trenches. Against all odds, which I truly have come to realize, Jordan raised the flag at Iwo Jima.

Being accustomed to Jordan being exposed to a multitude of new situations, Mollene had the drill down for presenting Jordan's resume. Upon setting up a meeting with the principal and the man who was to be Jordan's counselor at West Hills Middle School, she gathered her arsenal of weapons and prepared to do battle. After the usual perfunctory greetings, she was pleasantly surprised by the cordial welcome she received. By this time the principal had already heard about Jordan from the elementary school and Mollene feared that the pervasive attitude had ensued.

Mollene began trying to tie ten years of information into five minutes. Only through her ability to rattle off a massive amount of information in one breath was she able to tell the story without interruption.

The principal responded, "That's quite a great saga for a ten-year-old boy."

"There really is much more to tell, however due to time constraints, I've tried to condense it into an outline of the important facts," Mollene said.

"Are you aware that the entire middle school hearing impaired program is housed here at West Hills?" asked the counselor.

Mollene replied, "Sure, I've been told that all the hearing impaired kids are here."

The counselor asked, "Why isn't Jordan in the program? Our hearing impaired program is one of the finest in the state."

Getting the raw feeling of opposition in her stomach, she countered, "Jordan may be hearing impaired, but he has not been taught in the same manner as the majority of the other kids. He does not sign, he uses speech as

his only means of communication, and he has never been with anyone other than hearing people.”

The counselor said, “We have many kids in our program who speak. Why would it be a problem if Jordan was in class with them, and then mainstreamed for certain classes?”

“I mean no disrespect to the program here, but I have been in the hearing impaired classes, and no one here speaks with the clarity of Jordan. Also the statistics show that hearing impaired children are on an average of two years behind grade level in reading. Jordan reads at grade level, and putting him in those classes would be a tremendous step backwards. He does not need to be mainstreamed. He has never been in any situation where he wasn’t in regular classes.”

The principal interjected, “It sounds like we have a rather unique situation here that we haven’t encountered before. Mrs. Levin, it appears that you and Jordan are well prepared to tackle middle school. Our staff has been exposed to numerous hearing impaired students, but seemingly none like Jordan. I’m sure with appropriate education about him, they will do everything necessary in order for him to succeed.”

Mollene explained, “Basically what I have done in the past is meet with the teacher prior to the semester to talk about Jordan. The largest issue for a teacher has been facing the class when speaking. Jordan gets most of his information from lip reading. He uses his hearing, but at distances more than a few feet, lip reading totally takes over.”

“That doesn’t sound like it would be too much trouble for the teachers,” the counselor assured Mollene.

“There is more. If there is going to be a test or a quiz, Jordan needs to be informed separately, just in case he misses it. Also being unable to look up and write at the same time, it will be necessary for him to get notes from a friend. In the event a movie is being shown, Jordan will get very little of the audio, so if it is possible, the teacher should provide him with the script or information that comes with the film. We have the creativity to conquer every situation, and his teachers should not excuse him from anything. Jordan requires no special treatment, and will be upset if any is afforded to him,” Mollene explained.

Mollene hesitated before she finished, “There is one more thing to be discussed. I just ask for the opportunity to speak to his teachers together to cover what I have explained to you. If someone else repeats all my information, I’m afraid some points may be missed, which could create problems down the line.”

“By all means I would want you to have a meeting with his teachers yourself. I’m sure they need to hear this information directly from you.”

The last thing the principal said was, “I want middle school to be a totally positive experience for Jordan.”

Mollene and the school administrators concluded their current meeting and Mollene left with a content feeling, confident that Jordan's middle school experience was about to begin on an upbeat note. Positive that she wouldn't need them, she let her guard down and put away her weapons.

Getting prepared for middle school at our house seemingly took as much preparation and coordination as the allies landing at Normandy. Mollene and I began the countdown on the Friday before the final weekend.

D-Day minus 3.

What was the weather going to be like and what was Jordan going to wear? Did he have all the notebooks ready? Was he prepared to introduce himself to the teachers and fill them in about himself? How would the teachers respond to having the responsibility of a hearing impaired student, unlike the other hearing impaired children who were being watched by a separate counselor? Being thrown by a new situation, the anticipation of Jordan starting middle school sent shockwaves of trepidation up and down my spine. Not being able to sleep was minor, compared to where my blood pressure must have topped out at over the weekend.

Just to be safe, we woke Jordan up an hour early, in order to allow for the usual unexpected emergency. Somehow, Jordan was the living model for Murphy's Law. However carefully we would rehearse our strategies, Jordan had the uncanny ability to make sure the unexpected happened. Bad hearing aids, broken tubes, dead batteries, or an ear infection were the norm rather than the exception.

D-Day arrived and surprisingly enough, nothing went south. Since Jordan didn't have much need to sleep, he was ready to rock and roll a couple hours prior to post time. Unlike a championship thoroughbred horse who was giddy getting into the gate, Jordan was just plain giddy.

Eating breakfast was a three-second ordeal, because eating two spoonfuls of cereal didn't take too much time. Poor Brian had to endure the constant pestering of Jordan throughout his meal. Brian was a diner and enjoyed his meal time, and although he never expressed it, I am quite sure he would have preferred a quieter setting for his meals than what Jordan brought to the table.

Approaching eight years old, Brian must have had some strong opinions about his life as Jordan's little brother. Although we made sure Brian experienced his share of attention, he must have had felt a bit neglected. We made sure Brian was involved with everything we did and had a multitude of his own activities. However, Jordan still commanded more than his share of attention. Unfortunately, due to the amount of time needed to keep Jordan on top of his game, it still troubled me to think about the long-term effects on Brian.

“Be good, talk clearly, and pay attention. If you miss something, make sure to ask a student or the teacher. You’re going to middle school, and you can’t afford to miss anything,” I explained.

