

# SEE/HEAR

A QUARTERLY NEWSLETTER ABOUT VISUAL IMPAIRMENTS AND DEAFBLINDNESS FOR FAMILIES AND PROFESSIONALS  
A collaborative effort of the Texas School for the Blind and Visually Impaired and Texas Commission for the Blind

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## Kate's Corner

You can not separate the needs of the child from the needs of the family, and this is especially important to remember when that child is visually impaired or deaf-blind. I was reminded of this truth while attending the "Making a Difference" conference in El Paso this past weekend. Jean Robinson and I were privileged to be a part of this wonderful learning experience for families and their children with visual impairment and additional disabilities, or deaf-blindness, that was cosponsored by Texas Commission for the Blind - El Paso and the Children's Disabilities Information Coalition. The weekend began for the TCB families at a barbecue, with entertainment provided by a high school dance troupe from Ysleta. On Saturday they joined the CDIC 10th Annual Disabilities Symposium at Del Valle High School. There were many wonderful speakers offering individual short sessions for the parents, as well as a key note address from Derrick Dufresne. A variety of fun activities for the kids included such things as face painting, arts and crafts, and bingo. That evening the parents of children with visual impairments had a dinner, while they were serenaded by a group of singers who

**Kate's Corner - continued on page 19**

### **Josephine L. Taylor Leadership Institute (JLTLI) 1999**

By Lars Anderson, Vice President NAPVI, Vice Chair AVIT and  
Parent of 10-year-old Kari who is totally blind

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First, I would like to thank Texas School for the Blind and Visually Impaired (TSBVI) and Texas Commission for the Blind (TCB) for generously sponsoring my attendance at this year's conference. Without their assistance, I would have been unable to attend. I would also like to say that the American Foundation for the Blind (AFB) had four scholarships, for parents who had never before attended JLTLI, go unclaimed this year. I hope that the many active parents in Texas are able to snap those up in the future.

A little over 5 years ago, my wife LeiLani and I were "typical" parents. When Kari was diagnosed with retinal degeneration, our lives changed forever. We were slapped in the face with the alphabet soup: ARD, IEP, VI, LRE, IDEA, TSBVI, TCB, TEA, O&M, and it took quite a while to get our bearings. Since that time, we have tried to stay active - in order to know enough to help Kari directly, and to volunteer time to help 'the cause'. We joined the National Association for Parents of the Visually Impaired (NAPVI), which was started in Texas 20 years ago by the way, and I made contacts with the Dallas offices of TCB and AFB. We found both of these to be of great help, and the staff to be very friendly and knowledgeable. Through AFB, I became involved in the Alliance of and for Visually Impaired Texans (AVIT).

From what I have seen and learned in the last 5 years, I want you to know that Texas has a system of support for persons with visual impairments that is nationally outstanding. Certainly there are things that can be improved, and most of these are nationwide problems as well, such as not enough certified teachers of the visually impaired being graduated to serve the national needs, etc. Also, there are pressures from all corners to change the system that we have, and not always in ways that improve services. This year, Texas Commission for the Blind escaped being combined into a "generic" rehabilitation organization, in large part due to the grassroots support of parents and others who wrote letters, visited congressmen, and personally testified during the open hearings in Austin last fall. I want you to know that the system in Texas is worth defending, and I urge you to do what you can to keep Texas services for the blind and visually impaired the envy of the nation. At a recent meeting at TSBVI regarding Parent/Child programs/services there were three observers from Wisconsin in attendance. Obviously those people felt it was worth their time and money to travel 1000 miles to see how we do things in Texas. *(Editor's note: At this time, there are many proposals still being considered by the Texas Legislature that might have an impact on TCB's services.)*

The Josephine L Taylor Leadership Institute 1999 was held in Washington, DC on March 5 - 7. It is a forum for exchanging ideas, working on common goals, networking with other professionals in the field, and nurturing future leaders. The keynote speech was given by retired congressman Representative Fred Grandy, who is now CEO of Goodwill Industries. (Before becoming a congressman, he played Gopher in the Love Boat - believe it or not.) Fred's speech was very entertaining and informative, but one key point I want to share is how important it is to focus on the mission, on the goals of the organization - then do what you can to accomplish those goals. This advice is not only useful for nonprofit organizations, but for parents who have a torrent of sometimes conflicting input and concerns when planning on behalf of their children. Focus on the goals, compare your actions to the accomplishment of those goals - and that will be your compass.

Advocating for our children at ARD meetings and advocating for services with our representatives share a common thread; both involve negotiation, and both are less stressful if we know our rights as parents, and the rights of our children. JLTLI-99 had a special session this year on "principled negotiation," in which we were trained in methods of reaching agreement, even when you feel "out-gunned." Some of the main points that were stressed in this training were: "*be hard on the issues, but soft on the people,*" and "*try to get to the why behind the what.*" The first point relates to digging in your heels without creating enemies, always a fine line to walk. The second point relates to the fact that frequently agreement can be reached if you can get to the underlying concerns of the stated positions. The example was given of two people sharing a table at a library who were arguing about whether the window should be open or closed. There appeared to be no compromise possible, until the librarian asked them what their concerns were. The first person said he needed fresh air and the second said his papers would blow off the table if the window were opened. After getting to the 'why behind the what', the librarian opened a window across the room and both were satisfied.

If you are not already familiar with the goals of the National Agenda, I urge you to take the time to get acquainted. TSBVI Superintendent, Phil Hatlen, is one of the directors of the national project which aims to improve services and education for children nationwide. Two specific National Agenda goals were specifically addressed this year in the Education Working Group of JLTLI-99. The two goals were 1) ensuring that adequate numbers of certified teachers are produced by programs nationally, and 2) that textbooks for students are produced in accessible formats. I attended the electronic textbook sessions and was not surprised to find out that again, Texas is leading the way. There is much to be accomplished, but the breadth of expertise present in the working group sessions was impressive.

AFB held a reception at JLTLI-99, and the president of AFB, Carl Augusto told me he feels a special affinity for Texas. He made me promise to call him 'Carl Bob', to affirm his status as honorary Texan. There were tons of Texans (and ex-Texans) there. I would say that there were probably 20 Texans at JLTLI-99, which again speaks volumes as to Texas's role in this field nationally.

NAPVI held a free parent training session on IDEA after JLTLI closed. Delta Gamma Sorority provided day-care for children of the attendees (thank you Betty Guthrie), and the session was well attended by about 40 people from across the US, including one gentleman from Japan. The presentation was very focused and inspirational, even though the final regulations for the IDEA legislation are not yet released. NAPVI will have more parent training sessions on IDEA in the near future, and definitely some in Texas. (*Editor's note: The final IDEA regulations have just been released. TEA provides information about the new IDEA on their website at <<http://www.tea.state.tx.us/special.ed IDEA99/>>.*)

NAPVI and the American Council of the Blind are cosponsoring the ACB-99 conference in Los Angeles in July of this year. There will be family events, IDEA training, events for children, and more. For more information contact ACB, or NAPVI at (800) 562-6265. Also, please call NAPVI for general information on our organization.

## What Makes Families Resilient?

By Jean Robinson, Family Support Specialist, TSBVI, VI Outreach

As a social worker and parent I have often wondered why some families and children do well in terrible circumstances and others, even with the best resources, do not. What factors determine which families stay together and which ones fall apart? When stressful events happen, how do families recover? Are there characteristics that increase the risk of adverse outcomes? Researchers with the Institute for Health and Disability at the University of Minnesota looked at family strengths in their study focusing on characteristics of families that contribute to positive outcomes. The top four indicators are:

- Family members emphasize positive rather than negative reason for a child's disability.
- Families are not preoccupied about why the condition happened.
- Family members manage the demands of the child within the context of family life.
- Families have a coherent explanation of the cause of their child's condition that is consistent with the world view.

How families explain and think about disability impacts their ability to move ahead and find stability. When they can explain the disability in such a way that makes sense to them and fits their beliefs, they are more likely to find coping strategies that allow them to move ahead with their lives. Resilience includes taking action to address a stressful situation. Resilient families actively learn about the disability and find needed services for their child. Better outcomes are found when families use flexibility in setting rules, establishing roles, and defining expectations.

These families have learned to work together. They learn interdependence with others and find a sense of coherence and balance in their life. They don't just survive, they thrive.

The next three articles validate the research. The first article, "If Only . . ." originally appeared in the Parent to Parent of Georgia newsletter, FOCUS, Summer, 1997. The second article, "Lessons Learned" by Cathy Allen was developed from a response to a parent on the CHARGE listserv, and Cathy graciously allowed us to share it with other families. It gives wonderful, practical strategies for families to maintain resilience. One strategy not mentioned in this article is Cathy's practice of keeping a journal that updates her extended family and friends through e-mail. She finds that it is a quick, easy way to keep loved ones up-to-date and is a form of "therapy" for her. The third article, written from a father's perspective, is titled "One Dad's Story." It first appeared in the Family to Family Network newsletter, published by Family to Family support organization in Houston. Accompanying these three articles is an article resulting from research done by the University of Minnesota on families of children with disabilities.

