# CHARGE STORIES

## Contents of Stories

## COLOBOMA

by Tim Hartshorne

Jacob's retinal colobomas were diagnosed during his first year. The coloboma in his right eye involves the macula and accounts for significant visual loss. His right eye is also smaller than his left. The coloboma in his left eye involves only part of the macula, and he seems to receive useful vision in that eye. His acuity in both eyes is poor, especially his right eye. In addition, he has astigmatism in both eyes.

A recent, functional vision evaluation found that Jacob could detect objects in his lower, right and left visual fields, but not in his upper field. His responses to visual stimuli were consistent with poor depth perception.

Jacob wears corrective lenses. He received his first pair at under a year of age, and wore them very consistently for a few years before developing a habit of throwing them. After several years of consistent effort, his school staff managed to teach him to wear his glasses while at school. However, at home he prefers to not wear them. When he is wearing his glasses he appears to be more attentive to the world around him.

Jacob's eyes are checked twice a year. A major concern with retinal colobomas is retinal detachment. So far Jacob shows no detachment.

## HEART

by Jackie Kenley

Our daughter, Laura, was born in 1985 at the University of California San Francisco hospital. On her second day of life, a heart murmur was detected by the pediatric staff. The cardiology staff was then brought in for a consult and after an echocardiogram it was determined that Laura had a major heart defect common to children with CHARGE, tetralogy of Fallot. Laura had a good birth weight and we were advised that it would be optimal for Laura to grow and be older before the heart repair. As our family was dealing with the other problems our new little girl had (such as hearing and vision loss), we were grateful that the surgery could be put off. We took Laura home and cared for her while she gained weight. She also became a loving part of our family.

At thirteen months, the cardiology team felt Laura was ready for her repair. Her brother, then 6, and sister 2, were taken to the hospital. A member of the staff explained the procedure to them and showed them where Laura would be. It was a long procedure with Laura on a heart lung machine. After the first surgery, Laura had bleeding complications which only occur in a small percent of the patients. We knew at that time that Laura often fell into the "small percent" population. She had to go back on the heart lung machine while they found the area that needed suturing. Finally Laura was taken to ICU. After surgery, it was eight days before Laura could be extubated. She was kept "knocked out" with morphine during this time. It seemed an eternity for us, but finally Laura was able to come home for a quiet recovery.

Laura has had another surgery for mitral valve repair...thirteen years later. This time, Laura quickly extubated herself (much to the staff's surprise) in the ICU. Her nurses noted she was breathing fine on her own and did not seem to be in distress! She had gone into the hospital on Thursday and came home the following Tuesday! We have all witnessed an increase in learning and overall activity since this repair.

Laura's brother and sister seemed much more emotional and concerned by the second surgery. I know that they were very relieved when it was over. We do not foresee any further heart surgeries. However, with Laura, we know there is always the possibility of needing care for her heart. Our family is thankful daily for her "well-repaired heart"!

## ATRESIA OF THE CHOANAE

by Debbie Matasker

My son Michael was born in 1997. He had a very eventful birth. We knew there were problems at 33 weeks, because I had developed polyhydramnios. I had an emergency C-section because of fetal distress. The polyhydramnios was probably caused by Michael's choanal atresia.

My son was delivered, cried once and then turned blue. The neonatologist tried to pass catheters down both nares but they were completely blocked, so he was immediately intubated. A CAT scan showed bilateral bony and membranous choanal atresia. The doctors at the hospital where he was born had only seen this six times in 20 years.

At two weeks of age, Michael had his first choanal atresia repair. Stents were placed for two weeks. After one week of having the stents out, his passages closed. The ENT operated again, same result. A third operation was done, again unsuccessfully. I finally got Michael discharged from the hospital were he was born and got him to Columbia Presbyterian-Babies Hospital in NYC. The ENT there operated on him for the fourth time, placing stents that had no resemblance to the other stents. These were huge stents that even stuck out of his nose and were inserted through his upper lip. This ENT left the stents in for a long eight months. Our new ENT performs about eight choanal atresia surgeries a year and sees approximately two new kids with CHARGE a year.

The stents were removed under anesthesia by our new ENT. The other ENT removed them by clipping the sutures inside the nose, which hurt Michael. Now at 26 months, his passages are still wide open. Another ENT, Dr. Cotten in Cincinnati Children's Hospital, who has the most experience in this area, said that our ENT did an exceptional job, just as he would have done. Dr. Cotten is known worldwide for tracheal reconstruction and decannulating children in cases that were particularly difficult.

Hopefully Michael's passages will remain open; our ENT feels confident that they will. This was a major medical milestone to have surpassed.

## AIRWAY MANAGEMENT

by Susan Appell

Abby, our five-year-old CHARGER, has swallowing dysfunction resulting in copious secretions requiring frequent suctioning, tracheomalacia, bilateral choanal atresia (repaired), sleep apnea, obstructive airway as well as other medical conditions related to CHARGE syndrome. Abby's respiratory complications resulted in repeated pneumonia, pseudomonas, and frequent respiratory infections during the first year of life. During this time, Abby's cardiologist indicated that pulmonary hypertension was evident in her echocardiogram.
At 10 months old, Abby was hospitalized at Johns Hopkins Children's Center in Baltimore for pneumonia or pseudomonas. Her pulmonary physician ordered a sleep study which determined Abby had sleep apnea/obstructive airway. She explained that Abby could not grow or develop properly if she was not going into the appropriate levels of sleep which allowed her body to properly oxygenate itself. We had two options: placing a trach or using the Bi-Pap Airway Management System when Abby was sleeping. Abby has used the Bi-Pap machine from 10 months of age until today. It has been a true blessing and has allowed Abby to develop mentally and physically. Since there is no evidence that Abby suffers from pulmonary hypertension. She is able to fight off colds and has not used an antibiotic for over three years. Her secretions remain copious and her swallowing has not improved, however, if it were not for this machine, Abby would be trached or worse she may not be alive today.

The Bi-Pap Airway Management System is exactly that - it is a machine that helps manage a person's airway when he/she has difficulty breathing due to sleep apnea/obstructive airway. It does so by blowing a predetermined amount of pressure into a person's airway when they inhale with a predetermined amount of constant air pressure when they exhale. The machine can be adapted to a person's specific needs. Our Bi-Pap is made by: Respironics Inc., Murrysville, PA, 15668-8550, 412-733-0200, FAX: 412-733-0299, 800-345-6443.

The machine itself is smaller than a computer monitor and is portable. The unit filters the air and has adjustments to control the air pressure. Air pressure adjustments are made as a result of a sleep study and then routinely checked by our medical equipment company which services our machine every three months in our home. One short piece of special tubing comes out of the main machine and attaches to the humidification chamber. The humidification chamber is a small plastic bowl that sits on a hot plate. The hot plate has a temperature control which monitors the water temperature. Another tube leaves the chamber and is attached to the mask which has little portholes to allow air to escape so that carbon dioxide levels do not build up inside the mask. The child wears a little silk bonnet around her/his head which Velcro's to the mask. There are various masks available depending on your child's needs. We have learned to prepare her machine first (turned on and distilled water poured in chamber). We put Abby's mask on and then attach tubing so that air doesn't blow in her face while attaching the bonnet. We also learned to put a piece of duoderm on the bridge of her nose to reduce the pressure from the mask to prevent a pressure sore and to place Lacrilube in her eyes to prevent any drying in case the seal around the mask loosens and air blows toward the eyes. We requested an alarm system be attached to the machine so that in case of a power outage or Abby's pressure dropped an alarm would alert us.

Abby has gone from a very sickly infant who woke up every half an hour due to coughing, to a happy and fairly healthy five year old who now looks forward to going to bed and eagerly wants her mask on. She knows that this machine helps her and it surely shows when she is able to stretch out across her double bed and relax to enjoy a sound nights sleep without interruption. When Abby is on her Bi-Pap her secretions stop and unfortunately this is the only time she gets relief.

## GROWTH

by Marilyn Ogan

For two years, Kristin followed a pattern of growth that ran below but parallel to the standard growth curve at the pediatrician's office. Kristin's growth then began to level off, falling further away from the normal curve as the curve began to climb. Dr. Sandra Davenport suggested we consider an endocrinology evaluation for Kristin. We consulted a pediatric endocrinologist, who reviewed her growth pattern, evaluated Kristin's nutritional intake and energy expenditure and ran some tests. The testing involved L-DOPA stimulation and blood drawing every hour for 4-5 hours. Kristin "failed" the test and was diagnosed with severe growth hormone deficiency.