Raising his eyebrows and sighing was his signal that he had heard the previous message somewhere in the neighborhood of 10,000 times. He didn’t even make an attempt to give a verbal reply.

“Did you hear me?” I asked. “Jordan?”

Not about to budge and give me the satisfaction that he heard me, he turned and jumped into the car, casually turned back and displayed an all-knowing grin.

Slower and slower the day dragged on, as we anguished over what might be transpiring at school. At 3:15 Jordan and his friend Jeremy bounded up the back steps of the deck, returning from the first day at middle school.

“I can’t believe how big that school is and how hard it is to get around. I don’t know how I’ll ever figure it out,” Jeremy rattled on.

Mollene asked Jordan, “How’d it go for you?”

“No big deal,” Jordan responded.

As Henry Ford II said, “Don’t complain, don’t explain.”

Chapter 35

Although the atmosphere in middle school was a great improvement over elementary school, the arduous procedure of preparing Jordan daily became harder. Jordan would not or could not remember any facts about a subject without an incredible amount of repetition. A simple test with a ten-word list of definitions could require four hours of preparation. When Jordan came home with such a list, it must be noted that the teacher probably had already gone over the list, but Jordan realistically hadn't gotten anything from the discussion. We would first go over the list, including spelling and then definitions. Immediately after taking a short break, we would go back and do the entire list. This could find Jordan getting a few new successes, but forgetting a few of the ones he remembered the last time. We continued this process, which could possibly take a minimum of an hour, until Jordan could get all the words. This would be fine except the next morning the list could look totally foreign. We had to keep in mind that he had four other subjects that required the same attention.

The following morning, in order to double-check Jordan's readiness for his quiz, we would have a morning review. First I would prepare breakfast, set him at the counter with his word list, allow him to look it over before we began. At the same time, I usually had to get ready for work, so I would quiz him long-distance from the bathroom. The bathroom was a straight shot from the breakfast counter. I would sit down with his list and shout the words down the hall. Through a combination of hollering and lip reading, Jordan could be quizzed.

I guess you could call that effective time management.

"Jordan," I would say, "Spell it and give me a definition."

There would be a long pause, and then echoing across the hall, he would respond, "I don't remember."

"Come on, think about it. First spell it," I yelled.

He would usually get the spelling okay because he was taught to speak phonetically, and had a good shot at it, although he might not have remembered it.

“Come on. That’s one of the words you got right every time last night,” I begged.

Usually by that time I began to pump up the volume, which really made no difference to him at that distance, but certainly served to increase my frustration level. I then would tell him the definition and proceed to another word. This went on for half an hour or so until I had to take him to school. By this time, we had probably spent upward of two hours on the simple ten-word list. If he had two tests that day, our day would begin an extra half hour earlier at a minimum.

This ordeal went on every day, day in and day out. How Jordan ever maintained his composure is beyond me. The pressure was intense for both Mollene and me to keep up with Jordan’s needs and maintain a normal life for Brian. A very high percentage of couples with hearing impaired kids divorced. Also to be considered was that most of the couples were not trying to do what we were. The majority would have the kids learn sign and be in a hearing impaired program which put the burden of education on the school.

Fortunately, Mollene had a much more even personality than I, and had the ability to put the situation in better perspective. Leveling out my compulsive actions became part of her job, which was the glue that held us together.

Along with the homework, there was daily speech lessons and he still saw Karen a couple days a week. However, making sure that he didn’t miss anything, Jordan played hockey, baseball, windsurfed, and both snow and water skied.

One of the most interesting times of balancing schedules would be in the spring when Jordan was playing spring hockey and baseball at the same time. No sooner had he come home from school then we would begin analyzing his homework needs. If he had assignments, he would immediately get them done. If he had a test, I would help him begin to study and get together a road package for the car.

Mollene would drive to the baseball game, with Brian in the front seat, and I would be quizzing Jordan in the back seat. After he finished the baseball game, we would discuss the game while we walked to the car. Jordan would then change into his hockey equipment and we would proceed to go over the test material again.

The situation would become much more complicated when Brian also had a hockey game and one of us had to drive him, while the other one did double duty with Jordan. After the hockey game, a quick review of the material was done on the way to McDonald’s, for a fast meal zooming through the drive-through. After taking a shower, Jordan would hit the sack, only to arise six hours later to review for his test. Fortunately, his complete high energy personality worked in his favor, and he could keep up that pace. The same could not be said for Mollene and me, as we would crash, fatigued beyond belief.

Interestingly enough, Jordan did quite well in middle school and so did I. Many of the concepts I really never grasped in science and math became very clear.

Chapter 36

“All my friends are going to Hebrew School in order to have a Bar Mitzvah. How come I’m not?” Jordan queried.

“Well to tell you the truth, with everything else you’re doing, we didn’t really consider it,” Mollene responded.

“What about it?” Jordan wanted to know.

“Dad and I will have to talk.” Mollene answered.

Always waiting for a new situation to present itself was usually short-lived. We had grown accustomed to a non tranquil existence, where every day brought a new challenge, but this one seemed intimidating.

Jordan had been attending a Sunday religious school class at the Birmingham Temple which believed in Humanistic Judaism, which has many differences from traditional views.

The Birmingham Temple is part of the world movement of Humanistic Judaism, which believe that Judaism is the culture and civilization of Jewish people and that this culture was created by the Jewish people over many centuries; that a Jew is someone who identifies with the history and culture of the Jewish people; that men and women have, and have always had, the power and responsibility to shape their own lives independent of supernatural authority.

In preparation for a traditional Bar Mitzvah, the boy usually begins learning how to read Hebrew around eight or nine years old. The education would continue until a boy reached thirteen and had learned to read from the Torah, which would be part of the Bar Mitzvah service, representing a Jewish boy being ushered into manhood.