### If Only

By Lucy Cusick, Parent, Georgia

Reprinted with permission from Parent to Parent of Georgia,  
from FOCUS, Summer 1997

...How many times have I thought those words. When Josh was born three months prematurely, I thought *if only* I hadn't had that decongestant before I knew I was pregnant; *if only* I hadn't worked so hard; *if only* I could not feel so guilty! The "if onlys" still drive me crazy. *If only* we exercised him more; *if only* we hadn't put him in a power wheelchair; *if only* we had surgery; *if only* we hadn't had surgery; *if only*...

My husband calls this “shoulding on myself.” Not a very nice term, but quite accurate. As a mom of an eleven year old with lifelong disabilities, I have decisions to make. (My husband helps too, but often I feel I’m the one that does the doctor appointments, so I’m the one most educated to make the decision.) How do I know what is the right decision? Which class, which surgery, which therapist, which medicine, which doctor... these are often not clear-cut issues. Doctors can advise, recommend, prescribe, but often there are decisions to make with no black and white answers. Parents ultimately make the decisions.

So, as I’ve traveled in this world of disability, I have several guidelines when making decisions:

- 1) List the pros and cons, a tried but true method of decision-making. Seeing it in writing can help.
- 2) Think how this decision affects the rest of the family. Yes, daily therapy may be ideal, but other members of the family have needs, too, and there are the small issues of dinner and laundry.
- 3) “Decide to decide” and don’t look back. Make the decision based on the information you have at the moment. Get a lot of information. Talk to other parents with children with similar problems. Take your time. If the decision is a permanent one, i.e. surgery, then make your list, check it twice, check it again and decide. When new procedures come along five years down the road, remember you did the best with what you had. If the decision is not permanent, i.e. which class to fight for, then try not to burn bridges. Try it. You might not like it and want to try another. Don’t slam doors that might need to be opened again... And don’t “should on yourself”.

## **Lessons Learned**

By Cathy Allen, Wife to Tim, Mom to Joshua (9), Caleb (6), & Rachel (CHARGE,3<sup>1/2</sup>)  
Mesquite, TX (allentc@juno.com)

My daughter, Rachel, has CHARGE Syndrome and is only 3<sup>1/2</sup>, and so I’m not sure I can qualify as a veteran “special needs parent” yet. But I guess since we’ve made it through the year or so of all the really life-threatening stuff (as opposed to the “normal” life threatening stuff that we have settled into), maybe it counts.

In the beginning there were several things that Tim and I had to realize about our marriage that helped us to get through this really terrible time. When the caseworker gave us the statistics about families breaking up it made us stop and consider what was really important. We decided that our family (including Rachel, our marriage, and two sons) was the most important thing to us; so we made other decisions based on that priority. I survived the guilt of leaving my possibly dying daughter with nurses for several days while my husband, other children and I took short vacations to be together and just play. We made sure that Rachel did not seem to be the most important member of our family. Her care may take more time, but everyone in the family must have their needs met.

Life had become so serious; Tim and I realized that we never laughed anymore. So, we set out to get as much laugh therapy as possible. We didn’t read or watch things that were very intense or made us depressed (we lived that already). Instead we only rented light hearted movies, and we invited our friends over to play games instead of going out (which we could no longer afford anyway). By the way, I have found “I Love Lucy” and “The Dick Van Dyke” shows to be some of the best laugh therapy resources available.

There were also things we had to understand about each other. My way of coping was to get busy and get everything done. I mean, there was no time to relax because there were too many things to learn and read and

do, and it completely consumed me. But it was good for me to feel like I was doing something. My husband's way of coping when he got home was to plop down in a chair and veg-out. Well, needless to say, we were really getting on each other's nerves by wanting each other to cope the same way.

Somewhere along the way I realized that I got to talk to nurses, therapists, caseworkers, and doctors almost every day. I got to cry when I was upset. I got to see Rachel and her progress (or lack of it), and deal with it by talking about it. I know that I suppressed a lot of my grief for awhile just because I didn't feel like I had time to deal with some of it, but I did get to process this new life we had been thrown into.

My husband, on the other hand, did not have the same opportunities that I did. I had to quit my full-time job when Rachel was born, and my husband had to be at work every day. Sure, it helped take his mind off of things, but he also had to push away his grief and his feelings and even much of his thoughts about Rachel. This was too much to deal with in the very short time he had to actually think about it.

At first I was offended by his stand-offishness, but then I saw that he was compensating in ways he felt he could. He didn't think he could really help with Rachel, though he did try. But he took over some of the things around the house and with the boys which left me more free to be the "doctor" of the house. Allowing each other time to grieve and deal with things in our own ways was very important. Now, we are much more balanced. Tim can easily take care of Rachel if I'm not around even though I'm still the resident "medical professional."

One thing we always said to each other when we were going through a particularly hard time was, "I don't understand you right now," or "You're really getting on my nerves right now," or "I don't want to be around you right now, but I know things will eventually get better and when it does I will still be here and we will make it." With so many uncertainties about the future, Tim wanted me to know that he had committed himself to this marriage. Whether or not he was going to stick it out with us wasn't something I had to worry about. And I want him to know the same thing.

## **One Dad's Story**

By Rick Tisch, Parent

*Editor's note: This article appeared in the February, 1999 newsletter of Family to Family (F2F) Network of Houston. F2F's website is <<http://www.neosoft.com/~fam2fam/>>.*

It's a funny thing, being a dad. Before it ever happened to me, I knew what kind of dad I wanted to be. I could see myself in many different types of leadership roles with my child, roles that would require wisdom, good sense and, most of all, much love and caring on my part. And, when my wife became pregnant with our first child, I knew I was up for it. I knew I could do all those things, and more. I knew I could be one fantastic dad.

And then my son was born.

They say that nothing ever happens the way you expect it to. When you have a child with a disability, that little saying becomes the biggest understatement of a lifetime.

For years, I was either in a race against time to "fix" my child, or I was just plain numb. We did it all, every kind of therapy to try to lessen the gap that was there. We lost friends during this time, and many family members made themselves scarce emotionally. It was worse in public. People stared and pointed at my son because he looked different. Others went overboard with pity.

Then, somehow, my feelings of helplessness and despair began to change. I know that Ryan, my son, is the reason. He wanted to do things that other kids were doing. He wanted to be involved. My wife was in a panic when Ryan wanted to sign up for T-ball. How could he do it? Won't the other kids be mean to him? But, Ryan showed a strength and determination that I will always admire. The first time he hit the ball, his whole team stood up and cheered. Okay, so maybe he ran the wrong way around the bases, but who cares? He did it.

Now I have the goal, and I have the determination. I'm trying to model myself after Ryan. Or, maybe he gets a little bit of it from me. But, I want to make some changes. I want Ryan to continue to be fully included in school, and in life. I also want to work to make that chance available to other kids.

I know now that the dreams I had about being a father are coming true. They're a little different than I thought they'd be, but not so much. Because I have the chance to show all three of my children the way to become strong. And I can, each and every day, teach them how to be loving and caring human beings.

## **The Resilient Family**

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<http://www.peds.umn.edu/Centers/ihd/>

Families don't stand still. They are constantly growing and changing. In the process of developing resilience, a family ebbs and flows, but there are some constants to be aware of. A resilient family can:

*Balance the demands of the child with the chronic condition with other family needs.* This does not mean the family is never at its wit's end. It means that, more often than not, the family has enough energy to attend to the child's developmental needs as well as the need of the chronic condition. Normal family routines are maintained most of the time, and there is time for everyone in the family. In a balanced family, the universe doesn't always swirl around the child with the chronic illness or disability. It just feels like that sometimes!

*Maintain clear family boundaries.* While everyone needs to pitch in once in a while, these families have the time and energy to meet the need of unaffected children. Siblings may have responsibilities, but they aren't treated like little adults. While families need to develop connections to service providers, they also need to maintain their own integrity and sense of control over their lives. Resilient families are not over-directed by what professionals want them to do.

*Develop communication competence.* Effective families are able to solve problems, make decisions and resolve conflicts. They are able to express feelings, even when the feelings are negative and seem to be unjustified.

*Attribute positive meanings to the situation.* Families who are able to think positively about their situation and develop positive attitudes, manage better. These families often acknowledge the positive contributions their child brings to family life and how they have developed a new and more meaningful outlook on life.

*Maintain family flexibility.* Flexibility is one of those family resources that benefits all families, particularly when long-term demands are present and when day-to-day life is not predictable. Being able to shift gears, change expectations, and alter roles and rules contributes to better outcomes.

*Maintain a commitment to the family.* Of all the family resources, cohesion - the bonds of unity and commitment that link family members - is probably the single most important protective factor for families who have a child with a chronic illness or disability.

*Engage in active coping efforts.* Resilient families actively seek information and services, and work to solve problems.

*Maintain social integration.* The ability to maintain supportive relationships with people in the community is another important protective factor for the child and family. Support from other parents who have a child with a chronic condition has become a major resource to many families.

*Develop collaborative relationships with professionals.* The quality of the relationships families have with health care and other professionals is another protective factor. Taking time to share information, working together to make decisions about the child's care, respecting differences, and avoiding attempts to control the other [person], contribute to satisfaction for both parent and professional.