Kristin - Fall 2001

Kristin began growth hormone replacement therapy in October 1995. We have had more than three years of treatment and it seems to have helped her very much. She has responded well to the therapy. One of the first things we noticed was increased muscle tone. Kristin suddenly had more strength and endurance than before. Her development skyrocketed and she was GROWING! In the 18 months prior to testing, Kristin had grown only 1/4 inch! Kristin has now reached the stage where the faster-than-normal growth rate is declining, but she is still progressing and responding to therapy. Our endocrinologist stated that Kristin was not now experiencing tremendous growth, but he felt that without growth hormone replacement therapy, Kristin would not be growing at an acceptable rate. We have to agree.

Kristin will receive growth hormone therapy for several years, until she achieves her maximum growth potential. The only drawback to the therapy from our point of view is that it is done by injection. Kristin gets a shot five nights per week. We rotate the injections between four sites. At age six, Kristin had already reached a stage where she asked to take a "rest" from the "help-me-grow shots." She had several years of treatment remaining. I anticipate it being a big issue for the family in the near future

If you suspect a problem or are concerned about your child's growth, seek appropriate services for diagnosis. A pediatric endocrinologist would be your best choice. Don't wait for puberty to see if the child "catches up" -- that is too late for growth hormone therapy to help. As a rule of thumb, any child who is only as tall as children two or more years younger or who falls away from his or her previous growth pattern should be considered for an evaluation. And remember,

children with CHARGE have lots of reasons for being small, but a few really do have growth hormone deficiency.

The Human Growth Foundation (HGF) is an excellent source for information if you have questions about growth patterns, deficiency, hormone treatment, and even ways for an individual to cope with short stature. They have multiple publications (for small fees), publish several newsletters, and offer a parent-to-parent support program.

Human Growth Foundation, 7777 Leesburg Pike, Suite 202-S, Falls Church, VA 22043
(800) 451-6434 phone (703) 883-1776 fax
http://www.medhelp.org/web/hgf.htm email: hgfound@erols.com

Another source of information is the MAGIC Foundation for Children's Growth. Their website has some marvelous information about growth hormone therapy. the Frequently Asked Questions page is very informative.

MAGIC
1327 N. Harlem Avenue
Oak Park, IL 60302
(708) 328-0808 phone

## BEHAVIOR

by Ana Saruski

When my son Joel's behavior became an obstacle in school and social situations, I consulted his neurologist and tried several medications to address mainly his aggressive behavior towards his peers and sibling. This aggressive behavior included pushing, pulling hair, and kicking. Several trials of different medications failed to help improve his behavior. After seeing the negative effects of some of these medications, and reading about the potential side effects, I decided to consult a natural nutritionist, who put Joel on a sugar free diet for his behavior, and dairy free diet to improve his asthma. I immediately saw changes in his behavior, which I attributed to this diet and the combination of vitamin supplements that the nutritionist recommended. His aggressive outbursts decreased, and his teachers and therapists commented on the changes in his behavior, and felt that he was much easier to work with since he started on the diet.


Joel's diet consists of pureed foods. On a daily basis, I mix the following supplements in his food: acidophilus to prevent yeast overgrowth; amino acids for protein supplementation; B complex to improve his behavior; calcium supplement to replace the calcium he used to get in dairy products; and a natural multi-vitamin. Joel has been on this diet for nearly one year. In the past month I also added a DHA supplement called "DHA Junior", which is especially designed for children 3 and over. The DHA supplement is meant to provide fatty acids which are believed to improve brain and eye function.

## EARS - DEAFNESS, and LANGUAGE

by Yuka Persico

Keith, who is now almost 10, has been trached since he was six weeks old. Because he had difficulty voicing around the trach, when he was about a year old, I decided to begin signing with him. Because I believed at that time that he had hearing but couldn't voice, I only was learning and using nouns, adjectives and verbs - children picture book language. His first signs were 'more', 'please' and 'read book'. By the time he was two he was using about twenty signs, and when he was three he had a vocabulary of over 300 signs, often stringing several words together to shape a concept. Since he was learning the signs so nicely, we were becoming quite detailed in our list of fragments to describe things.

When Keith was three his hearing was routinely tested for placement in special education preschool we found that he is profoundly hard of hearing, with a 90-120 dB loss. At that time, the infant assessment team had targeted Keith for the orthopedically handicapped classroom, as he had a trach, a gastrostomy, was not independently walking and had balance issues. I had contacted the deaf and hard of hearing (DHH) teacher because I was eager to place Keith in her class even before I knew he was deaf, because signing was his mode of expression. When the DHH teacher called me back, I had already absorbed the fact that Keith was deaf; she however had not heard the news yet. Our conversation was awkward, but revealing. She began by politely outlining for me all the reasons non-deaf children use sign. She praised the IEP presentation I had prepared for Keith and was impressed by his vocabulary and my documentation of it. She began to explain how being deaf is different than being hearing and utilizing sign when I interrupted her and said "But Keith is deaf. He has a profound hearing loss!" It seems odd to say but she was very excited about this, mostly because she is a wonderful teacher and exceptional at reinforcing language. Now she was attached to Keith and to his agenda - that he needed a complete language.

There was something in the beginning of the conversation we had, before she realized Keith was deaf, and she was talking about language and vocabulary that the green light went on in my head. I had given Keith a vocabulary, but not a language. I hadn't really thought about that difference yet. I frantically began to fill in all the blanks in my signing, trying to create whole sentences, sign all the words in a storybook, and even sign all I said to anyone. Since I was quite determined about this, it really limited my conversation for a while. I was frustrated by my limited progress, and how awkward at times it was to learn the signs from a book and use them with any conviction.

Keith started special day preschool in the orthopedically handicapped class with a full time sign language interpreter, who was a deaf education student from CSUN (California State University – Northridge). When I saw her comfortably and fluently sign a complete language, I knew this is what we needed, and I invited her to come work in our home, and just sign sign sign. She came three days a week. She signed storybooks. She sat in front of the television and signed videos. She signed when she talked to me and she patiently answered all the questions I had from literally "how do I sign this.." to questions about deafness and its culture. I put ads up at Moorpark College and CSUN, and found two more college signers to come into the home the other days. Our entire family social life was based on these wonderful students and at dinnertime our table was always full of hungry students signing signing signing. I wanted not only the direct language presented to Keith, but the richness of the passive receptive language that hearing children naturally benefit from by simply being in the room when adults are speaking. I wanted to bring Keith's language to that place of fluency that deaf children of deaf parents demonstrate.

It really took about 4 years for Keith to start signing language back. At five he was indicating his preference for certain nicknames - like any three year old might do, and at six he would dictate simple repetitive stories. At seven he began to be able to read, spell and speak intelligibly, and that's when the whole thing took off. He went from simply always doing his best, to doing his best and doing fantastically. When Keith had just turned nine, he attended Space Camp in Alabama, and won the "Right Stuff" Award, ran for Vice President of Student Council for the entire Elementary School where his DHH class is located and won, and has been on the honor roll every quarter since letter grades have been given. As much as language has been the key to his emotional independence and "coming into his own" he also seems to love language, playing with it, using it and reading it.

With language, not only could we now know our child intimately, but he could freely unleash himself upon the world with joy. It's not so much that Keith is "all caught up," because he isn't, but now his progress is no longer bittersweet and we no longer compare him to the "normal" life he would never have. He has complete ownership of his own person, just like anyone else. He has his own strengths and weaknesses just like anyone else. He has become completely equal and stands on his own without qualification or explanation.