We actually discouraged Jordan from going to Hebrew School. We felt for once that he had more than enough classes and activities that he was involved in. The burden of learning Hebrew could be too much for him to tackle.

Birmingham Temple had a relatively different approach to a Bar Mitzvah. A boy chose a Jewish hero to study who had an impact on the Jewish community.

After looking at numerous people, Jordan settled on Albert Kahn who was one of the foremost industrial architects in the country.

Albert Kahn developed a style of construction where wood factory walls and supports were replaced with reinforced concrete. The buildings were better protected against fire and had large, unobstructed interiors. The Packard Motor Company's factory was the first plant built on this principle, soon followed by the Ford Highland Park plant.

Ten Kahn buildings have Michigan historical markers:

- Battle Creek Post Office
- Dearborn Inn-the first airport hotel
- Detroit Arsenal Tank Plant
- Edsel Ford House
- Fisher Building
- Michigan Alpha Chapter House of Phi Delta Theta
- Packard Motor Car Company
- The Detroit News
- The Detroit Free Press
- Willow Run Airport

Since Kahn's brilliance was to be only appreciated visually, Jordan decided that he wanted to take pictures of some of Kahn's buildings to be used in his presentation. Mollene was a photographer and had a huge selection of cameras at Jordan's disposal. Jordan had earlier expressed an interest in photography and had a rudimentary understanding of how to use a camera. As usual in Jordan's life, time was a huge obstacle in getting him to work on any project. Since we were photographing buildings, weather and time of day were critical to getting good images. The ornate interior of the Fisher Building was a must, so we felt a Sunday would be the best bet, considering there would be less foot traffic.

Through the course of the next couple of months, Jordan and I dragged Mollene's photographic equipment all through the city of Detroit in search of the perfect image of Albert Kahn's masterpieces. Since the buildings had all been built more than half a century prior, they were all located in the confines of the city, which was twenty-five miles from our house.

Following a few months of outings, Jordan had taken some very accomplished images of some of Kahn's work. They included the General Motors Building, Fisher Building, Temple Beth El, and the Detroit Free Press Building, just to name a few. All images were shot in black and white to give the maximum effect of the fascinating architecture.

The next step was to begin writing, which at the time was not Jordan's forte. Jordan's lack of expertise was probably due to a myriad of issues. The first was due to his limited vocabulary compared to most of his peers. No amount

of work at that point, due to his hearing loss, and his disinterest in reading, limited his vocabulary exposure. Another cause may have been his lack of confidence in his ability to convey thoughts on paper.

I should take a considerable amount of blame for his confidence issues. First, it took him a long time to read an article, and it was nearly impossible for him to gather the appropriate information to put down on paper. Rather than toiling over the task longer than I deemed necessary, I was guilty of actually giving him the words to write down many times. In hindsight, I should have let him slave over the material until he began to improve. Due to my lack of patience, I did it for him, thus not allowing him to improve.

Since studying Albert Kahn was an added burden to Jordan's already overloaded schedule, forcing him to study and write even more didn't always make for a happy camper. I continually reminded him that he had asked for it. After months of blood, toil, tears, and sweat, quoting Winston Churchill from his famous 1940 speech to The House of Commons, Jordan and I finished his Bar Mitzvah project about Albert Kahn. After weeks of rehearsing under duress, Jordan actually became quite an orator, which was an endless source of pride for Mollene and me. Following the original diagnosis that he wouldn't be able to speak, yet being able to speak well enough to present a speech in public was an accomplishment that couldn't be rivaled.

Months of planning went into putting the entire Bar Mitzvah program together. Finally the big day arrived and Mollene and I were in a state of permanent, frazzled nerves.

Jordan was undaunted.

He calmly walked up, spoke eloquently with the poise of John F. Kennedy, smiled, and sat down.

There never were two more proud parents in history.

Now confident, about his new speaking conquest, Jordan, unprompted, approached me and said, "I read the notice that you gave me about the ten-year anniversary of the Toronto Voice Conference, and I would like to speak at it."

"What caused you to think about doing that?" I asked him.

"I thought the other people would like to know about me and what I have done," he answered.

I responded, "I think that's a great idea. I'll call the people at the conference and see if they are interested in you speaking," I informed him.

After making a few calls, I connected with the right person who was thrilled to have Jordan speak at the conference.

We arrived at the conference and went into the hotel to register. I glanced over at Jordan, and didn't understand what he was staring at.

"What's up?" I asked.

He half-grinned at me and said, “I’ve never seen so many kids wearing hearing aids. It looks kind of weird to see so many deaf kids in the same place.”

Just as Jordan said that, Mollene poked me in the ribs, “Shh, you have to listen to the kid behind us.”

I paused and tried to listen to the voice above the din of the crowd. Awkwardly I half-cocked my head to hear what was being said.

I turned to Mollene, “What’s the big deal? Sounds like another hearing impaired kid with so-so speech.”

She answered me, “I saw his name tag. He’s one of the kids who originally spoke ten years ago. He must be about seventeen or eighteen. Jordan is much more articulate than he is.”

“No doubt. You’re going to hear him speak more later,” I responded.

The next morning, our family of four headed into the auditorium and began to listen to the five kids in their teens, who were from the original panel ten years earlier. They spoke of their trials and tribulations of being hearing impaired in a hearing world. The five of them discussed the issues of being in class, taking notes, and being in large group situations. Each student spoke of his or her experiences and made us very aware of some of the problems that may arise when Jordan became older.

What was most striking to Mollene and me was that not one of the kids spoke as articulate as Jordan. I’m not trying to say that his speech was perfect or that he sounded totally like a hearing person, but his speech quality was head and shoulders above the panel kids. Just prior to the panel finishing, Jordan, who was due to speak next, said he had to go the bathroom. He stood up and disappeared, giving us cause to worry when he didn’t return after a few minutes. Although he was now a much improved version of himself, Jordan still had a mind of his own and was impulsive. However seconds before his introduction, he confidently strolled back into the auditorium.