## **To Make a Better Citizen**

By Cadet Major Justin Jones, Waco, Texas

*Editor's note: This article was submitted by La Tonya Richardson, Orientation & Mobility Specialist at Region 12 Education Service Center in Waco, who thought we might enjoy hearing a young man who is blind tell us about being in the Air Force Junior Reserved Officer Training Corps. After reading this story it struck me that Justin teaches us more than just what a young man with visual impairments can do, but rather how anyone, sighted or blind, must be in order to be a successful cadet and student. Justin is a graduating senior at Connally High School.*

Not many people have heard of a blind, or visually impaired ROTC cadet, but you are about to read about one. I have decided to write this to tell other visually impaired or blind people about my experiences in AFJROTC. The first question that probably comes to mind is "What is AFJROTC?" It is an acronym for Air Force Junior Reserved Officer Training Corps. ROTC at the college level is where people train to become officers in the armed services. At the high school level there is Junior ROTC. The mission, or goal of a JROTC unit is to make better citizens out of cadets by teaching leadership and some of the Corps's values. I am not going to explain all of ROTC's goals and ideals but you will get the general idea.

JROTC is not a full-blown military organization, but we do wear a uniform. The uniform signifies the type of JROTC you are in, such as Army or Air Force. We have a chain of command in the organization with cadets taking many of the responsibilities. The idea behind this is that the cadets run the whole thing, with a few exceptions. My JROTC unit (Connally AFJROTC, TX935) has three levels of command. We have a Group Commander, then below him, two Squadron Commanders, and below them, six Flight Commanders. In a classroom you refer to your peers as your class, but in JROTC you refer to them as your flight. In my unit, a flight consists of about twenty people. Three flights make a squadron and two squadrons make a group. My unit is not big enough to be a wing. We do have rank (an enlisted chain of rank) and officers. In my unit, the highest enlisted rank is Cadet Chief Master Sergeant and the highest officer is a Cadet Colonel. The highest ranking officer in my unit at this time is Cadet Lieutenant Colonel.

In JROTC, you can get ribbons to decorate your uniform which, in my unit, is worn every Wednesday. At the moment I have seven different ribbons on my uniform.

The one last thing I need to cover is the extracurricular activities in JROTC: Unarmed Drill Team, Armed Drill Team and Color Guard. Unarmed Drill Teams train for competitions where they march in formation and go through complicated movements. Drilling is routine in JROTC, but not very fancy movements. Armed

Drill Teams are more involved as they drill with demilitarized, impossible to fire, M1 Rifles. The rifles weigh about fourteen pounds. Members of the team learn how to perform using normal unarmed drill movements while marching. A Color Guard presents the flag at football games or other events that require the raising of the American flag. This group uses rifles, the same as the Armed Drill Team, but the rifles are not the focus of a Color Guard team at a competition. Please note that Armed Drill Teams and Color Guards are not part of everyday JROTC.

I have been in JROTC three years, and I have done and seen a lot. Currently I am a Cadet Major and Chief of Staff for my unit. I started out like everyone else, a Cadet Airman, the lowest rank, my first year. My first year I did very little other school activities, but I did contribute on Veteran's Day. There was a parade, and guess which JROTC was going to march in it? I decided to volunteer and march in the parade. Just imagine a huge column of blue uniforms marching down the street. Marching in that parade was one of the hardest things I had ever done. I was not good at marching, and I had trouble. The second year I was a lot more active. When my high school had its homecoming parade I marched with the rest of the cadets who volunteered. I was better at marching then. That time, we had a Color Guard with us. I am not sure where they were, probably in front of the rest of the cadets marching. That was not a pleasant experience, due mostly to the heat. That same year, I participated in my first and last Color Guard event. I had some training with a rifle, as I am on the Armed Drill Team, so I marched as a guard. A Color Guard consists of two people carrying flags and a left and right guard each carrying rifles. This was for a parade that the elementary school was having, and they wanted three Color Guards, so I volunteered to go along. That parade was the hardest. Try marching in formation with screaming little kids stopping in front of you, a flag blowing in your face, and a fourteen pound rifle on your right shoulder!

Later that year, I performed an armed performance at the ROTC banquet. Working with a normal team with rifles was not a good idea for me. Getting clubbed in the head by a fourteen pound rifle is not a good way to start a performance, so I became the Solo Exhibition Armed Drill person. At that ROTC function I performed in front of a bunch of people. Wearing a coat and tie was a serious inconvenience but everyone loved it; and I snagged a ribbon to add to my collection.

Last summer, I had my toughest challenge. I went to Summer Leadership School. It was like being in the military. We got up at five- thirty in the morning and lights-out was at ten o'clock. Being the only visually impaired person there was very difficult. Try getting up everyday and only having about fifty minutes to take a shower, brush your teeth, get dressed, and get your room ready for inspection. Yes, we had room inspections, and everything had to be in order and arranged a certain way. Furthermore, if your roommate screwed up his side, it would count against you. Later in the day we had personal inspections, which means that we got graded on how we wore our uniform. A day at the Summer Leadership School consisted of getting up, getting ready, going to raise the flag, eating breakfast, personal inspection, drilling for a bit, listening to several lectures on how to run a Cadet Corps, eating lunch, more lectures, other activities, retreat, dinner, sports activities, and finally to bed. That was what I did for five days in a row. We had to drill for competition and received third place. The way it worked out I was in the back right corner and the person to my left held onto my sleeve and kept me in line with the others. This worked perfectly and I received many positive comments from the instructors. I graduated from the school with the "Most Admired Cadet" award. It is a silver cup trophy that sits on my table in my room at home.

The message that I am trying to convey is that if I can go through ROTC, become an officer, go through Summer Leadership School, and obtain a high place on the chain of command, any other blind or visually impaired person can. In the future, I hope to become the first visually impaired person to join the United States Air Force and become an officer.

## Bragging Rights

By Jean Robinson, Family Support Specialist, TSBVI, VI Outreach

Tommie Taylor, eighth grade student at TSBVI, won the 1999 Photo Imaging Education Association First Place Award for her photo “Mirrors.” Tommie’s photography teacher, Denise Elliott submitted the picture in this international photography contest where it competed with 3000 student entries. Her photo will be among 100 others exhibited throughout the world over the next two years. In April her work was part of the “Art of the Eye II” exhibit at the Dougherty Arts Center in Austin.

Tommie has not let her visual impairment (due to albinism) keep her from developing her creative talents. She elected to take photography this school year upon the advice of school staff and her mother. Although her vision is 20/400, Tommie is able to view photos on a computer screen by using a digital camera. She is very adept at using the computer to change the look of the picture. She also has experience in the dark room using traditional film, but the developing chemicals irritate her skin. Currently she is interested in taking pictures of nature and old buildings, but also enjoys people as photographic subjects.

Tommie enjoys all aspects of photography, but winning an award is the best part. She’s received congratulatory calls from friends and teachers commending her work and was featured in an article in the Lake Travis newspaper. She will receive a 35mm camera, film supplies, and photography books for her first place award. Tommie plans to continue practicing her photography skills and hopes to become a professional photographer.

Tommie has typical aspirations of any student. In addition to her interest in photography, she is a cheerleader and is on the track team. She said, “At TSBVI I don’t feel different, and I have become confident enough to ask for help when I need it. I want to go to college and get my degree in photography.”

“Mirrors” can be viewed on the websites of TSBVI, <[www.tsbvi.edu](http://www.tsbvi.edu)> and Photo Imaging Education Association at <<http://bobcat.tamu-commerce.edu/~stang/PIEA/99results.html>>.

## Dreams of Being an Olympic Ice Skater

By Mayra Lopez, BVICP Caseworker, TCB, San Antonio, Texas

One of Chrissy Kobylak's latest dreams is to become an Olympic skater. We think she has the persistence to make it. Legally blind since birth due to colobomas and glaucoma, 11-year-old Chrissy is an A-B honor student and thrives on excelling in everything she does. She began skating about two years ago. Chrissy's self-esteem was low at the time and, as her caseworker, I suggested to her parents that she might benefit by getting involved in a sports activity. Her mom decided that ice skating would be a unique activity.

TCB sponsored several lessons to get her started. Chrissy absolutely loved it. She has since participated in three competitions and has won first place in each. Chrissy said, "I could do anything I want on the ice." In one of her most recent competitions in Dallas, *Inside Edition* heard about her and decided to do a story. They also arranged a surprise visit for Chrissy to meet her lifetime hero, Tara Lipinski. It was quite an emotional moment for both of them.

Nothing has stopped Chrissy. Her positive attitude and her determination have made her overcome all barriers in an effort to fulfill her dream. We are all so very proud of her!

## Cooking Up a Party

By Tamee Argo and Doylene Land, Texas Commission for the Blind, Odessa, Texas  
and Lu Cleere, VI Consultant, Region 18 Education Service Center, Midland, Texas

The fourth annual Christmas Party for students in Region 18 and Texas Commission for the Blind consumers took place December 7, 1998. This party was somewhat different from typical parties because the students were responsible for preparing the evening meal for their parents and other guests. The students were allowed to participate in this activity as a school function instead of going to their afternoon classes. They received instruction in cooking skills, appropriate social interaction, and making decorations.