Keith walking his dog, November 2001

## CAITLYN, AGE 6

Jeanne McMullen, mother and frequent contributor to the list
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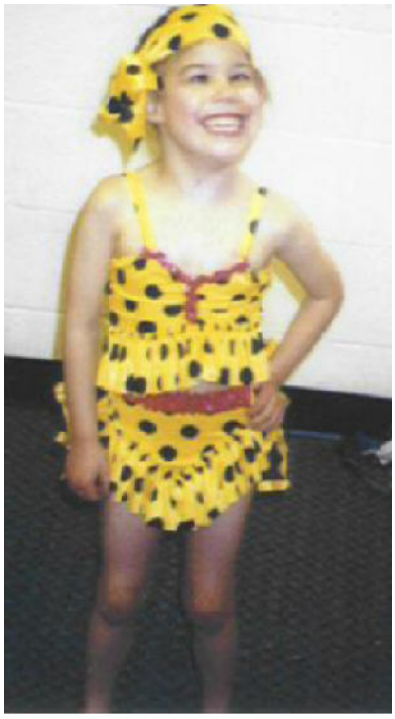


Caitlyn, 6, at dance recital

With Caitlyn's severe heart problems, respiratory problems, and developmental delays, I never thought she'd be able to take ballet class, unless it was designed for special needs children. Yet I found a teacher who was more than willing to have Caitlyn in her class. Though Caitlyn's abilities are very limited and she tended to wander during class, she DID
take ballet class and did participate in the recital. It brought tears to my eyes every time I saw her in her leotard and in her costumes.

It has been a long road to this point. Here are some of my observations on what helped us with Caitlyn:

*"All of her hospitalizations have taken their toll on her nervous system."*

**SENSORY INTEGRATION**

One of Caitlyn's most distressing issues have been related to sensory integration (SI). All of her hospitalizations have taken their toll on her nervous system. The bright lights of the ICU, the constant beeps and alarms of the monitors, repeated IV sticks, blood tests, and so on. This has left her a very anxious child who is easily overstimulated by her environment.

As an infant, Caitlyn didn't want to touch anything including her toys, nor did she want to be touched. She arched her back when we tried to hold her and cried when we caressed her skin. We soon learned it was only a firm, deep touch, and vigorous bounce that she found calming. She cried most of the day and night for most of her first two years. She refused anything in her mouth, teethers or food. Due to her resistance to stimulation, her development was stagnant.

"*OT is NOT job training, but is fine motor therapy"*

What helped Caitlyn tremendously was occupational therapy (OT). I didn't realize until she was almost two years old that OT is NOT job training, but therapy for is fine motor and daily life skills.

OT often includes SI therapy which is crucial to CHARGErs like Caitlyn. SI therapy helps desensitize a child to her world. Desensitizing her sense of touch, her mouth, her ears, and eyes. I would recommend that every CHARGEr have OT from birth, particularly those who have spent a lot of time in the hospital. SI therapy also covers vestibular disorders (a lack of balance) common in CHARGErs due to their ear abnormalities. Starting OT at age two was much too late because she had missed a lot of critical development periods, and it has proven impossible to catch up.

An important part of Caitlyn's SI Therapy is the brushing program. It must be done under the supervision of an OT and it must be done as prescribed to get the full effects. This means every two hours, for the initial two weeks, which can be difficult. A handy way to stay on top of it, is to do the brushing with every diaper change. Though there was a slight improvement with the implementation of the brushing, it was only after we made a concerted effort to do it every two hours that we saw a breakthrough and progress in her development began.

**GROSS MOTOR**
Caitlyn has had low tone and vestibular problems, so early physical therapy has also been important. I want to stress that parents should consider using their private insurance to help pay for private services to supplement the early intervention (EI) services for their kids. The added therapy can make a difference in the gains a child will make. Often EI does not have as much equipment as the private programs do, and much of it is too large and bulky to be transported to the home. Also, often EI therapist may not recommend medical enhancements that may benefit the child such as orthopedics or walkers. By providing more intensive therapy during the critical stages of development, the child's prognosis may be far better.

**ORAL MOTOR**
Oral defensiveness is also a common problem with CHARGErs, particularly those who are tube fed, even for a short time. For this problem we used a NUK brush found in Gerber's first toothbrush set, the brush with the round, rubber-nubbed tip. For starters she would only allow it in her mouth for a second. Progress was slow. Eventually we were able to massage her gums, tongue, and all around her mouth, and finally we were able to dip the tip in aversive textures in order to make great gains in this area. An occupational or speech and language pathologist can recommend a treatment program to assist in this area.

To stimulate her speech, we attempted a variety of games. We imitated her coughs and sneezes to make a game of it, then encouraged her to imitate our coughs and sneezes. We then were able to gain her cooperation in imitating animal sounds. Early on, we purchased a good sign language dictionary and signed to Caitlyn as we spoke, emphasizing the main words of the sentence such as "Bath" "Bedtime" "Eat" etc. Soon Caitlyn had created a few of her own signs and thus had started communicating her basic needs.

Sign language truly helped reinforce the concept that all words have meaning and the importance of communication. It did NOT discourage her verbal speech, but rather promoted it. This principal applies to BOTH hearing and deaf children, and was very beneficial to Caitlyn who has normal hearing, albeit with a delay in processing.

*"I think this helped her to keep from falling further behind"*

**COGNITIVE**
In addition to working hard with Caitlyn on the skills she was lacking, we also took the extra time to walk her through age-appropriate activities that were well beyond her means. Using hand

over hand and other modifications, we eventually learned that though Caitlyn had very poor motor skills, her cognitive skills were indeed a strength. As her motor skills were almost stagnant, our efforts brought about great strides cognitively. The key was remembering that Caitlyn did not have to accomplish each milestone before moving onto consecutive ones that required alternate skills. Identifying letters and numbers were taught *and learned* before she mastered stacking blocks and doing puzzles. We then were able to build on her strengths to accommodate her weaknesses.

At age 3, though unable to manipulate many baby toys such as crib gyms and pop up toys due to her poor fine motor skills, Caitlyn knew her name, address, and phone number. By age 4, she knew her upper and lower case letters, all her numbers and shapes, and colors. At age 6, Caitlyn read her first book, "*Green Eggs and Ham*". She has a memory that far exceeds her age, another strength. We build and take advantage of that.

*"Social skills are some of the most important skills for children"*

**SOCIAL SKILLS**

I don't know what to say here other than if I had been a better advocate for my daughter at her doctor appointments she might not have spent most of her life acutely ill. Many of her medical problems went months and sometimes-even years out of control. This prevented her from participating in community activities and play dates. It seems as though the majority of Caitlyn's medical problems were addressed by the appropriate doctor until the problem had reached such a climax that it created irreversible and permanent damage.

Social skills are among the most important for children, particularly a disabled child. Relying on their peers for assistance will be critical as they mature. Yet these skills are often overlooked by doctors in the early years as being trivial compared with the severe medical problems these children face.

Caitlyn becomes very anxious around peers and is very disconnected from play. She appears mildly autistic in many ways. She prefers to spin around in circles and make odd vocalizations when children are playing nearby. She is unable to focus on any particular toy or activity instead always flitting about from toy to toy much more so than other
children her age. I think the most important thing we did do for Caitlyn's social skills was to remind her of her strengths, of our love for her, and make the most out of nonclinical times to get a smile out of her. She is a very happy and social child among adults.

*"Even if vision services are inaccessible on a regular basis, go for evaluations"*

**VISION**

Vision services should be available from birth through early intervention and through your closest School for Blind Children. Take advantage of these services with or without the presence of colobomas. Caitlyn has crossed eyes and it wasn't until 1-1/2years that we started getting vision services. That was when we learned she couldn't track objects at all--a three-month skill. Tracking is critical to depth perception, which is necessary for safe mobility and locating objects. Some children also have visual processing difficulties, cortical visual impairment, or other vision issues. Vision therapists can often recognize and treat such conditions that may go unnoticed by the parents and other professionals.

Even if vision services are inaccessible on a regular basis, go for evaluations and consults every few months to learn what exercises can maximize your child's vision. Children can

compensate for even significant visual deficiencies particularly when taught proper techniques. Therapy can maximize what vision a child has, and also prevent delays in other areas. Therapists can recommend modifications and alternatives to traditional toys to make them interesting to a child with low or no vision. Vision services can be quite beneficial even when a child's vision difficulties originate in the brain.

Orientation and Mobility Therapy is also important to children with visual deficits. Some vision therapists are trained in O & M therapy, yet some are not. O & M carries it's own evaluation and therapy.

*Don't be afraid to sign your child up for "typical programs*". Often you will face prejudice and ignorance and be turned away, but keep looking to find programs that will suit your child. He will benefit from the experience.