He stood up to the podium, and spoke with the confidence and poise of a politician who knew just how to mesmerize a crowd. Mollene was attempting to video the speech, but holding still while crying was not an easy task. Jordan calmly told about his traumatic birth, finding out about his hearing loss at the age of two and a half, and what he had accomplished by the tender age of thirteen. He explained how he was treated like everyone else, and that his parents never gave him a pass on anything due to his hearing loss.

When he concluded his story, there wasn’t a dry eye in the place. People came up and congratulated him, his mother, me, and even Brian for being his brother. Everyone wanted to know what we did special to get Jordan the way he was. Understanding that this was a group of people who were involved

with the hearing impaired world, and they realized how successful Jordan was, made the accolades all the more sweet. All our efforts had been to not allow Jordan to be different than anyone else in the hearing world, but at this moment I believe it was the first time in his life that he comprehended how special he was.

Chapter 37

Entering the teen years in any child's life creates major stumbling blocks. The journey through those years can be a rather tumultuous time. Jordan came with his own unique set of issues, well beyond those of the average child. In his favor was his general social acceptability. He was easy going, had a likeable personality, and was a nice-looking kid. Being an athlete opened many other doors which assured him fitting in. He had a small group of friends, whose lives primarily focused on some form of athletics. Balancing schoolwork, sports, speech lessons, and having the time for plain old fun was a delicate balance. Lessons with Karen had to be reduced to twice weekly, while we scampered to continue with speech lessons on the other days. I'm only speaking of formal speech lessons, since every moment we spent with him constituted speech work.

I am truly convinced that during some times, Jordan dreaded seeing my face. I was relentlessly intolerant of sloppy speech. Fortunately, Mollene had a much more subtle way of demanding good speech, rather than my get-in-his-face approach. Possibly my demand for perfection stemmed from my acceptance of mediocrity in some facets of my own life. The biggest stumbling block was still finding enough time to study without eliminating all other areas, which made Jordan a well-rounded, socially adjusted kid.

Conversing by telephone became much more common, and created a whole new issue to deal with. Obviously Jordan could not hear well enough to carry on a conversation on a normal telephone. Mollene got her research hat on again and began to seek a solution. She found that certain special phones would amplify the higher frequency sounds in order to make up for the deficiencies in hearing. There were other phones that would just straight out amplify thirty percent more. We ordered both of these types of phones, but neither provided an adequate solution. Jordan did not have enough hearing, for either of these options to be beneficial. Never to be deterred by conventional logic that said, nothing would work with a profoundly deaf person, we sat down and attempted

to figure out another solution. Not that we hadn't been in this corner before, but this dilemma did have its complexities.

When using a telephone only one ear is used, but for Jordan he functioned best, using both ears. Keeping that fact in mind, we brainstormed and came up with the idea of a speakerphone. That way he would be able to have the advantage of using both ears. We ordered the phone, and came up with a way to check it. We had my mother call and Jordan tested it out, by picking up the phone.

"Hello." Jordan said.

My mother said, "Hello Jordan."

No response

"Pay attention." I said.

"Hello Jordan," my mother repeated.

All of a sudden a huge grin appeared on Jordan's face.

"Hello Nonnie," he quipped.

Hearing the happiness in her voice, she said, "How are you?"

"Fine." he replied.

My mother continued with a variety of complicated questions, that Jordan could not pick up. At that time we realized that Jordan could use the speaker phone for a limited conversation, but it was not effective for more details. Having drawn the conclusion that the speaker phone was not the total answer, brought us almost back to square one.

"I'm sure that we'll need to supplement his hearing somehow. How about if one of us is with him during the conversation?" I asked.

Mollene responded, "I didn't think Jordan is going to buy us listening to his conversations."

"I don't think there is a choice if he is going to use the phone." I stated.

Although not being pleased with the entire concept, we explained to Jordan that the speakerphone with one of us providing the details was the best solution available now. Being used to us totally solving every problem, left Jordan a bit dismayed, but being Jordan, he accepted it.

Now came the fun part, actually putting the phone into real use. When Jordan spoke to his friends about simple matters of time and place, the speakerphone worked okay. However, when the subject matter became more complicated, we had to be available, which in actuality, was most of the time. We had to, with one ear listening to the conversation, be ready to jump in and mouth the words of what was being said. Jordan's friends knew that we were on the other end listening, so they were somewhat careful in what they said. Listening to the conversation worked out well enough for kids' plans, senseless chatter and homework, but what about speaking to and about girls.

Girls created an entirely new and much trickier problem. There was no way, he could handle it all by himself, but did he really want his parents

listening to boy-girl talk? Realizing someone had to do this, Jordan knew Mollene had to be the one. It was decided when it came to girl talk, that no one would know that Jordan had a coach in the background. Fortunately, by the time the conversations became a bit more detailed and risqué, Brian was old enough to handle the duties.

Chapter 38

All of Jordan's life was not pressure packed, due to the fact we made sure he had all the experiences of other kids, plus more. One of the most bizarre stories, comes from a zany Halloween experience. A friend of mine, Jordan, Brian and my friends' two boys were driving around the night before Halloween. We had gone to dinner and were telling scary stories in the car. As we passed a small cemetery at our corner, I told everyone how Norm Cash, a Detroit Tiger had just been buried there. Everyone knew Norm was a big party guy, and was always up for a good time. In order to see where this conversation went, it has to be known that my family is a bit off the wall.

"Norm would never want to miss this crazy night. Maybe we ought to get him," I said.

"What do you mean?" Jordan asked.

His friend Jeremy said, "Like dig him up."

It has to be remembered that two of the kids were ten and the other ones were six.

Brian asked, never quite sure if I was telling the truth said, "Are you going to really dig him up?"