Students, teachers of the visually impaired and cooking instructors arrived in the early afternoon. They began by reading the large print and braille recipes, organizing the ingredients, obtaining the right utensils, and putting on their aprons. The boys received cooking instructions and baked twelve pies, three cakes, and dozens of cookies. The girls learned how to prepare fresh tossed salad, spaghetti sauce with meatballs, vegetables, and French bread.

While cakes and pies baked and spaghetti sauce simmered, the students sang Christmas carols, visited with each other, and played games. A bubble gum blowing contest proved to be a sticky situation with bubbles going all over the students' glasses and cheeks. A student who was blind received a hands-on demonstration from another student with low vision about just how large the bubbles were. He would place his hands around the other student's mouth according to the size of the blown bubbles.

The students worked cooperatively moving tables, covering the tables with cloths, and making various decorations. They set up the serving line and served

food to the eighty parents and guests in attendance that evening.

The evening's activities included a guest speaker describing her feelings about raising her own child who is visually impaired. Later the younger students joined the older students and siblings in making Christmas arts and crafts to take home.

After the last pumpkin pie was eaten, the students assisted with cleaning the dishes and the building. The students left the party that evening with a holiday spirit, satisfied and proud that they prepared a successful holiday meal for their families and friends.



## Award Winning Beep Baseball Team Visits Camp Teen Challenge

By Tina Herzberg, VI Specialist, Region 12 Education Service Center, Waco, Texas  
& Mary Ann Riggs, Vision Teacher - Consortium of the Visually Impaired

Education Service Center Region 12 and the Texas Commission for the Blind, Waco Regional Office, sponsor Camp Teen Challenge, a summer camp for teens with visual impairments who have completed the 6<sup>th</sup> grade through the 12<sup>th</sup> grade. Camp Teen Challenge turned into a sports camp when the Austin Blackhawks, the World Cup Champion beep baseball team, visited last summer.

The Austin Blackhawks explained the game to the campers and then demonstrated how beep baseball is played. After a couple of innings, the Blackhawks asked for volunteers to try playing the game. Every camper chose to participate. They were able to play the different positions, such as outfielder, batter, pitcher, and catcher. They enjoyed the game and wanted to continue until well after dark.

As the campers played, members of the Blackhawks gave them tips on how to play each position. The campers also asked the Blackhawks questions about life as an adult with a visual impairment: “How did you like going to Taiwan?” “Do you live with your parents?” “How much do you practice beep baseball?” “Wow, you live in an apartment by yourself.” “How do you take care of your guide dog?” “What do you do on the weekends?” “Do you have a job?” “How do you get to work?”

Beep baseball originated in the early 1970s when Telephone Pioneers of America volunteers wanted both the sighted and non-sighted to be able to play our national pastime – baseball. They perfected the idea of putting a sound-emitting device inside a softball and established some basic playing rules. Thus, beep baseball was born. In the mid 1970s, John Ross modified the original game to make beep baseball more like the game of baseball. Today, the balls and bases are still made by Telephone Pioneer volunteers, an organization of 800,000 communications industry employees and retirees.

Like baseball, the game consists of innings with three outs per side. There are only six players for each team – all blind or visually impaired. To keep it fair, all players wear blindfolds. Batters are allowed four swings. Fielders don’t wear gloves. There are only two bases, first and third. The bases are four foot padded cylinders with speakers that are placed a hundred feet down their respective baselines.

Each team has its own sighted pitcher and catcher. The catcher creates a target for the pitcher to throw toward. Before each pitch, the pitcher says “Ready” to let everyone know he/she is about to throw the ball. As the pitcher releases the ball, he/she says either “Pitch” or “Ball”. The batter knows to wait a split second before swinging. When the batter hits the ball, a base operator (a volunteer behind the catcher) activates one of the bases and the batter must identify which base to run toward. In order to score, he/she must reach the base before the ball is fielded.

In the field, a sighted spotter calls out the player numbers (one – first baseman, two – right fielder, three – middle fielder, four – left fielder, five – third baseman, and six – back fielder) to indicate where the ball landed. The player must head toward the ball, locate it, and establish control of the ball. In order to get an out, the player must field the ball before the batter gets to the base.

For some of the campers, playing beep baseball was their first experience with organized sports. The Blackhawks also gave the campers ideas about what their futures hold, and convinced them that they CAN play sports. The campers were excited to discover that there are several beep baseball teams across Texas including Houston, Tyler, Austin and Dallas-Ft. Worth. Everyone found the game to be a lot of fun and would

like to have a team someday in the Waco/ESC Region 12 area. If you would like more information about beep baseball, please contact Jeannette Bigger, secretary of the National Beep Baseball Association, at either (785) 234-2156 or jb4208@aol.com. Wanna play?

## **Fine Motor Development**

Reprinted with permission from Awareness, Spring 1996

Published by the National Association of Parents of the Visually Impaired

*Editor's note: These materials were prepared by the Early Childhood Unit of the Overbrook School for the Blind especially for use by parents in the home with young children who are blind or visually impaired.*

Your baby's fine motor development is crucial. He/she needs to learn to use his/her hands well in order to manipulate toys and to acquire self-help skills such as feeding and dressing.

Babies who have good vision explore their environments from the very beginning by using their sight. They learn to coordinate their eye and hand movements so that they can soon manipulate a variety of toys and use their hands well. The beginning of "reaching" occurs with a baby's eyes. Babies who are blind or visually impaired must learn to coordinate the movements of their hands and arms with their hearing. They need to learn to use their hands in ways which will be functional, motivating and enjoyable. Your baby will need extra practice and many, many opportunities to learn to use his/her hands. Babies who do not use their hands for motivating and useful activities may begin to develop behaviors such as hand or finger flicking or tapping on a surface. Hands which are "busy" playing with toys are less likely to be used for self-stimulatory behaviors.

Play is a child's "work." Babies and young children need to have plenty of opportunities to play. Those who are blind or visually impaired need to be shown how to play with toys; they need to get satisfaction from their play so that they will be motivated to continue to explore and play. The goal is for them to get as much information as possible through their hands and to take that information and use it in meaningful ways.

All fine motor activities (i.e., braille, writing, hand writing, eating, dressing, etc.) are built upon four important skills. These four skills must be learned before a child can go on to more complicated tasks. They are:

- Grasping objects
- Reaching out to objects
- Releasing objects deliberately
- Turning the wrist in various directions

The connection between weight bearing and learning to use one's hands is very important. Weight bearing gives the kind of feedback that makes the baby aware of his/her arms and hands, and shows him/her how he/she can use them. Weight bearing causes a baby to open his/her hands, straighten out his/her arms, and raise his/her head and trunk.

### **REACHING AND GRASPING**

Grasping is the ability to hold onto objects and use them for specific purposes. Young babies have a reflexive grasp; their hands automatically close tightly when pressure or stimulation is applied to their palms. As a baby becomes more aware of his/her hands, he/she is able to open them voluntarily and develop a "true" grasp. The reflexive grasp is inhibited as a baby takes more and more weight on his/her hands. It is replaced by a series of different holding methods which, over time, involve more thumb participation. You cannot teach your child to grasp, but by observing the type of grasp your child shows, you can provide toys and activities that will help him/her move along to the next developmental step.

## Some Ideas

- Give your child lots of opportunities for weight bearing on his/her hands (i.e., lying on his/her tummy and pushing up on his/her hands, rocking on hands and knees, crawling).
- Place various objects in his/her hands. Choose items which are about the size of his/her hands - the reflexive grasp will force him/her to hold the object, but his/her hands will be more open and less fistful. Examples are: rattles, foam hair curlers, pegs. Use a variety of textures, sizes, shapes and weights.
- Provide lots of dangling objects in the crib, in front of your baby's infant seat, from a hanger over the changing table, etc. Your baby will, at first, find them by accident and respond to them reflexively; when he/she is ready for deliberate grasping, he/she will expect to find dangling objects.
- Portable "bars" which can be placed in front of your baby's infant seat or on a blanket overhead are excellent for holding "dangling toys." Century makes "crib bars" (available at Best's Kiddie City, and maybe other toy stores.) Sears has a similar toy in the "Disney Babies" line.
- Encourage your baby to bring his/her hands together and grasp his/her own hands. Gently stroke his/her hands, rub or pat them together, or pat his/her hand on yours.

## BILATERAL COORDINATION

Bilateral coordination is the ability to use both hands together to manipulate an object. This begins at an early age where an infant is observed to hold objects using two hands (in midline), progressing through transferring objects from hand to hand, to where each hand is used for different functions.

It is very important that children who are visually impaired or blind learn to manipulate toys well with their hands. When their hands are "busy" playing appropriately with toys, they are taking in a lot of information and learning from their environment. They are also less likely to use their hands for self-stimulatory behaviors such as eye poking or tapping. Following are some suggestions to help your child to use his/her two hands in a coordinated fashion:

- Clapping hands is often a good motivator for children who need practice with bilateral coordination. It stimulates the muscles in the hands and arms and can be practiced during songs, listening to music, and clapping games. When the child is able to hold a toy in each hand for a good period of time, begin banging games (using hand over hand if necessary).
- Use tactile exploration activities where two hands can work together:
  - \* shaving cream
  - \* water
  - \* sand
  - \* rice or macaroni
  - \* finger paint

Make sure he/she gets both hands into the materials, and help him/her to use two hands to pick up lot of sand or to smear fingerpaint over the entire page.