*"It was only after five years of hounding that Caitlyn finally was referred to an immunologist*"

One final note:
Caitlyn always had either croup, bronchitis, pneumonias or other severe upper respiratory infections with only a few days between each illness, if that. Each illness was treated individually as it arose with nobody putting together that she was always sick, really sick. Only after five years of hounding her doctors was Caitlyn finally referred to an immunologist for testing which led to a diagnosis of a primary immune deficiency. Caitlyn is now thriving with her IVIg (intravenous immunoglobulin) treatments. Though I am thrilled to have found answers and a treatment for her, one that has changed and improved our lives drastically, I am saddened by all the years she has lost socializing, playing, growing, and developing. Immune deficiencies have rarely been mentioned in CHARGE literature, however, it has frequently been discussed how sick our kiddos get, even in the CHARGE manual. I would be very interested in seeing more parents whose kids are always acutely ill as Caitlyn was, pursuing this problem as a cause. Caitlyn's doctors didn't take her illnesses seriously, even though her temperatures frequently were well over 104 degrees, even though they resulted in a number of hospitalizations. I feel that many of her developmental and behavior problems are a result of her constant, acute illnesses. Parents must be proactive in order for their child to receive appropriate treatment.

***Editor's note: Here are two more stories from Jeanne and Caitlyn.***

**A WEEK IN THE LIFE OF CAITLYN, AGE 6**
**What have we been up to this week? Let's see**.

**Monday** A.M.: Ophthalmologist recommends another eye muscle surgery, but advises that after 4 unsuccessful surgeries, her odds of success are poor. He is understanding when we decline.

**Monday** P.M.: Our regular cardiologist is on vacation, so we are forced to see an alternate one. Of course this means reinventing the wheel. We have come to terms with her prognosis after obtaining three previous opinions on her heart, all agreeing that she is not amenable to surgical intervention. Yet today, we are asked to strongly consider going ahead with a surgery attempt. This, in light of advice that if it is not successful, will greatly diminish her quality of life and possibly be fatal.

And these doctors wonder why I'm so cranky at appointments!

**Tuesday** A.M. Psychiatrist talks about adding Prozac type drugs to her already daily dose of 10 medications.

**Tuesday** P.M. pediatrician notices she has developed allergies and puts her on Claritin--medication #11!

**Thursday** P.M. Pulmonary changes all her asthma meds because he confirms my suspicions that she's still aspirating and can feel that she is not exhaling fully anymore (again). Cannot increase GI meds because they're maxed out.

**Friday** A.M.: New Neurologist stands us up. Her secretary forgets to call us to cancel. I catch the neurologist on my way out whom I've seen before, but who has never met me. I chew her out ranting and raving for 15 minutes--so livid I was shaking. After all, I got my kid up at 5:30 in the morning and listened to her tantrum about it for an hour. To top it all off, she woke up that morning with pink eye! Then dragging her to the hospital (hoping to get antibiotic eye drops to save another trip back to the pediatrician) only to be stood up. At the same office that always makes patients wait at least three hours for a fifteen minute visit with the doctor. Fifteen minutes which last time were spent entirely on lecturing his accompanying students on the CHARGE facial features before them (in my daughter). I have to admit I just love it when they point out her colobomas--SHE DOESN'T HAVE ANY! Anyway, I can't BELIEVE they didn't call security!

**Friday** P.M. After three urgent phone calls to the pediatrician, I can wait for a prescription no longer. I leave for our GI appt and keep her on my lap the whole two hours in the waiting room to keep her from touching anything. GI doc increases her GI meds--even adding yet another medication (make the grand total 12!) and increasing the dosages that she's on.

**Saturday**: I hear back from the pediatrician who calls in a prescription for antibiotic eye drops. I sadly call to cancel the birthday party we were supposed to go to remembering the last one she was invited to she missed due to a hospitalization.

**Tomorrow** (Sun): She'll be getting her IV infusion so can't make that birthday party either. (Yes, I am very grateful that she's been invited to so many parties this year).

Editor's Note: A year later, Caitlyn is only on nine medications, only six of which are daily. Ten kids attended *her* birthday party, which was a grand success.

## 2) Caitlyn's Christmas story

Every Christmas we receive a letter from a wonderful family. The story behind it is beautiful. It is with tears in my eyes and pride in my heart that I share this story.

When Caitlyn was admitted to the hospital for an emergency open heart surgery at 3 weeks of age, I sat in the cardiology waiting room crying. A woman approached me and gave me a big hug offering words of encouragement and prayers. She introduced me to her 9 year old granddaughter and we chatted briefly. During such a scary time, the kindness of this stranger left an impression on me that I wouldn't easily forget.

At 3 months of age Caitlyn was in severe heart failure and septic. She had arrested several times that day, and had to be in a medically induced coma to stabilize her. The surgeon said she had developed an aneurysm from the previous heart surgery and that he had to operate as soon as he could stabilize her enough to withstand surgery. He said for the first time in his

career, he called the Ronald McDonald House and told a family that drove in from out of town that their surgery would have to be canceled to accommodate Caitlyn. He said he didn't even know if she'd make it till morning.

Caitlyn's surgery was very rough as she suffered a lot of complications. It was very touch and go for days. That Sunday, as I sat in the ICU waiting room with my husband, a woman greeted us warmly with a big hug. She saw my lost look and asked if I remembered her. She recounted the experience in the cardiology waiting room several months earlier, and I slowly recalled the experience. She said her daughter, Karlye, had just had open heart surgery that day that had been rescheduled from the previous week due to an emergency. She said, "A baby was dying and needed the surgery right away." My husband and I said shocked--Dr. Siewers at 7:30am Thursday? She said, "How did you know?" We said "It was our baby." She nearly fainted.

The woman described what had happened Wednesday night after getting the call from the surgeon. She told us how Karlye was so upset about having to drive back home several hours away only to come back and get worried all over again but her mother said, "You're 9 yrs old and have lived with this heart condition just fine your whole life and you can wait until Sunday. This baby can't wait until Sunday, she'll die if she doesn't have the surgery tomorrow."

The girl said "Then if I wait until Sunday so she can have my surgery slot tomorrow then would I be helping to save this baby's life?" Her mom said yes. The girl asked if the baby would still be at the hospital on Sunday and her mom assured her most probably. The girl asked if she could go shopping for a get well present for the baby and her mom agreed.

The woman showed us the stuffed bear Karlye picked out for Caitlyn. I asked them for their address to send a thank you note to the girl. A year later, I sent them a Christmas card with a picture of Caitlyn and a note thanking them for their kindness and telling them how much it moved me. I wrote that though they probably don't remember me, I'll never forget how deeply they touched me. They replied with a letter detailing how much their daughter talks of Caitlyn as the highlight of her life. How she says she "helped save Caitlyn's life".

It's been five years since our two brief encounters in the hospital. This past year marked the first time that the girl, now 14 wrote me herself. Karlye wrote that Caitlyn was an angel, a true angel and a miracle child. I asked Caitlyn if she knew what that meant because so many people say that about her all the time. After some thought she said, "I think it means to know me is to love me."

Caitlyn, age 5-1/2 helping mom make birthday cake

## HUMOR

Casey Fisher, mom, Founder of the list serve, and a major advocate for CHARGE California

Humor has been our family's saving grace. Aari uses it too. When people ask him what happened to his ear his standard reply is that "Daddy forgot it at the hospital." When he had his first choanal atresia repair, the doctor used a bright red-orange tube for the stent. After six months of getting asked the what the devil happened, I started replying to the obnoxious ones that his doctor got stuck in an old Laugh-In episode (boy am I telling my age on that one).

At a meeting with the school one day, I said that Ari was a FLK. The school psychologist began writing furiously, saying she was gonna have to look that one up as she hadn't heard of a syndrome or medical condition called FLK. Air's teacher and I got to laughing so hard it took a while to explain to her that FLK meant Funny Looking Kid.

Once when we were out somewhere, Aari was reading a book. Being so little, about the size of a 4-year-old (he was about 7 at the time), some lady asked him if he would like her to read it to him. He looked up and told her "Thanks, but I'm quite able to decipher written language." The look on her face was priceless.