All of a sudden in unison the kids started hollering, "Let's go get Norm. Let's go get Norm!"

At that point, just to keep the mood going we drove to my house. I went into the garage and came out with a couple of shovels. The kids faces in the car turned immediately pale.

"Are we really going to dig him up?" Jordan asked.

My friend Ron replied, "Sure, you don't want him to miss out on Halloween, do you?"

Still sitting in disbelief and a bit terrified, we finally let on that we weren't actually serious.

Never letting go of a good story, I came up with the idea of taking the kids to the cemetery and shooting pictures of the kids next to Norm's grave. My friend Sudz came with us and the kids in a most sacrilegious manner were running through the cemetery screaming, "Where's Norm?" I have to make mention that this was the first time that either Jordan or Brian had ever been to a cemetery. After finding the grave, Mollene took pictures of us around the stone. Not quite sure what to do with the pictures, I came up with the idea that in order to carry out the original theme, we needed a skeleton in the pictures to prove that Norm came with us. We decided to dress the skeleton in a Tiger baseball uniform to give Norm some authenticity. Knowing that there was a skeleton in the elementary school, I had to be creative in order to use it for pictures.

Mollene called the principal and told a little fib that we needed some pictures of a skeleton for a photo project she was working on. Knowing that the principal was a stick in the mud, telling the truth wasn't going to fly. After some serious deliberation with herself, the principal consented to let her shoot a few pictures right after school. We knew we had to be prepared and ready to strike before attempting to pull off our mission. We borrowed a uniform from a friend and plotted our strategy. Jordan and Brian were lookouts, while Sudz and I dressed the skeleton in the uniform and hat. After Mollene shot the pictures of the skeleton by itself, we called in our lookouts and she took pictures of the group around Norm. We quickly undressed the skeleton and scurried out before the principal came by. Following developing the pictures, we decided we would superimpose the picture of the skeleton in the uniform into the group picture around the tombstone. The results were fantastic. We then printed a card on the computer with the picture. The caption said, "Norm and the gang wish you Happy Halloween."

We never had the nerve to send a copy to the principal.

Chapter 39

Almost on a daily basis, Mollene and I were presented with a school situation that needed a solution. At least our problem solving skills were kept extremely sharp. Somehow, no matter what was going on, we managed to fit a speech lesson in on a daily basis. Just mentioning speech lessons to a pooped fourteen year-old boy, brought out some of the best excuses and dirty looks that could be imagined. Threats, promises and deals were made with Jordan in order to get him to cooperate. It would be impossible to estimate how many times I said, “Sit up. Pay attention. Enunciate. Don’t open your mouth so much. Take a breath. Keep the air out of your nose. Better breath control. Project your voice. Please let’s get this over with. You’re wasting too much time.”

Homework remained to be the biggest stumbling block in managing enough time to get everything done in a day. Tests could really throw a monkey wrench into planning. If test preparation wound up being the night of a baseball or hockey game, we knew we were in for a late night and an early morning. Luckily, Jordan was still Mr. Energy and could survive with a minimal amount of sleep. Fortunately, I could almost keep up with his pace, but I do admit to a few power naps at lunchtime and plenty of late night TV dozing.

The ending of a semester, and the prospect of finals, cast a giant shadow over the household, because everyone knew that those few weeks would bring major pressure and tension to our family. Finals competed with hockey tournaments in the winter and in the spring competed with hockey combined with baseball games on the same day. When finals were approaching, all the subject material and the teachers review sheets had to be gathered. This sometimes was a tough task, because Jordan wasn’t always the most organized kid on the block. The other issue was that while studying for finals, Jordan had to keep up with his normal class work. This really created a double whammy and made time a premium.

Biology was always a particularly trying subject because of all the details. Once Jordan got the material together, and we got through eating, and took bathroom breaks, neither one of us was in much of a mood to study. However, Jordan's studying and my second trip through high school could not be derailed by fatigue or questionable excuses. Frustrating for both of us was his lack of retention. Many times we would go back to the beginning of a semester's work, and Jordan did not have any idea that he had previously seen the material. What made the situation more maddening was that in most cases he had done very well on the test. I do not want to convey the impression that Jordan was a poor student, by any means. Because of our team effort Jordan maintained a three-point grade average. The problem was that it took Jordan three times as long to cover the same material as another three-point student.

A typical study session would usually follow this scenario.

"Jordan, do you remember the difference between an animal with an endoskeleton and an exoskeleton?" I would ask him.

"I don't remember." He answered.

"Come on. Think about the words. What do they sound like? Exo, Endo." I pressed.

No response

"Okay," I said. "An exo skeleton is external which supports and protects the body. An endo, just like in, is inside just like a human. Now tell me which is which?"

"Say it again." He would ask.

This could go on for four or five of these exchanges before Jordan could remember it. That doesn't mean he could recite the right answer five minutes later or the next day. In order to expedite the study session, I would extract the relevant information from the book or notes. If I allowed Jordan to do this, we would have never finished anything. This method came with a double-edged sword, it allowed us to keep up the pace, but it kept Jordan from developing adequate study skills. At that time it was a conscious choice that I made. In order to maintain his schedule successfully, it had to be done in this way.

Continuing with final exam preparation, put everyone in the house on edge, including Brian's cat, Snickers. Snickers had an unbelievably calm demeanor, but even she would back pedal, turn and run when she saw me approaching. Actually I didn't blame her, because I was not pleasant to be around in the midst of finals. We would have to go through each section of a subject every single night for two weeks, and review it for three hours prior to the test in the morning. Due to the fact that Jordan had four or five other classes that had finals at the same time, an average study session could go solid for eight or nine hours after school.