- Try two-handed activities, where one hand holds, the other hand manipulates:
  - \* hold container in one hand and put objects in other
  - \* hold container in one hand and take objects out with other
  - \* hold stick in one hand and put rings on with other
  - \* hold stick in one hand and take rings off with other
  - \* hold pegboard down when pulling pegs out
  - \* stabilize ring stack to put rings on
  - \* hold down paper with one hand and scribble with other
  - \* thread toys using wooden dowel as needle
  - \* wind jack-in-the-box
  - \* pour water from one cup into another

- Try two-handed activities, where both hands move actively:
  - \* putting “jack” in the box
  - \* tinker toys
  - \* putting pop beads together
  - \* stringing large beads
  - \* screw kegs

## My Hands

By Amanda Stine

Reprinted with permission from DB-LINK

My hands are . . .  
 My Ears, My Eyes, My Voice . . .  
 My Heart.  
 They express my desires, my needs  
 They are the light  
 that guides me through the darkness

They are free now  
 No longer bound  
 to a hearing-sighted world  
 They are free  
 They gently guide me

With my hands I sing  
 Sing loud enough for the deaf to hear  
 Sing bright enough for the blind to see

They are my freedom  
 from a dark silent world  
 They are my window to life  
 Through them I can truly see and hear

I can experience the sun  
 against the blue sky  
 The joy of music and laughter  
 The softness of a gentle rain  
 The roughness of a dog’s tongue

They are my key to the world  
 My Ears, My Eyes, My voice...  
 My Heart

They are me

## Making a Difference

By Lu Cleere, VI Consultant, Region 18 Education Service Center, Midland, Texas

In January, after the football season was over, the spotlights were pleasant memories, and the equipment and uniforms were all put away, two boys found themselves digging through boxes to find their uniforms. These two boys were suiting up in their uniforms for a trip across town for a special appearance at an elementary school classroom. What made this so special? Well, they were going to see a very special little boy.

Aaron is a six-year-old boy in a communication enhancement classroom. Even though Aaron has difficulty communicating some of his basic needs, you can easily understand him when he says, “Go Broncho.” Also, Aaron can not match his colors or ABCs, but he can match trading cards of professional football players.

So Aaron’s classroom teacher, Mrs. Becky Bilyeu, used his fascination with football to facilitate progress on his toileting skills IEP goal. Early in the year, Mrs. Bilyue started telling Aaron that “Broncho football players go potty in the toilet, not in their pants.” Aaron’s grandmother even made him some “Big Boy” underwear out of material featuring footballs. By the end of football season, Aaron had started making progress on his toileting IEP goal.

So as a reward, the two star football players suited up in their football shirts and went to the Elementary School to see Aaron. These “big guys” on the high school football field took the time to talk to Aaron about how glad they were that he was potty in the toilet. Then they gave Aaron a football.

Now as the end of the year is approaching, Aaron has made enough progress on this IEP goal that he has put away his Pull-ups training pants. Aaron is even finding the teacher, Mom, or sometimes Dad, to tell them “I go potty.” So, with this classroom teacher’s willingness to throw out her textbook strategies on toileting skills and use the interests of this child, this teacher made a difference.

## **CCRC Cane Splint**

Kathi Tucker Young, O&M Instructor II, Criss Cole Rehabilitation Center

We've all had it happen; you're teaching a lesson and your client/student's folding cane breaks at the joint. This normally puts a stop to your lesson, right? I started thinking, “What happens to those folks that are out there by themselves, perhaps business people in town for only a few hours. What do they do?” So I decided to come up with something compact that could fit in one's pocket. Something that, by itself, could temporarily fix the cane well enough to use it. No screwdrivers or tape needed. I'd like to thank Ed Mullen and Lois Grandmaison, our intern from Stephen F. Austin University, for their invaluable help in designing the cane splint.

To make this cane splint, all you need is a length of ½" diameter hot water PVC pipe, a table saw with a blade for cutting plywood, and a piece of sandpaper. Take a length of the PVC pipe and mark the top and bottom into quarters. Then take the table saw and cut out one-quarter of the diameter lengthwise. Cut the PVC pipe into 4" lengths. The edges of the PVC pipe that you cut will have a blunt edge; take the sandpaper and smooth them so that they slant in towards the center of the PVC pipe. Now, you should have a simple tool that will enable you to temporarily fix a broken folding cane. Snap it onto the cane so that the splint covers the broken joint equally on both sides. Be sure to NOT leave the splint on a cane any longer than it takes to get a new cane; the splint WILL stretch out and be unusable if you do so.

## **Texas Commission for the Blind Transition Services:**

### **Making a Successful Transition from School to a Career**

by Lori Wells, Transition Consultant, Texas Commission for the Blind

Throughout our lives we experience numerous changes that provide us with opportunities for exploration, discovery, and decision making. Adolescents face a major life-change or “transition” upon completing high school and meeting the challenges of adulthood. In an effort to assist students who are blind or visually impaired and their families prepare for this important period of adjustment, the Texas Commission for the Blind has developed a system to help bridge the gap between high school and the world of work. The transition process includes the active involvement of the adolescent consumer, parents, educators, and rehabilitation professionals. The basic goal of this effort is to provide our youth with the information and services they need to make a successful transition from the education system to adult life.

### **THE TRANSITION PROGRAM**

The Transition Program was developed to assist adolescents with permanent visual impairments make an effective transition from secondary school to adult life and the world of work by helping these young Texans develop the skills and self awareness to make informed choices about the type of employment they would like to pursue.

Transition services that are available to assist young people in the initial pursuit of their vocational goals may include:

- eye exams,
- vocational assessments,
- adaptive technology for post-secondary education and/or work,
- vocational rehabilitation counseling and guidance,
- career exploration activities,
- summer work opportunities,
- college preparation classes,
- confidence building activities,
- leadership training,
- camps and seminars,
- case management,
- referral to other resources,
- advocacy,
- mentoring, and
- support during ARD and ITP meetings.

## **INDIVIDUAL TRANSITION PLANS**

Texas Commission for the Blind works with consumers, their families, local education agencies, educational service centers and other community resources to develop Individualized Transition Plans (ITPs) and to assist students in clarifying their goals related to employment, independent living, recreation and leisure, and post-secondary vocational training. Texas state law requires that an ITP be developed by the local education agency for all students receiving special education services by their 16th birthday.

Transition Counselors assist consumers and their families prepare for an ITP meeting by helping them plan, problem solve, clarify goals, and identify potential resources. Whenever possible, the Transition Counselor will attend ITP meetings with the consumers and their parent(s). The Transition Counselor is particularly interested in assisting consumers to identify summer programs they would like to participate in and helping them to make vocational plans for after high school.

With the proper training and support, blind and visually impaired youth can become successful and independent adults. The transition program strives to provide the opportunities and training needed to assist the young people that we serve gain employment in a career field wherethey are likely to be successful, and find enjoyment.

## **Public School Internet Access for Students With Disabilities**

Reprinted with permission from Texas Assistive Technology Partnership

The Internet is becoming a very important way that people communicate, get information, and even do business. Texas law created the Telecommunications Infrastructure Fund Board to provide money to libraries and schools to purchase computer equipment so that all Texans can have access to the Internet. This includes persons with disabilities.

Federal law requires that libraries and public schools make their services accessible to persons with disabilities. People with disabilities may require special computer hardware and software to make computers and the Internet accessible.

The Texas Assistive Technology Partnership (TATP) was formed in 1992 to lead and coordinate Technology-Related Assistance to Individuals with Disabilities Act (Tech Act) activities in the state of Texas. The TATP is based at the University Affiliated Program (UAP) of the University of Texas at Austin. In addition to the TATP, the Tech Act project in Texas includes protection and advocacy services provided by Advocacy, Incorporated, and training provided by United Cerebral Palsy of Texas. The National Institute on Disability and Rehabilitation Research, U.S. Department of Education, oversees Tech Act project grants in a total of fifty-six states and territories.

Public schools that have Internet services for students to use, must make those services “accessible” to persons with disabilities. This checklist will help you find out if your school is meeting this important legal requirement. You will probably need to ask a teacher or school staff member to help you complete this checklist.

### THE FIRST STEPS TOWARD ACCESS

The school staff should have completed these first steps so that they will know what they need to do to provide access to students with disabilities.

- \_\_\_\_\_ Has the school staff examined their facility to determine if there are existing accessibility problems?
- \_\_\_\_\_ Has the school staff surveyed students to determine disability access needs?
- \_\_\_\_\_ Does the school have a staff member in charge of disability access?
- \_\_\_\_\_ Does the school have a plan for disability access?

### HOW ACCESS IS PROVIDED

A school may have a special computer or computer workstation designed to be accessible to many students with disabilities.