## TRANSITIONS

JULIA, age 18
Marie Patterson, mom
Australia

We have Julia, now 18 and what an experience it is raising a teenager who we think cannot do lots of things, and it brings us to reality about their ABILITIES not their disabilities. Julia is doing three day a week work experience, and next term she will be going to work experience at McDonald's, clearing tables, wiping up, etc. This is just one of the milestone we enjoy. With all the down sides of a child with CHARGE, it is nice to get some light stuff. Our problem looming is what happens aft school. There are very limited opportunities for Julia working in an environment without support staff. Finding a uniform to fit her is also a problem (she is only as tall as an eight-year-old). Another problem in Australia is the Proof of Age Card does not necessarily admit her to a club where her size says NO GO. We are working on the discrimination process and believe me I will find an answer. Because of the mileage barrier for clubs in New South Wales, we have to prove she lives outside the area but without a driver's license or residence proof, it is difficult.

## MY FAMILY IS A WONDERFUL INFLUENCE IN MY LIFE

Andy Prouty, age 19

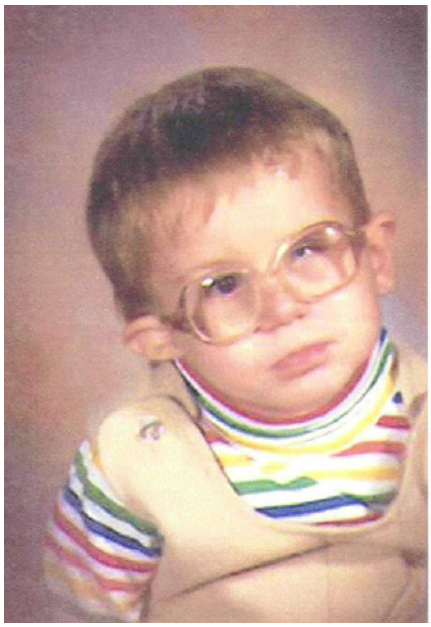
When I was born, my parents learned that I was deaf and had vision loss. They wanted me to be successful in my life. My family also treated me equally to my siblings. I have the same responsibilities and education needs.

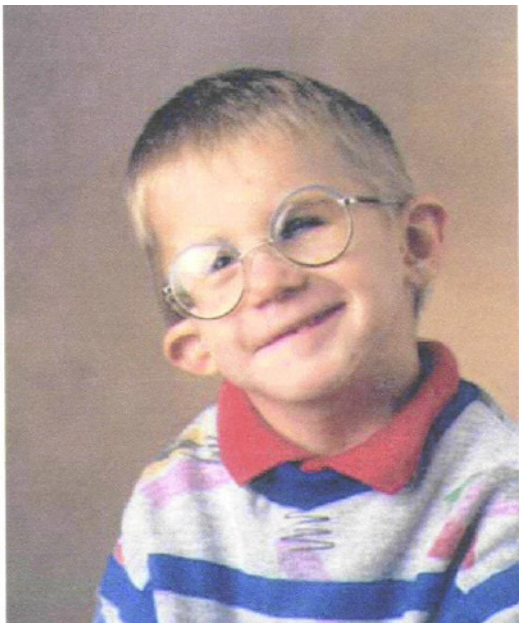
The most important thing my parents learned was communication. Since I am deaf, they need to learn to sign so they went to programs that teach sign language. My siblings learned how to sign by copying my parents. Also my closest relatives have learned to sign to communicate with me.

Besides communicating with me, my parents give me best services possible. I get many services from State Service for the Blind such as monocular to see faraway objects, magnifiers to see fine prints, and orientation and mobility training. My elementary, Junior, high schools, and Vector, a program in Hennpin Technology College, for people with special needs, also give me good services such as 1:1 interpreters teachers who are well aware about deaf-blind culture. Finally, I went to a deaf church, Bread of Life. This church has high technology that allows me to see the pastor far away with a video camera and a monitor, and everyone signs!

My parents also want me to have many fun opportunities in the community. They let me fly to New York City alone to visit a friend. I also traveled to North Carolina and Ohio to go to American Association Deaf-blind. I attended group activities such as Teen Group, Children Linking Families, and Summer Transition Program. Also I took karate classes when I was young. Now I am taking pottery classes every Saturday afternoon. All these experiences help teach me independent living skills and social skills. Those activities are useful for my future.

I have many support services and activities in my life because my family wants to help me become an independent adult in the future.





## LET ME TELL YOU A LITTLE ABOUT MYSELF

Andy Prouty, age 19

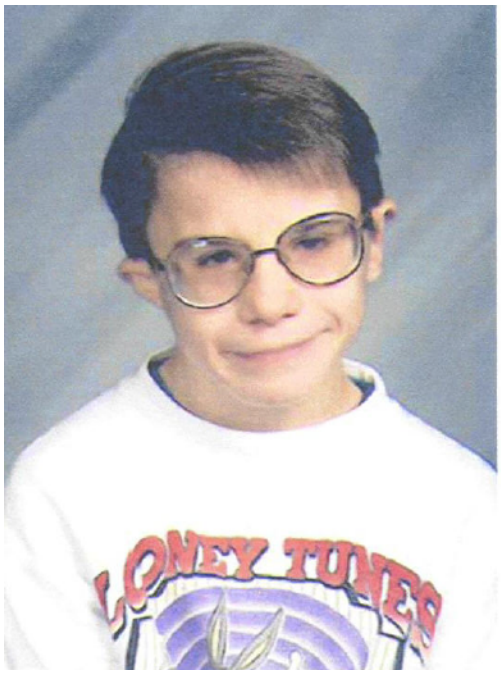
I was born in Oregon in 1981. While I was growing up, my family moved to many different states including Oregon, Washington, Utah, Maryland and Minnesota to find the best services. Our final stop was in Minnesota 13 years ago.

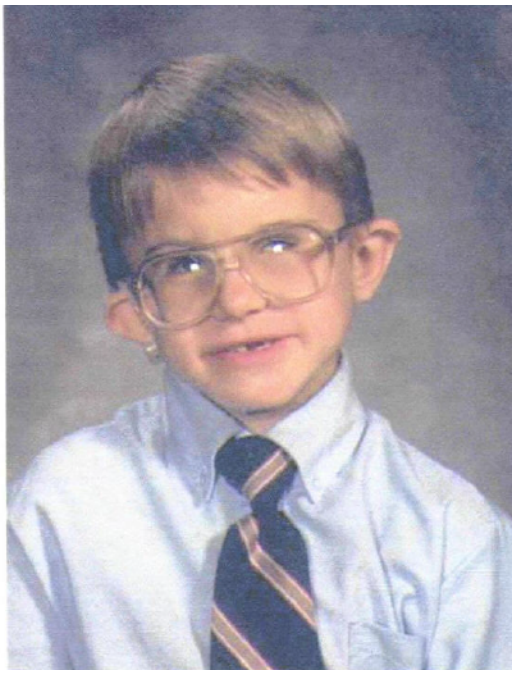
I am deaf and legally blind. I cannot see with my left eye but can see with my right eye. I can see general shapes, sizes, colors far away but hard time seeing details such as small features of an object. I wear glasses to help me see things more clearly. I only take my glasses off when reading and using the computer.

We live in the suburbs of Minneapolis-St. Paul, Minnesota. My parents both come from large families so I have lots of cousins who live all over the United States. When we get together at my grandparent's cottage in the summer we have so much fun. They try to sign with me but we also write notes back and forth.

I have many interests and hobbies. My outside activities include jumping on the trampoline, swimming, water skiing and kneeboarding. My indoor activities and hobbies are pottery, reading books, playing video games, watching movies, drawing and playing games on the computer.

When I was little I enjoyed reading teenager mutant turtles and the Berenstein Bear books and I had EVERY ONE of them. Then I liked to read Disney Books. Every time I went to a new Disney movie, we bought the book about the movie so I could understand the story better.





I also love comics, especially Garfield. I think I have 10 of those books on my shelf. I liked short books until I began reading Harry Potter stories. I've read all 4 books and can't wait for the next one to be printed. While I wait, I read "Girls to the Rescue" Books. I think those books are great.