To Jordan's credit, he had amazing stamina and could keep this pace up. Being able to survive and flourish, and not be destroyed mentally by this type of pressure is a real testament to Jordan's character. In between all of this he maintained his hockey and baseball schedule, thanks to my patented "teaching while driving method." To this day, I cannot fathom how I didn't get into an accident while concentrating on helping Jordan with his schoolwork.

Chapter 40

In his usual manner of not being thrown by a new environment, Jordan blended into the high school scene rather easily. Jordan just had this uncanny ability to ride the waves better than anyone I had ever met. This is the kid who would go to hockey camp not knowing a soul, and know everyone in an hour. By the end of the first night, he would be demonstrating how far away he was able to lip-read the kids.

There's no question that life wasn't always easy for him, and he was always getting thrown a curveball when he was waiting for a straight fastball. However, as in his baseball career, he learned patience and handled pitches he didn't expect.

He had made the high school hockey team and hung out primarily with those guys, but was comfortable with pretty much anyone he came into contact with. Through his involvement in sports, everywhere he went someone knew him.

Experiencing girls brought out Jordan's shy side, but he did however manage to have some female friends, from time to time and was able to round up a date for most of the important school functions. Although women were relevant in his life, everything took a backseat to sports.

Life with Jordan was a whirlwind adventure, and high school flew by in the long run, but the day-by-day, studying remained an arduous affair, until a miracle from out of the blue occurred. Mollene was speaking to a friend about her daughter's diagnosis of ADHD. Always interested in something that could be relevant to Jordan, she asked the friend if she had any literature about ADHD.

I said, "Mollene, why are you wasting your time? We had Jordan tested five years ago and the psychologist did not mention ADHD."

"I realize that, but what's there to lose reading up on it?" she answered.

"Nothing, but I'm sure he would have been diagnosed with it before now. One of his teachers probably would have picked up on it," I replied.

“Come on, you know as well as I do, none of his teachers have a clue as what we do to prepare him for class. We have kept all his learning problems a secret, so that he wouldn’t get any grief about being in regular classes.”

His teachers really didn’t know anything about him, other than he required more attention because he was hearing impaired. Even that was something we played down as much as possible.

All Mollene had to do was read the first page of the book, and she knew Jordan was ADHD. The first paragraph described him to a *T*. She immediately handed him the book.

“Jordan, just read the first paragraph,” she insisted.

Hesitantly, he began to read. Through the years I had given him hundreds of articles to read and he figured it was just another one of my trivial fact articles.

He looked up and beamed, “That’s me. That paragraph describes me.”

Just as he discovered he was hearing impaired by reading it on captioned TV, he now realized he was ADHD. Not having the patience for a formal diagnosis, I read up on treatments, and decided Ritalin was our first medication to try. Unable to prescribe that class of drug, I spoke to a physician friend of mine who prescribed a small dose of Ritalin to try. Not expecting much after all these years of struggle, I waited not so patiently as Jordan took his first dose. After twenty minutes, he sat down to read. He hadn’t read more than five minutes when he leaped up all excited.

“I can concentrate on this stuff. I know what I’m reading. When I’m looking at the words, that’s all I see. I can’t see anything around me. There are no other ideas going around in my head.” he explained.

Being a bit of a skeptic, I said, “Do you have any kind of vocabulary lists?”

“I have one from English. I’ll get it.” he answered.

We did five words, and I knew life had changed. Jordan knew them all in a matter of minutes. Before taking the medication learning five vocabulary words could have easily taken an hour, and then another hour at a later time.

Jordan also realized that life as we knew it before had changed, Jordan grinned and hugged us both. Miracles do happen. Perhaps some of them are bit slower to happen than others.

Chapter 41

Now that Jordan was a senior in high school and did not have that many serious academic classes, life became much more peaceful in our household. This is not to say that Jordan buzzed through his classes without help, but much less time was spent on homework.

Overcoming his lack of having good study skills, presented a continual challenge. This probably was mostly due to my intervention through the years, but if I hadn't done what I did, he never would have been able to keep up, and probably would have wound up in special education classes. Having Jordan on Ritalin changed the path of his life. There have been many articles written that Ritalin is over prescribed, but in this case, it was a lifesaver. Although his symptoms were very different, Brian was subsequently diagnosed with ADHD, and also prescribed Ritalin. Brian went from a student with a one-point grade average in ninth grade to an honor student, who eventually graduated with honors from the University of Miami Law School.

When Jordan was accepted to Michigan State University in October of his senior year, we were elated. Mollene had MSU banners all over the house to greet Jordan when he came home from school, the day of his acceptance.

After the excitement wore off, Mollene and I had the same thought.

She looked at me and said, "What happens when Jordan is on his own without you helping?"

"Don't think that has not crossed my mind a million times. We've come up with a solution for every hurdle, why not this one?" I answered her confidently.

"Seventy miles away is a lot tougher," she responded.

"You've been pretty creative so far, so you'll have to keep it up. We have almost a year until he starts, so let's try not to worry about it now." I answered her.

That summer Jordan decided who his college roommate would be and we headed up to MSU in East Lansing, for orientation. Diligently, Mollene and I attended all the parent programs, and walked away relatively impressed

with what was said by the speakers who were well trained at putting anxious parents at ease.

Having spent Jordan's entire educational career denying any help due to his hearing impairment for fear of being pressured into putting him into deaf education classes, we now decided to switch gears and seek out any help we could get. Two avenues had to be pursued, one being the hearing issue, and the other being considerations for being ADHD. Knowing Mollene's tenacious approach to seeking out the right people with the right answers, we knew she was the one for the job. Finding the right department at MSU that could theoretically help Jordan was not a problem, and Mollene was able to relay the information to Jordan that he needed to make an appointment.

After the meeting Jordan called. "I spoke with the people there, but unfortunately since I don't sign, I can't be helped much. There are interpreters available, but since I speak and read lips, they really don't have any services that would help me."