- \_\_\_\_\_ Is there a computer designated as “accessible” to students with disabilities?

If yes, does it include:

- \_\_\_\_\_ 1) a table and keyboard tray that are adjustable?
- \_\_\_\_\_ 2) a color computer monitor, 20" or larger?
- \_\_\_\_\_ 3) screen Reading software and either a sound card or speech synthesizer with speech output?
- \_\_\_\_\_ 4) screen enlargement software?
- \_\_\_\_\_ 5) a sign designating the computer or computer workstation as accessible?

- \_\_\_\_\_ Is there a school staff member available to help students with disabilities use the accessible computer or computer workstation?

A second way that a school may provide access to students with disabilities is to modify a computer to meet the access needs of specific students with disabilities who use the computer.

- \_\_\_\_\_ If there is not a computer or computer workstation designed to be accessible to a broad range of students, have any computers been modified to meet the needs of specific students?

### PROBLEMS WITH ACCESS

There may be students with disabilities in your community who are unable to access the Internet using the computers in their public school.

- \_\_\_\_\_ Are you aware of anyone who has experienced problems accessing the Internet in a public school because of a disability?
- \_\_\_\_\_ If yes, has the school taken steps to provide that individual access?

Libraries that have Internet services for the public to use must also make those services “accessible” to persons with disabilities. TATP has a similar checklist for public libraries.

TATP wants to hear from you! Please let us know about Internet access in your community. The Texas Assistive Technology Partnership may be reached by calling our toll free number: (800) 828-7839, by e-mail: johnz@utxvms.cc.utexas.edu, or by mail: Texas Assistive Technology Partnership, The University of Texas at Austin, George I. Sanchez Building, Room 252, D5100, Austin, TX 78712-1290.

## **Statewide Leadership for Three Low Incidence Disabilities**

By Fred Shafer, Special Education Director, Region III Education Service Center

Region III Education Service Center in Victoria, Texas, has been assigned by the Texas Education Agency the decentralized statewide leadership responsibility to establish and implement an effective system to provide services to three low incidence disabilities. The three low incidence disabilities include students with severe and profound cognitive disabilities, students who are medically fragile, and students with deafblindness.

Region III ESC will work in coordination with the other ESCs in the state to establish a 20 region network that will enable the ESCs to work together to improve services to students identified as having one or more of the three low incidence disabilities. As the statewide leader, Region III ESC will provide statewide leadership in staff development and technical assistance to school personnel and parents of students who are severely and profoundly cognitively disabled and/or medically fragile.

Region III, in collaboration with the Texas Deafblind Project, will assist in the establishment of deafblind specialists in each of the 20 ESCs in the state. At this time, Region III ESC and the Texas Deafblind Project are developing competencies needed by the regional deafblind specialists. The development of the regional deafblind specialist is one of many activities that Region III will engage in to support the goals of the Texas Deafblind Project. Region III ESC and the Texas Deafblind Project will establish an ongoing working relationship to better provide services to students with deafblindness. Those who are interested in knowing more about the statewide leadership for the three low incidence populations can contact Mary Scott, Education Specialist at Region III ESC, at (361) 573-0731.

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### **Kate's Corner - continued from page 2**

were visually impaired. On Sunday the parents heard inspirational presentations from Steve Booth and Derrick Dufresne, while the kids participated in a karate exhibition. The final event of the workshop found parents sharing what the workshop had meant to them and their child.

I was truly touched by what the parents shared and how much they needed (and had found) hope to dream about their child's and their family's future. Now I know that part of finding that hope had to do with the excellent information presented by the speakers and the networking they did with the professionals in attendance. However, what really gave them the most hope was connecting with other families just like theirs. The support and encouragement they found from being with each other and meeting each other's kids was incredibly powerful. Those that conduct research on what families need most would not be one bit surprised by this piece of information.

We all need connections with people who share our interests and concerns. As you read this edition of SEE/HEAR, I hope that you (family members, professionals, and community members) find some connection with others in our state who are concerned about children with visual impairments and deaf-blindness.

# Pervasive Developmental Disorders in Children with Visual Impairments

By Marnee Loftin, Psychologist, Texas School for the Blind and Visually Impaired

Pervasive Developmental Disorder is a psychiatric/psychological term for a broad category of disorders characterized by disturbed patterns of social interaction and language. PDD is also accompanied by a variety of unconventional self-stimulatory behaviors. These conditions are all generally noted early in life and often associated with an additional diagnosis of mental retardation. Although the specific cause of PDD is not known, it is often associated with other medical conditions, such as chromosomal abnormalities, congenital infections, and structural abnormalities of the central nervous system.

Within this broad category of PDD, there are four different types of disorders. These vary primarily according to the age at which the behaviors are first observed. Numerous excellent resources are available that completely describe each of these types of PDD. The following is a brief summary regarding each of these types.

## RETT'S DISORDER

- This disorder is only reported in females.
- Profound to severe retardation is most likely to occur.
- Symptoms first appear after the age of five months, with the condition usually being diagnosed in the first four years of life.

Characteristics include:

- Normal development through the age of five months and then loss of skills;
- Loss of purposeful hand movements between five and ten months of age with subsequent development of a stereotyped hand movement that resembles hand wringing or hand washing;
- Poorly coordinated gait or trunk movements;
- Severe impairment of both expressive and receptive language as well as physical movement.

## CHILDHOOD DISINTEGRATIVE DISORDER

- Recent data suggests that it is more likely to occur in males.
- Onset is most frequently noted between three and four years of age.
- Frequently the onset is preceded by periods of irritability, increased activity level, and anxiety.

Characteristics include:

- Normal development through the first two years of life and then progressive loss of skills;
- Impairment in social interactions, communication, or presence of stereotyped patterns of behavior.

## AUTISTIC DISORDER

- This disorder is most frequently noted in males.
- Mental retardation is an accompanying disorder in approximately 75% of the cases.
- Profiles in psychological testing will often show an extreme pattern of strengths and weaknesses. This

is present even in cases where mental retardation is also present.

- Symptoms first appear before the age of three years.
- Generally the diagnosis will be based upon behaviors that are exhibited after the age of two years because of the subtle manifestations of Autistic Disorder during infancy.

Characteristics include:

- Impairment in social relationships such as: difficulty in developing peer relationships that are appropriate to their developmental level, lack of social or emotional reciprocity, lack of any attempts to share enjoyment, interest, or achievement with others;
- Impairment in communication such as: delay or lack of development of spoken language, no attempt to compensate for this lack, marked difficulty in initiating or sustaining conversation;
- Idiosyncratic language such as lack of make believe play appropriate to their developmental level;
- Stereotyped and repetitive behavior, interests and activities such as: preoccupation with certain objects or activities, inflexible adherence to routines, repetitive motor movements, preoccupation with parts of objects.

## **ASPERGER'S DISORDER**

- This disorder is most frequently noted in males.
- Intelligence is most frequently in the normal range, but will sometimes be as low as borderline.
- No delays are noted in language development, cognitive development, or areas of adaptive behavior, with the exception of social behaviors.
- The disorder will most likely will be diagnosed in adolescence or as a young adult.
- Psychological assessments will generally reveal high scores on items that measure memory, but lower on items that measure social comprehension and judgment.

Characteristics include:

- Impairment in social relationships such as: failure to develop peer relationships, lack of social and emotional reciprocity, lack of seeking to share enjoyment, interest, or achievement with others;
- Stereotyped and repetitive behavior, interests and activities such as: preoccupation with objects or activities, inflexible adherence to routines, repetitive motor movements, preoccupation with parts of objects.

## **DIFFERENCE BETWEEN AUTISM AND ASPERGER'S DISORDER**

Though there are some similarities between Autism and Asperger's Disorders, there are also significant differences, including the following:

- Individuals with Autistic Disorder will generally have no interest or awareness in others. Individuals with Asperger's are often keenly interested in and aware of others, but do not have the skills to engage them successfully.
- There is no delay in language development in individuals with Asperger's Disorder. Frequently their language skills are well developed, but often quite bookish. They will talk for long periods of time with considerable knowledge about topics that others are not interested in discussing.

- Motor skills are often an area of significant strength for individuals with Autistic Disorder. Individuals with Asperger's are often quite clumsy and poorly coordinated.
- Individuals with Autistic Disorder will often have an area of interest/ability that is a splinter skill. For example, they may be able to tell the day on which a certain date will occur. Individuals with Asperger's will have an interest that will become an obsession. The various topics may change (for example from discussing snakes to discussing railroads) and the amount of information will be factually correct but excessive in discussions.
- The diagnosis of Asperger's usually occurs much later than that of Autistic Disorder. The social and communication deficits are much less severe, and are often perceived as something that the child will "grow out of" as they approach adulthood. This is a significant factor in the relatively late identification of Asperger's.
- Often there are motor mannerisms in a person with Asperger's that may not originally be seen as self-stimulatory behaviors. They are subtler and include behaviors such as flicking of fingers, manipulating glasses in a stereotypic manner, etc. Generally these behaviors will become less frequent as the child becomes older. They may reemerge in times of stress. The self-stimulatory behaviors in an individual with Autistic Disorder are more intense and are likely to appear more unusual. In addition, rates of self-stimulatory behaviors tend to remain high even as the child becomes older.
- Individuals with Asperger's seldom have the neurological disorders that are commonly seen in Autistic Disorder.