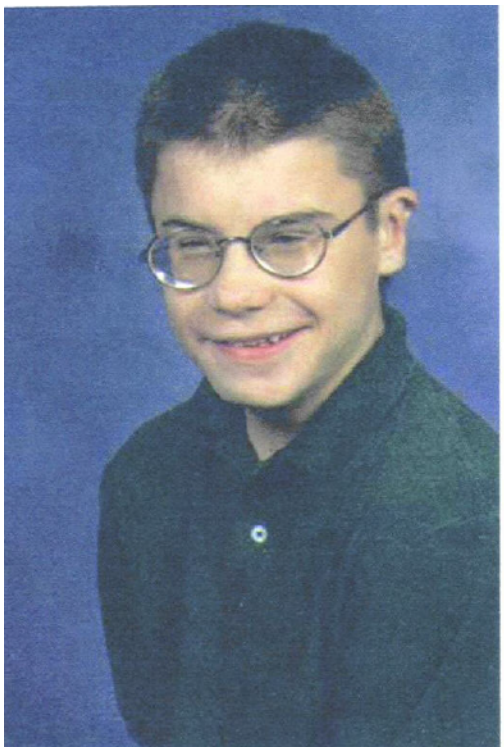
I took pottery classes in high school and when I graduated, the school gave me an old potters wheel that I use in my basement. I have taken a pottery class in Minneapolis with an interpreter and it was fun.

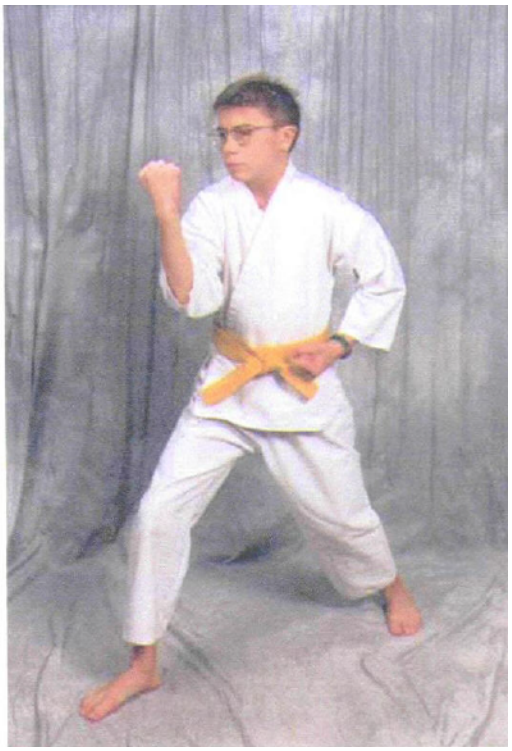
## Interveners

Andy Prouty, age 19

I have had many interveners though my life. My two first interveners were my parents! I have had interveners in school and in the community. All of my interveners were wonderful influence on me because they taught me many things I need to know. After my parents, I had other interveners. When I was a little boy, age 2, my parents hired two teenager girls who helped me learn. Wendy was in high school and Kim was in college. They both knew a little sign language.

When I was 2 years old I started school. My parents made sure my teachers and interpreters understood how to work with me because I couldn't see as well as my deaf friends. They always made sure the DeafBlind Technical Assistance Project came and gave an inservice to the staff before each school year.





I have interveners in the community too. First, it was in our home and then in our neighborhood. As I got older, we started going to stores, museums, fairs and other fun places. My interveners not only taught me and gave me access to my community, but we also had fun! We often go to the community to do various activities such as Mini Golf or Valleyfair. As we had fun, I learned how to buy clothing, foods, and many different kind of life skills I need to know.

One intervenor I had was a real neat guy. He was about 25 years old, deaf, and a professional social worker. Keven was my favorite intervenor. He was also a role model, and a good friend.

In the future, as I become more and more part of the adult world, I might not need an intervener. But I can have good friends that can give me good advice, and support me. I already have two very good adult friends that help me now.

Maybe some day I will become an intervenor for some young person who needs my help. Maybe I can be a role model for someone. People have helped me all my life; I want to help them when I can.

Well, this is kind of a short speech, but I hope I will have a chance to visit with you all weekend. I look forward to trying to answer any questions you have. I love family weekends in Minnesota and Wisconsin. This is my first North Carolina family weekend. I hope I can make it more interesting and informative for you!

## HOW MY SON HAS INFLUENCED MY LIFE

Sally Prouty

Before I get started, I want to say, the past 19 years have been incredible. The journey has been incredible, I have learned so much about myself, advocacy (both medical and educational), and "the system", I would do it all over again. It hasn't been easy, but nothing really good ever is easy. Please feel free to read the article my husband and I wrote about our journey. You may have read the analogy of going to Holland in the past, but we matched it to our experience and how it proved true for us. (I did spend two weeks in the Netherlands last year and it REALLY IS a wonderful place!)

Here is a synopsis of our family's experiences and how we coped.

When our son Andrew was born 19 years ago, we felt like we were the only people on earth (except Helen Keller's family) who was having the experience of a child who was DeafBlind. If I saw then the audience in front of me today, I would have felt much differently about those early years. I have learned over the years that there are many devoted, caring, and knowledgeable people like you, but finding them is like a needle in a haystack. Let me tell you about my family's journey.

I was living what I thought was the American dream with my husband Mike, (who by the way is my Rock of Gibraltar), and son Billy. I was a stay-at-home-mom and Mike had a job working for the United States Forest Service that allowed us to live where people vacationed. We literally lived at the end of the road at the base of Mt. Adams in Washington State. Bill was a happy 2-year-old who we knew would have a perfect, carefree life.

In September of 1981 our second child, Andrew, was born. Within two days, Andrew was diagnosed with CHARGE syndrome. What a shock! First we were told he was profoundly deaf; then we were told he was blind. We had never met a Deaf person or a blind person. What were we going to do? We cried, we hoped for a cure and we cried lots more, but fortunately for Andrew we did our best to face reality and realized within those first months that we were wasting precious time feeling sorry for ourselves and our lost dreams for Andrew. We had to pull ourselves up and provide a meaningful life for him.

Once the major medical issues were taken care of we knew we needed to focus on his communication and future independence. We wanted to know that when we were old, we could feel satisfaction in knowing we had provided Andrew every opportunity to be as independent an adult as possible. Our goal has always been to develop a tax-paying citizen.

Fortunately for Andrew we were hooked up with "the system" by the time he was 2 months old. Don't get me wrong. I wasn't enthusiastic about it, **I was scared** – this wasn't what we expected. W didn't know where to start; we had never done this before. I occasionally remind professionals I work with that they purposefully got into the profession, parents DIDN"T! Andrew says he is like a pop-quiz to me.

Within this system, we were fortunate to meet great people early on and have positive experiences. Getting connected to resources early was very important to us and crucial for Andrew's future.

The twice a week, 200 mile round trip drive to Portland's Infant Hearing Resource Center was wearing on us. We knew we needed to move closer to services but to where? Strangers loaned us a motor home, we researched programs for DeafBlind kids across the country and set

off to find “Nirvana” - you know, a classroom of little DeafBlind kids. Guess what? No such thing!

As a family, we knew we needed to find the right balance of three priorities:
1) medical and educational services for Andrew
2) a lifestyle and living environment we could enjoy and
3) Mike’s career. We kept these priorities in our mind continually.

First, we transferred to Southern Oregon where we were blessed with the talents of a DeafBlind specialist. We discovered the McInnes’ Canadian model of Intervention was the answer for Andrew. His eyes and ears did not permit him to access his world so we approached our Lady Lioness club to help fund an Intervenor for the summer. They did and through that experience became convinced that the only way Andrew could access his environment was by 1:1 learning. The school provided a 1:1 Intervenor in the classroom as well.

By the time Andrew was 3 years old we heard about an Intervenor program in Utah so we packed up and transferred there. Again, we had experiences and met people who impacted our lives. Andrew and my husband Mike successfully lobbied the state legislature to fund a DeafBlind specialist. Three years later a job opportunity opened in Washington DC. After researching our other priorities of education and medical as well as lifestyle for the family, we decided to move on.

I should interject that I would NEVER recommend this nomadic life to any family. It worked for us but we also gave up a lot. We left wonderful professionals who also became our friends with every move. Fortunately, our oldest son, Bill, was young enough to think each move was an adventure. I often wonder what life may have been like if we had stayed in our small town of Trout Lake.