I responded, "Well, whatever it is, we'll have to deal with it. You'll have to buddy up with someone in each class to get notes. Find someone smart."

Jordan chuckled, "I've been through this enough times."

Obviously one of his friends was helping him on the phone, because he was getting too much detail. Having a friend help with his conversation was great but it limited our asking Jordan any personal questions.

"What about the ADHD? What kind of accommodations do they make?" I asked.

"Students are allowed to have extra time with exams. I'm going to need a copy of my evaluation," he explained.

"I don't think that will be a problem, I'm sure we can get a copy of your evaluation from Steve Ceresnie, who is a friend and a doctor that specializes in ADHD," I answered.

"Okay, let me know."

It was disappointing that there were not better services to help Jordan with note taking. However, we had been jumping hurdles for years and another one wasn't about to ruin the race. Jordan was quite resilient, and he'd figure out how to get notes.

Around that time, someone told Mollene that through the State of Michigan, tuition money was available through Michigan Rehabilitation for Handicapped people. We had never pursued any services available to us because we had denied all our rights with the schools. At this particular time in our lives we were open to any assistance we were entitled to, either academic or financial. When Mollene spoke to the supervisor at Michigan Rehabilitation, she came away with some interesting information. First of all, she was informed that there was money for tuition, but what was fascinating was the conversation

about who Michigan Rehabilitation was serving. After carefully explaining to the supervisor about Jordan's hearing loss, and where he was educationally, she found that the rehab center had never dealt with another person like Jordan. The supervisor kept saying that if they gave Jordan tuition money, they could help him get a job. However, the jobs that they were speaking of, were entry-level, manual labor type positions. Nothing could be done to explain to them that Jordan was a college student, on the path to a professional career. Unfortunately, the center had only dealt with deaf people who signed, and been in positions, where they needed assistance in acquiring entry level jobs.

Mollene didn't know what to do to get them to understand about Jordan. I felt that once they met him, they would understand more about him. However when push came to shove, it was insignificant what they thought as long as Jordan was given some financial aid. After a process that involved a huge amount of red tape, Jordan did receive some financial aid.

Chapter 42

It wasn't long before the first college-related crisis came up. Not expecting it so soon, I started getting that old elementary school, sick feeling in the pit of my stomach.

"Dad, I have a problem with the professor in my biology class. He has a huge mustache, and I cannot lip read him at all." Jordan complained.

"Great, what do you think you need to do? There were tons of things that I figured would give you trouble, but honestly I didn't consider this one. Tell him to cut it," I joked, half seriously.

Jordan laughed but knew something had to be done.

"I checked and found there is another section, and I looked in there and the prof. doesn't have a mustache. The problem is that the section is not open and no one will let me in."

Of course I responded with, "You know that *no* is not a good enough answer. You need to speak to the head of the biology department and tell him your problem."

Being used to us solving everything for him, Jordan said, "Can't you call him for me?"

"No way. You need to begin solving your own problems. Talk to him yourself. In person, you're going to be more effective than us calling." I answered.

"Okay, okay I'll speak to him." he said.

Within a few days, Jordan was able to speak to the head of the biology department. After a short discussion, Jordan got into the closed section. He was on his way to being his own advocate.

A few days went by before the phone rang, and a new situation arose, which required the usual ingenuity to solve. Jordan called, in somewhat of a panic, that he had to write a paper. In the past, I had always done major overhauls on most of his compositions. As mentioned before, I was partly to blame for his inadequacies, but Jordan's writing skills had suffered due to

time constraints. Since treating his ADHD, I was confident that he would be capable of being a better writer, but he had a long haul to develop the skills he was missing. Just like developing study skills, I knew the same principles held true for writing. The question remained what could be done to help him with the task at hand of a serious composition. Mollene and I thought about a solution, and driving back and forth to East Lansing to review the paper was not going to cut it. After being a bit stymied, we came up with the idea of faxing the drafts back and forth. This was before the ease of e-mailing documents so easily.

Following the solution of the day, Jordan found out that he could fax from the office in the dorm. However, after a few attempts, we realized that the process had to be done too many times and we needed a better solution. The next day, Mollene purchased a fax machine and drove it up to school. Jordan figured out how to set it up, which wasn't so easy then. For awhile until Jordan became more confident in his writing skills, his compositions were edited by me via the fax. Another potential problem bit the dust.

As the quarter went progressed, the usual questions came up; Was he studying enough? Was he keeping up? Getting notes and were the grades ok? Jordan had been home a few times that first quarter. We somehow came up with a way for him to keep a car in East Lansing. Freshmen were not supposed to have cars on campus, but Jordan parked his car at a friend's apartment complex off campus.

The big show down occurred when we came for parents' weekend at midterm. We sat down with Jordan and he informed us of his progress in terms of grades.

"So, how do your midterm grades look?" I inquired.

"Not bad." he replied.

Already apparent by the incipient cat and mouse game, I could tell it wasn't going to be good. I asked already anxious with increased blood pressure. "Yea"

"I got a B, two C's and a D." he responded.

Deleting a few expletives, I said, "What do you mean, not bad. That sucks."

Unfortunately, at that time we were going to dinner with other people and had to table the conversation for later. I didn't say much during the meal, and Jordan knew that he was witnessing the calm before the storm. Following the meal, Jordan and I proceeded to one of the lounges in the dorm, and had it out. The bottom line was what Jordan considered adequate studying was not enough, which was obvious to me, but not apparent to him. Part of the problem was how poorly prepared he was to handle the burden of studying by himself. Honestly I have to admit that I was not as rational about the situation then as I sound now, but I did get my point across that more studying was needed.

Jordan bought some books on study skills, and continued to improve and actually he wound up with a rather successful first quarter.

Jordan continued to improve his study skills, his ability to write and kept his grades up. This is not to say college was a snap, but with solving the occasional crisis, and the other normal trials and tribulations of a college student, Jordan thrived.