## DIAGNOSIS OF ASPERGER'S DISORDER

At this time there is no specific test or instrument to diagnose Asperger's. Much of the decision is based upon observation of the student as well as reports of family members and staff.

In general, individuals with Asperger's exhibit a number of disturbances in interpersonal relationships. They may express considerable interests in developing these relationships, but find this difficult to do. Relationships with peers are frequently one-sided with long conversations about a limited number of topics. Generally the topics will focus upon their own narrow topics of interest. They are unable to gauge the degree of interest (or disinterest) that others may have in their conversations. When peers attempt to direct their conversations to mutual topics of interest, the individual with Asperger's will ignore such attempts. They may refuse to respond or will simply redirect it back to their own area of interest.

In general, the topics of extreme interest for an individual with Asperger's are those that can best be learned in a rote manner such as weather, geography, construction, etc. They are less likely to choose topics that focus upon more aesthetic interests or abstract concepts. The topics may change over a period of time, and the individuals may not want to discuss topics that interested them during an earlier stage of development.

Individuals with Asperger's are quite often bright individuals who learn well in role play situations regarding specific social skills. However, they have great difficulty in generalizing a skill learned in one situation to another situation.

Psychological assessments will often reveal a pattern of strengths and weaknesses that is quite pronounced. These individuals have skills in rote learning of verbal concepts and verbal memory. They often have a large vocabulary and can easily repeat long strings of information. Reading skills are likely to be well developed, but they often have great difficulty making inferences based upon reading. Weaknesses are most obvious in

tactile perception, psychomotor coordination, visual-spatial organization, and situations that involve interpretation of social cues.

One of the most difficult tasks in diagnosing Asperger's Disorder is to differentiate between this disorder and other conditions, specifically Attention Deficit Disorder and Anxiety Disorders.

## **TREATMENT OF ASPERGER'S DISORDER**

At this time, there is no specific treatment or "cure" for Asperger's Disorder. Intervention usually consists of different psychological strategies or medication. Both types of intervention deal with decreasing the symptoms that appear. Examples of psychological strategies that might be used include:

- Behavior intervention plans to increase the rate of appropriate peer interactions;
- Role play various situations to increase skills to empathize with others;
- Specific social skills training to improve basic skills in group and individual interactions.

Medications are available to treat a variety of behaviors that are exhibited. Psychiatric consultation is critical in making such a decision. Different medications have been used to address the following groups of behaviors:

- Hyperactivity, inattention, and impulsivity
- Irritability and aggression
- Preoccupations, rituals, and compulsions
- Anxiety

## **PDD AND VISUAL IMPAIRMENTS DIAGNOSIS**

The diagnosis of both Autistic Disorder and Asperger's Disorder is a complex task that is even more difficult when the child is severely visually impaired. Although the cause of PDD is not clearly established, PDD is often associated with congenital infections and structural abnormalities of the central nervous system. Both of these conditions are also often seen as causes of visual impairment. Therefore children with visual impairment may in fact be at increased risk for some type of PDD. The diagnosis of any form of PDD is challenging. That task is significantly more complicated in children with visual impairments because of their unique developmental patterns.

In spite of these difficulties, in recent years we have seen a significant increase in the number of young children with visual impairments who have also been diagnosed as having some form of PDD.

Two issues are critical in this process. (1) Someone with a clear understanding of the unique developmental patterns of visually impaired children should be involved in the diagnostic process, to differentiate and note behaviors that may be of concern. For example, echolalic language and difficulties in establishing peer relationships are frequent issues in young children with visual impairments. These behaviors have little diagnostic significance (i.e., not necessarily indications of Autism) although they may be noted as areas of need for remediation in the educational programs. (2) Many young children with visual impairments have great difficulty in establishing peer relations because of the lack of opportunities for incidental learning. This should be identified as a need for direct training rather than a symptom of Asperger's.

After areas of need are identified, our responsibility as educators is to allow adequate time for maturity to occur and new skills to be learned. For the vast majority of children with visual impairments, these behaviors and concerns will correct themselves with appropriate instruction and maturation.

When these behaviors continue to remain problematic, we need to ask ourselves why. We can be sensitive

to the different developmental patterns of children with severe visual impairments, but we must not let this interfere with our ability to determine when these differences have become significant deviations from the usual developmental patterns for children. An important goal is to develop consistent means of gathering data that will allow us to monitor changes in social interactions, communication, and ritualistic/stereotypic behaviors that occur as a child matures and education progresses. Appropriate identification of children with visual impairments and some type of PDD will allow modifications of their educational program and better access to adult services.

## **Optic Nerve Atrophy Pediatric Visual Diagnosis Fact Sheet™**

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### **DEFINITION**

Optic Nerve Atrophy (ONA) is a permanent visual impairment caused by damage to the optic nerve. The optic nerve functions like a cable carrying information from the eye to be processed by the brain. The optic nerve is comprised of over a million small nerve fibers (axons). When some of these nerve fibers are damaged through disease, the brain doesn't receive complete vision information and sight becomes blurred. Atrophy (wasting away) may be partial in which some axons are damaged or profound in which most axons are damaged. A child's ability to see clearly (visual acuity) is affected due to nerve damage that occurs in the central part of the retina responsible for detail and color vision (macula). These areas of the eye are more vulnerable to the effects of atrophy. ONA is the end result of damage to the optic nerve. It can affect one or both eyes. It may also be progressive, depending on the cause.

### **CAUSE**

Many diseases and conditions may lead to optic atrophy. Tumors of the visual pathways, inadequate blood or oxygen supply (hypoxia ischemia) before or shortly after birth, trauma, hydrocephalus, heredity, and rare degenerative diseases have been identified as causes of ONA. When hereditary, the pattern is dominant. This means that one parent with the condition would pass the gene to 50% of his/her children. If caused by a tumor, the process of ONA may be halted by removal of the tumor.

### **DIAGNOSIS**

ONA in children is diagnosed by a pediatric ophthalmologist in a number of ways, including:

- Visual acuity and color vision may be found to be abnormal (if testable).
- Pupil reactions to light are diminished.
- The optic nerve, when examined with an ophthalmoscope, has a gray-white appearance, which may not be apparent for four to six weeks from time of optic nerve injury.
- Optic atrophy which occurs in both eyes from time of birth (bilateral and congenital) may cause rhythmic, involuntary eye movements (nystagmus).

### **CHARACTERISTICS**

Although there are several types of ONA, the following characteristics are common to most:

- Central vision is affected.
- Color vision deficits may be evident.
- It may be difficult for children with ONA to discriminate contrast, due to damage in the area of the eye responsible for detailed vision (macula).
- A wide range of acuity loss exists in this population.

- Onset of ONA may be gradual or sudden depending on the cause.
- A general decrease of sensitivity in all visual fields (depressed visual fields) may occur, also dependent on the cause of ONA.
- Many children with ONA have additional neurologic problems, such as seizures, developmental delays or motor problems, and Cortical Visual Impairment (CVI). (When CVI coexists with ONA, it may be difficult to determine which diagnosis is responsible for specific visual problems).

## VISUAL AND BEHAVIORAL CHARACTERISTICS

- Visual acuity may range from nearly normal to totally blind.
- Children with bilateral central blind spots (scotomas) may "overlook" in order to see a person or object.
- Children may have difficulty identifying colors based on their individual color vision defect.

## MYTHS

The following statement is NOT TRUE according to current research:

- ONA can be corrected with glasses.

## TEACHING STRATEGIES

Ongoing evaluation, and communication among family, medical and education specialists is essential to develop the best home and school program for the child with ONA. Assessment and services from a pediatric ophthalmologist, a teacher of the visually impaired, and a specialist in Orientation and Mobility who keep in close communication with caregivers will ensure maximum development for the child.

- Carefully observe a young child with ONA to gather valuable information about the way she sees best. Determine the best position for the child and her toys to accommodate for central field loss.
- The physical demands of looking at an object or toy for a long period of time may cause eye fatigue. Allow a child with ONA to rest between activities requiring vision.
- Use touch and spoken description to tell a child about present and future activities. The use of additional senses are necessary to enrich the learning process.
- Good contrast and lighting are essential for the child with ONA to see objects in the environment clearly. For example, offering dark colored food on a light plate, or a light toy against a dark background provides good contrast.
- Using bold colors (red, yellow, green, blue) and simple, clear pictures will help the child to see more clearly.
- Use familiar and real objects to encourage visual attention. Change one characteristic of a familiar object only after the child is able to recognize it consistently. For instance, after the child is able to recognize a cup that is blue consistently, change the cup to red.
- When introducing unfamiliar objects to the child, relate them to familiar objects and settings. Note: If a child with ONA also has Cortical Visual Impairment (CVI), strategies effective with the CVI population should be used (see CVI Fact Sheet).

## GLOSSARY

**Axon:** single projection from a nerve cell that under normal conditions, carries nerve impulses away from the cell body.