One year was all we lasted until our move to St. Paul Minnesota 13 years ago where, I am happy to say; we still live and have actually grown roots. We were happy to be back in the Midwest where we were born and raised and to provide extended family for our children and ourselves. Before buying a house, we researched school districts, looking for the one that would best suit Andrew’s needs and provide the services required. Remember the three priorities we had as a family? Good education and medical supports for our children (Andrew) Lifestyle we enjoyed and Career. We finally found the right combination in Minnesota.

Andrew has always attended programs for Deaf students with adaptations including an Intervenor, large print, Orientation and Mobility training, technology such as a closed circuit TV and adaptive physical education to name a few. Convincing his school he needed an Intervenor was a struggle. They worried about dependency, but we finally persuaded them his vision required it. The term Intervener was always questioned, so we played the game and said Interpreter/Intervener…… that way, we figured they knew he needed something extra.

We have always tried to be involved in Deaf Culture. We go to a Deaf Church, I went through an Interpreter Training Program, used only Deaf or children of Deaf People to baby-sit, and helped start the Children’s Discovery Project at DeafBlind Services Minnesota.

I'd like to share some lessons we have learned in our journey:

- Parents, please develop a communication system with your child as soon as possible. Don't waste precious time!

- Parents, maintain high expectations for your children and let professions know you do. They may buy in.

- Encourage decision making with your kids on day 1 and continue this practice all their life, it will make encourage independence.

- Parents know their child better than anyone. Trust your instincts. **You** know what's best. **You** will be with your child longer than anyone. Professionals will come and go but you are permanent and you must make decisions that will impact your child's life. Don't give up.

- Parents, remember Dorothy in the Wizard of Oz? Remember how she searched relentlessly for the Wizard to help her find her way back to Kansas? She was awestruck by his power. We did that for a while with Andrew. We went from doctor to doctor and teacher to teacher looking for magical solutions for his education and medical needs. We were looking for the answer. But guess what, like Dorothy, we had the answer all along ---trust yourselves.

- Professionals, please be willing to admit when you don't know the answer. Like all parents, I can't tell you how many professionals (doctors, teachers, therapists and others) we have trained over the years. I appreciate and respect hearing, "Gosh, I don't know, but I will try to find out." Don't feel you need to be a Mary Poppins drifting in with your umbrella to give a spoonful of sugar and make everything OK. It is not fair to you and it is not fair to families. It is really refreshing for a family to hear, "I don't know, but I'll work with you and we will learn together!" That REALLY builds good teamwork.

- Parents, develop the skill to be "Respectfully Demanding" when you have a need. A demand without respect puts people on the defensive.

- Parents, encourage active participation among people who work with your child. They will be much more enthusiastic meeting you for a breakfast meeting than a school meeting. They appreciate and remember an occasional thank you note or acknowledgment that you appreciate them. It's easier for them to say "yes" next time you have a request.

- Sometimes this doesn't work, sometimes people don't "get it." Twice we have taken our needs to the state legislature asking them to appropriate money for DeafBlind and both times we received it. Andrew testified at both, once when he was 4 years old and again a few years ago.

Andrew has always been full of curiosity so that he is in to EVERYTHING! When he was younger we were exhausted just trying to keep up with him.. It was also exhausting, but exciting to teach him about his world.

I'm delighted to say Andrew has far exceeded our early expectations. Fortunately he had enough vision to allow him to be a visual learner and attend Deaf Education programs where he has done well. People who see him think nothing is wrong with his vision until they really look. I would encourage you to use the term deaf-blind when it can get improved services for your children, and be careful in other situations; it is really scary for people. Learn to "work" the system and develop your skills to become *"respectfully demanding".*

## PATTY IS A MIRACLE! SHE IS A GIFT!

Bonnie Hagerty

*"When Patty was born we were told she would never walk, talk or be independent in any way"*

Patty (age 16) is developmentally delayed both medically and physically. She is about two years behind. Sometimes more, sometimes less. When Patty was born we were told-as everyone knows-she would never walk, talk or be independent in any way. They were wrong. I found right from the beginning that although doctors should listen to us, they often didn't. She was born full term. As soon as she entered the world I felt that I should do something, there was something wrong. I actually felt that she was born too early, or wasn't done developing yet but the doctors said it was just my emotions. They should have listened. I found the colobomas the next day. The doctors did the other tests, but apparently she came out fine and they sent us home. I still felt that something wasn't quite right. The next day at home after I fed her, my milk had just come in, and I gave her a bath. She just lay there, turned blue and went limp. My mother did CPR. The ambulance came, but on the way to the hospital she did it again, then again and again in the hospital. She ended up in Newborn ICU. It was a long night. They didn't think she was going to make it at first.

*"I realized Patty would live and if I held her close to my heart she would do her best to "be whatever she could be."*

After a while they told us to go home and get rest because we would need it. My world had turned upside down and I was walking without being inside my body. My mother took my husband and me home. On the way out of the hospital there was this statue of a mother holding a child. When I saw that statue a feeling came over me and I realized Patty would live and if I held her close to my heart she would do her best to "be whatever she could be." I still see and use that statue as comfort when she is in that hospital.

There were all these doctors coming and going who did not have anything at all positive to say. In my heart I knew they were wrong but had no way to show them. Patty didn't even hold her head up until immediately after her first choanal surgery around 9 months. All she would do is lay there. I do not really know if what I did that was right. I just went with what I felt she needed. I remember that as an infant, Patty needed to be wrapped tightly in her blanket, and held closely. Soft touches and caresses would make her distant and quiet. I held her often. I would also move her little arms and legs for her- again not softly but surely.

*"The first and absolute best thing that we did for her was to have early intervention right from the start"*

*"professionals spent most of their time working on her little body instead of what was going on within her little mind"*

*"I knew there was a mind and a will in there that had to be let out."*

Patty was such a sick little baby that professionals spent most of their time working on her little body instead of what was going on within her little mind. The first and absolute best thing that we did for her was to have early intervention right from the start. Our hospital identified her from the PICU and they came to the house once a week from the time she was sent home. When she was 10 months old I was already looking at the future for her. It was incredibly hard but we

sent her to a school for the disabled. Putting her on the bus broke my heart. I would spend much of the day in terror without her. But I saw the little gains she made here and there. She even learned to walk around age 2. I could see how determined this child was. Just when you would feel like giving up on her doing something, she would surprise you and accomplish the task. It just took her longer. But she was still like a porcelain doll. She seemed as though she would break sometimes. She had numerous illnesses and surgeries, but she also had this drive, this determined look in her eyes. I knew there was a mind and a will in there that had to be let out.

*"This was the first time that professionals listened to me"*

This first school was great for what she needed at the time. But there were children there with many different disabilities. I noticed she would model other behaviors and actions. I did not like some to the behaviors she was exhibiting. But at this school she learned how to grasp things and walk. She was not talking and they taught her some signs. That was good at first. She was able to communicate her wants and needs but somehow I felt that wasn't enough. Patty made guttural sounds only. As a matter of fact her voice box wasn't fully developed when she was born and it took a long time for her to make audible sounds. By the time she was 2 we knew she was hearing impaired. It seemed at the time she was making these guttural sounds as a way of trying to be verbal. The next BEST thing we did was to send her to a school for the hearing impaired. It was tough but she learned how to talk. It was an oral school that was intensive. This was the first time that professionals listened to me and worked with me and showed me how to help my daughter. That was SO important. They actually had extremely high standards for her. This was a first too. They pushed her to her highest level and yet they mixed that with love and compassion. They also made sure she was happy with herself. It seemed they found a joy to celebrate every day. Finally, Patty learned how to communicate! I feel that the educators in this school gave her life, to be part of the world we were in. They opened the door for her. She was still having her health problems but she was learning. They did not put limitations on her expectations. Without them I do not know where she would be now.

*"We were all a part of Patty!"*

I could not give my daughters much. Especially because with all the medical bills, we were now poor. But I could help give them an education. That is what I have continued to focus on. This school also provided all the other special needs, speech, hearing, PT, OT. We were all a part of Patty! There was one teacher and one aid to about 5 kids half of the day, and they other half there were "normal" children who these "hearing impaired" kids could model. This school was about an hour away from home.