He continued playing all of his sports, met his share of girls, and if you asked him, had a rather good time during his years at Michigan State. He graduated with over a three-point grade average, and a Bachelor of Arts degree in Business Administration.

Actually, what is more important than Jordan's academic achievement is that he is a confident young man fully capable of tackling the world. More important, he is a truly good person.

This is where my part of the story ends, and Jordan continues, because he can now speak and write more than adequately for himself.

Epilogue

Here I am, and I have reached the age of thirty-one, which coincidentally is my birth weight in ounces, and has kind of been a special number to me. Interestingly enough, I have finished reading my father's book—the one in your hand—and I have learned a ton of stuff that I didn't know or didn't remember.

Of all the tortures my dad describes, nothing really was as bad to me as he tells it. One of the worst daily events was putting on my hearing aids, because they were attached to my ears with double-sided carpet tape, so they wouldn't bounce around. I also dreaded taking the aids off because it hurt when they were removed.

Although I do not remember Karen Pawlick sitting on me during speech lessons, I have to say that I am grateful that she accepted to work with me.

Probably one of the key issues in my life was speech. I really have never been self-conscious about the quality of how I speak. Until I was older, I never gave it much thought, because I was unaware of being different and didn't realize that I didn't speak like everyone else.

I think I was much more self-conscious and aware of speech quality when I was with my parents. I knew they would constantly correct what I said if my pronunciation was not right. Since I still have to monitor how I pronounce words, they still are on me to properly enunciate when I speak too quickly.

School was always difficult, and was a challenge for both my parents and me. Since I only knew that I continually had to study with the aid of my parents, I was probably less frustrated with all the pressures than my parents.

I was pretty well sheltered about what a difficult undertaking teaching me was. No one told me that the odds were against me succeeding in regular school. I never realized that the elementary school principal didn't think I belonged there.

My parents never tried to analyze my feelings, thus I never realized I should feel any different than anyone else. The question of how I felt about

being hearing-impaired was never asked until we discussed this book. By not discussing the so-called handicap, I never dwelt on it, and just did what I needed to do.

I can truly say I have never been depressed about being hearing-impaired, because by the time I realized I was truly different, I had conquered most of the major obstacles. When I became aware of my deafness, I accepted it and knew that I couldn't change it, and if I were going to be successful, feeling sorry for myself wasn't going to help.

My dad asked me if I ever was self-conscious when I was in a situation with new people, such as being on a new hockey team every year. I don't remember that being an issue, except when I was around thirteen and I got this apparatus that went on my hearing aids to keep them tight under my hockey helmet. I wasn't comfortable putting the apparatus on, so I would turn my body and kind of put them on so that no one would notice. In most cases, I didn't realize I was that different, or didn't realize people had been making fun of me. Possibly my ADHD worked in my favor because I may have been unaware of what was going on around me.

I was pretty much untroubled by many different issues that may have troubled many people. One time when I was younger, we saw a sign that had a man with a Coke can for a head. Affectionately, my parents began calling me *Popcan*, which has stuck to this day. It's obvious that I was not sheltered from the teasing that every other kid had to endure. That probably helped to give me my hard shell, which lets ridicule just bounce off of me.

Using a speaker phone to speak to a girl with my mom listening created an uncomfortable situation, which is probably why I did not call many girls throughout high school. In college, my roommates helped, which made the situation more tolerable.

After college I still faced some of the problems that always existed. Meeting people in groups is still difficult for me, because by the time I turn to lip-read the speaker, I have missed the beginning of the sentence, and may respond with something that has already been said. Noisy parties and bars are tough, because the noise drowns out my own voice and it is hard for me to monitor how loud I may be talking. That doesn't prohibit me from being in those situations, but if I have my preference, I go for being in a quieter environment.

Technology has made my life much simpler and has put me on almost a level playing field with everyone else. Email that goes right to my Blackberry and texting keeps me right in the loop for all situations for work and social. My new phone has captioning right on it, so phone conversations are a breeze. I can converse well enough with people I know on my cell phone to get by in most situations. A captioned cell phone is being worked on currently, which will improve my communication ability even more.

While deciding what to do with the rest of my life, I decided I needed some time to give my brain a rest, and moved to Vail, Colorado. Originally I had planned to be a ski instructor, but when I found out that new instructors only taught the little kids, I realized that I wouldn't have enough time to ski. Instead I worked in a ski shop where they gave me time off during the day to ski. It was a dynamite year until I tore my medial collateral ligament after skiing ninety straight days.

After that I moved back to Detroit and owned a printing company which I subsequently sold. The travel bug bit me again and I moved to Miami Beach and lived with my brother who was attending law school at the University of Miami.

I was a manager at Target, and then sold real estate. I decided I enjoyed Michigan better. I missed being able to play hockey all the time, and although we lived at the ocean, I had to drive forty-five minutes to water ski. At home in Detroit our house was close enough to the lake and could ski everyday for free.

Currently I work in marketing and advertising and am a part-time personal trainer. I specialize in training young athletes to improve their skills. Ironically, after being told I would never speak, I do motivational speaking, and if I say so myself, I am quite good at it.

Actually I have lived a rather special life, and I have taken the hand I was dealt and ran with it. I have skied the Rockies, windsurfed the Pacific, and taken boat rides in the canals of Venice.

To add to that, I am engaged to a wonderful woman named Hillary. She is now a part of the newest chapter of my life.

I have lived by the motto of my mentor Ciwa Griffiths, "If someone tells you that your hearing impaired child can't do something, don't you believe it."

As a young child I came across a quote from Helen Keller which I have patterned my life, "LIFE IS A DARING ADVENTURE OR NOTHING."

Jordan is available to speak to your group nationwide.

HOW TO BE RELENTLESS IN PURSUIT OF YOUR DREAMS
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