*"From the beginning we have had to fight to keep "professionals" from limiting her"*

Our home district continued to "show us" how they could provide the same services for her. We brought her back to home district in kindergarten. (My father and grandfather had died that year and I was weak in fighting) They wanted to put her in the contained Special Ed classes but since at the other school she spent time in the Regular Ed classes there (it was a great program!), they did the same here. That's when the battles began. We have had to fight to keep her in Regular Ed. I feel it was their decision to bring her to our home district because it was cheaper for the town. I also believe they thought she would fail in Regular Ed. They probably felt they would show us they were right and we were wrong. They still to this day do not understand Patty. There were many wonderful educators who worked with Patty though. But from the beginning we have had to fight to keep "professionals" from limiting her.

*“Patty exhibited illnesses by behavior.”*

Then the behavior aspect came in. We were often told about her negative behaviors. It was often that I had to tell them when her misbehavior increased she was getting ill. By now her kidney problems were diagnosed. When Patty’s behavior was worse, I would take her to the doctor and she would have ear infections, bladder infections, phenomena, always something. Patty exhibited illnesses by behavior. I didn't allow misbehavior; I just tried to understand it. There were patterns.

*“They learned consistency was important for her”*

There were also times I would have to go in and tell them how to do things. At one point she was getting in trouble. I found out that one specialist would let her do something which another would reprimand her for. They learned consistency was important for her. So was modeling!!!! Patty continued to make gains but continued to be about two years behind. Again, it was a battle to keep her in Regular Ed but we did. I also discontinued intellectual testing because I felt there was no way they could accurately measure her on this. I still believe so. Again, this puts limitations on her. She has great gaps, especially in math. But she continues to thrive. And there continues to be modifications made which can overcome these gaps. Patty has continued in Regular Ed.

At one point I thought she had stopped growing intellectually. It was the same year she grew about 5 to 6 inches. I think her brain needed to rest while her body grew. Anyway, the special services she was receiving lessened. PT and OT were stopped, actually mostly on consult because they felt they had taken her as far as she could go. Preschool and early schools were good because they were children-based. By adolescence school is more curriculum-based. That gets harder. Still the fight was and continues to keep her in Regular Ed and to modify things to meet her needs.

*“Patty went from being social with everyone in elementary school to having very few friends.”*

The greatest lack in her life has been her social needs. Adolescence is hard for anyone. Add having multiple disabilities and it gets harder. Patty went from being social with everyone in elementary school to having very few friends. Actually at one point she had no friends at all. It has been my large family that has kept her busy and feeling a part of society. She has been lonely, for years. Patty has problems with correct social behavior. She doesn't get the little nuances of language. She perseveres though. Middle school was extremely hard for her. And one must remember that there are few children in Regular Ed with as many needs and differences as she has. We now had to fight for almost everything; both medically and educationally. I went from being the concerned mom to being the, I guess you could call it “irritable" mom who thinks she knows more than they do. Well, I DO. There were all these specialist who "thought" they knew what they were doing with my daughter and what her needs were. Who was I, just her mom?

We have had no community involvement unless we put her into something ourselves. By this I mean she was in our town’s sports program as a child and people included her because she was so cute. For example, we put her in basketball, the kids were great, and they would run and not run into her. She was tough. In softball they would just pitch and pitch to her until she hit the ball. The sports got to the point where it was beyond her abilities and became competitive and dangerous (around grade 2) so we had her involved in Special Olympics. She even did the torch run but then she wasn't "appropriate" for that either. I have put her in community theatre

once, again she was so cute, but now that she is older she auditions for it but she does not make it, yet her sister does. We tried the youth group in our church but because of the number of students in one room -teenagers- all talking at once she ends up alone and frustrated. There is nothing in our town that involves her outside of school so we have now given her guitar lessons. Children need to be involved in something, so we do it ourselves and always have. Otherwise, Patty is lonely or bored.

*"They took one look at her and said CHARGE*." "*There were little Pattys everywhere"*

Then, Patty lost all hearing in one ear. I was desperate to find our why because I feared her loosing her hearing all together. Months later we ended up in a geneticist office. They took one look at her and said CHARGE (Patty was 14 at the time!). That was the best thing that could ever have happened. Because of that diagnosis everything came together and started to make sense. We attended the CHARGE conference. Our daughter was no longer a misfit. Previously she didn't fit Regular Ed nor did she fit in Special Ed. No one was like her. Until then. There were a hundred babies and children there just like her. It was overpowering. There were little Pattys everywhere. Even the way these babies held their heads, rolled on the floor, were like Patty. It was spooky.

There were also a hundred parents just like us. I would look in the eyes of the parents of these babies and see the fear, longing and the hurt we had. I wanted to tell them it was all right. It gets better and they get older. But sometimes, that hasn't been true for everyone. I do not know why Patty has come so far. She has all the CHARGE characteristics and a few more. They call her mild but I honestly feel that is only because she has overcome so much and appears mild. They didn't see the sick little baby who I had to feed every two hours, took 45 minutes to feed and everything would come out her nose. This child has almost died on us many times yet here she is. She is our miracle. She continues to be. She also continues to be one tough cookie and is why I have so many gray hairs. I have had to be strong with her but I have also always just followed her lead.

*"These delays do not mean unable, just delay"*

With the CHARGE diagnosis there is finally an understanding about her delays. These delays do not mean unable, just delay. I do not think anyone should ever put limitations or labels on physical or mental expectations for our children with CHARGE. No one really knows what is inside them. You must let them reach their highest potential, whatever that is. I feel there are often higher possibilities than are ever said. With this CHARGE diagnosis we have been helped by professionals and other parents. We also try to help others. I get tons of information just from the parents alone. We also looked further at some medical aspects. She had her heart PDA surgery at age 13. I can't even think about how close she came. She had strep in her blood system twice. Had chicken pox in her blood system. We also got medical help that is more coordinated now instead of having one physical look at one thing while another looks at something else. We understand more now. We can embrace more in life. She continues to grow and seems to be closing some gaps. Others will always be there.

*"We now have medical professionals and professionals outside of our school district that understand CHARGE and all its impacts"*

There have been doctors and educators who still try to limit our daughters potential. It is a battle that we don't feel we should have to fight but we must. We now have medical professionals and professionals outside of our school district that understands CHARGE and all

its impacts. That is important and will help all the younger children. Patty's transition into life and adulthood is a battle for us. We have found that transitions are incredibly difficult for Patty. Some have been horrendous. The worse was when she has transitioned from one school to another with only one person having any experience with her, and her equipment (her FM unit) was malfunctioning too. You can go to meeting after meeting but when there are 10 specialists, then add other staff, meetings really don't do as much good as they are supposed to. They only hear the problems; not what Patty has really been about. After staff lacking experience with her, she has lacked experience of them. It was incredibly hard when she was younger to have different expectations from different people. This included her daily schedule. She also had a hard time transitioning with different schools. It takes her a while to get into the swing of things, when younger I would even dare to say almost half a year. Setting up for these transitions have been minimal after around 4th grade. It would have been wonderful if she could have attended the school she was transitioning to 9or even the next grade) while classes were going on, experiencing it. And this should be done more than once. It would have been good to have her and her educators meet, and more than once.

*"This transition will be the hardest."*

I have to say the transition into adulthood is where we are at and is what terrifies me the most. Again, finally we have brought in specialists to teach those who work with her about CHARGE and Patty's unique qualities. They have even started a Futures Personal Plan. Then they leave, then what-nothing. One of the problems is I have different expectations of and for than some specialists" in our district. I almost feel like they think I do not understand my child. They don't understand her. The transition planning should happen well before age 14, but we did not do that. We are now battling this. If nothing changes Patty will have a terrible time transitioning to adulthood. She needs to "experience" more. She needs more experience socially, vocationally. She needs technology to be independent. She needs someone to help her work to her goals, yet not limit them. She needs to be able to reach for the stars. She needs compassion and understanding, which is something she almost always gives but seldom receives. This transition will be the hardest.

We fight limitations and want her to be able to be the best she can be. We finally have people who understand this. She cannot go further without them. They will probably be with her for the rest of her entire future. But the main point is that she has a future. I, and now finally there are others, will do our best to let that future be healthy, happy and fulfilling for her. We have great dreams for her. It is not an easy task but one that is well worth every moment. Patty is a miracle. She is a gift.