**Optic Nerve Hypoplasia:** refers to underdevelopment of the optic nerve during pregnancy.

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# Optic Nerve Hypoplasia Pediatric Visual Diagnosis Fact Sheet™

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## DEFINITION

Optic Nerve Hypoplasia (ONH) refers to the underdevelopment of the optic nerve during pregnancy. The dying back of optic nerve fibers as the child develops in utero is a natural process, and ONH may be an exaggeration of that process. ONH may occur infrequently in one eye (unilateral) but more commonly in both eyes (bilateral). ONH is not progressive, is not inherited, and cannot be cured. ONH is one of the three most common causes of visual impairment in children.

## CAUSES

In most cases there is no known cause of ONH. Infrequently ONH has been associated with maternal diabetes, maternal alcohol abuse, maternal use of anti-epileptic drugs, and young maternal age (20 years of age or less), but these factors account for very few of the total number of cases. All races and socioeconomic groups seem to be affected by ONH.

## CHARACTERISTICS

- ONH may occur by itself or along with neurological or hormonal abnormalities. Hormonal problems not apparent in early life may appear later.
- Children with ONH demonstrate a wide spectrum of visual function ranging from normal visual acuity to no light perception. The effect on the visual field may range from generalized loss of detailed vision in both central and peripheral fields (depressed visual fields) to subtle peripheral field loss.
- A high percentage of children with ONH have associated involuntary rhythmic movements of the eye (nystagmus). In most cases, the nystagmus is associated with significant bilateral reduced visual acuity.
- ONH is a stable condition. Visual function does not deteriorate with time. A mild improvement in visual function may occur as the result of maturation processes of the brain. In some cases, reduced nystagmus may also occur.
- Depth perception may be more severe if vision loss is great.
- Mild light sensitivity (photophobia) may occur.

## DIAGNOSIS

ONH is diagnosed by direct examination of the eye by an ophthalmologist. No current laboratory or radiographic tests will establish the diagnosis. Many infants who are diagnosed with Optic Nerve Atrophy are, in fact, children with ONH. Sometimes visual functioning can be predicted from the appearance of the optic discs. However, it is very difficult to predict visual acuity on this basis alone.

## VISUAL AND BEHAVIORAL CHARACTERISTICS

- The child's vision is characterized by a lack of detail (depressed field), but this lack of detail is not comparable to the blurred reduction in vision when a person removes her glasses.
- In certain cases of ONH a specific field defect occurs. Children may not be aware of people or objects in the periphery.
- Children with ONH may be unable to locate objects in space precisely due to a lack of depth perception.
- Some children with ONH have mild photophobia. These children may squint, lower their head, avoid light by turning away, or resist participating in outdoor activities.

- When one eye is affected more than the other, an ophthalmologist may recommend a trial of patching the stronger eye, since the visual loss may be due to amblyopia.
- Some feeding issues are associated with hormonal problems. Lack of interest in eating may be due to absent or diminished sense of smell and taste. Children with ONH may have very restricted food preferences. Some children exhibit excessive lip smacking while eating.
- Behaviors of some children with ONH may be due to associated medical conditions, such as inattentiveness and irritability due to low blood sugar levels (hypoglycemia).
- The child with associated central nervous system problems may be easily distracted, quickly frustrated and act in a disorganized or an impulsive way.

## CONDITIONS ASSOCIATED WITH ONH

Associated brain and hormonal abnormalities are common in children with nystagmus and bilateral severe vision loss, and are less common in cases where vision loss is mild or unilateral. Abnormalities include:

1. Midline anomalies of the brain: septo optic dysplasia (absence of the septum pellucidum and the corpus callosum), encephaloceles, anomalies of the ventricles, anencephaly, cerebral atrophy, and rarely, tumors.
2. Hormonal insufficiencies: thyroid, growth hormone, pituitary, adrenal, anti-diuretic hormone (ADH).

Associated midline brain anomalies can be identified by either an MRI or CT scan. Hormonal insufficiencies require an examination by a specialist in hormonal disorders (pediatric endocrinologist). Children particularly at risk for having associated hormonal insufficiencies are those who had neonatal low blood sugar (hypoglycemia), had prolonged jaundice (hyperbilirubinemia), failed to grow normally (failure to thrive), have difficulty regulating body temperature in connection with viral illnesses, and/or had a CT or MRI scan showing an absence of tissue connecting the brain to the pituitary gland (the pituitary stalk).

## MYTHS

The following statements are NOT TRUE according to current research:

- ONH occurs in clusters due to use of pesticides in the environment.
- The associated midline brain anomalies have a profound effect on the visual outcome and/or spatial orientation of these patients.
- All mothers of children with ONH were drug users during pregnancy.

## TEACHING STRATEGIES

- Each child should receive medical monitoring and comprehensive, ongoing, functional and educational assessment. Teachers need to increase the size, contrast, and lighting of materials for a child who has nystagmus and bilateral severe visual loss because of generally depressed fields.
- When a specific field loss is identified, materials need to be presented within the child's visual field. The child should be encouraged to turn his head to look for people and objects outside his visual field.
- A child with ONH needs the opportunity to develop learned aspects of depth perception through fine and gross motor activities, including container play, nesting and stacking, ball tossing and rolling, pouring activities, and lots of practice with stairs, slides, foam wedges for crawling, and cardboard box play.

- The effects of light sensitivity can be minimized by adjusting lighting levels, wearing tinted lenses, and minimizing glare on surfaces.
- A child with ONH often has other conditions that need to be considered when developing an individual education plan.
  - A child who is easily distracted, frustrated, disorganized, and impulsive may be helped by predictable physical environments, dependable daily routines, and limited distractions.
  - Slowing the pace of activities and providing predictable transition routines may help reduce resistant and irritable behavior.
  - Offering frequent snacks to children diagnosed with hypoglycemia may be helpful.
- When a child does have feeding problems, parents and professionals need to agree on recommended strategies to create a positive feeding experience.
- When a child has no functional vision, an approach that uses all the senses for learning is needed.
- Evaluation by an instructor of Orientation and Mobility is essential in meeting the child's needs, due to loss of detail vision and vision field loss.

## GLOSSARY

1. Amblyopia: a reversible condition affecting visual acuity that can lead to loss of vision in an eye that is structurally capable of seeing.
2. Anencephaly: a birth defect in which all but the most primitive part of the brain, spinal cord, and overlying bones of the skull are absent.
3. Corpus Callosum: a mass of white matter that joins the cerebral hemispheres of the brain, allowing them to communicate with each other.
4. Encephalocele: a birth defect in which the brain protrudes through an opening in the skull.
5. Perinatal: describes the period between 28 weeks gestation through the first week following delivery.
6. Radiographic: refers to a picture produced on a sensitive surface by a form of radiation other than light.
7. Septo optic dysplasia: a syndrome which includes midline abnormalities of the brain and optic nerve hypoplasia.
8. Visual Acuity: ability of the eye to see clearly (which can be measured specifically), to perceive objects and to see detail within central vision.

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## Always a Way

By Stacy Nokes, Mother, Houston, Texas

The MAGIC Foundation (Major Aspects of Growth In Children for Children's Growth and Related Adult Disorders) provides support and education to families of children with growth disorders. They can be contacted by calling (800) 3MAGIC3, or by visiting their website at <[www.magicfoundation.org](http://www.magicfoundation.org)>. Their annual conference includes top-notch specialists interested in rare disorders such as septo-optic dysplasia (SOD). The 1998 Magic Foundation Conference was great, I learned a lot and met many interesting people.

We are not rich people, so we had to come up with ideas for funding our trip. Benefits were out of the question as this was not a medical expense. We decided to make crafts and toured the crafter's circuit. That didn't make nearly enough money so I went to Ashley's vision teacher for ideas. She gave me a list of resources, and I began calling right away. Texas Commission for the Blind and the Texas School for the Blind and Visually Impaired agreed to help with expenses for our trip. I went with another family from my area so we could share costs. We raised money through family and friends. We contacted the local VFW, Lion's Club, and churches. We rented a van and drove from Houston to Chicago in 19 hours, and it was well worth it.

Some of the things I learned from two doctors who spoke to the SOD families at the conference include:

- Vision will improve until age five in children with optic nerve hypoplasia (ONH) who already have sight. ONH is not a degenerative condition.
- There is a difference between hypopituitarism and panhypopituitarism. Hypopituitarism means a person is only growth hormone deficient. Panhypopituitarism means a person is growth hormone deficient and has other hormone deficiencies.

- Only 4% of all children with SOD/ONH truly have diabetes insipidus. In some children it may appear that they have diabetes insipidus because their thirst center (hypothalamus) is not properly working.
- Some doctors consider SOD and ONH the same disorder.
- All children with SOD/ONH should be tested for hypothyroidism.

If you are interested in learning more about SOD/ONH you can contact the SOD division directors, Cindy Rose or Pilar Hari at roses8@mindless.com or visit the website of Septo-Optic Dysplasia/ Optic Nerve Hypoplasia Support Group Homepage <members.tripod.com/~roses8/index.html>. They videotaped the doctors' presentations and are willing to share them with families who couldn't attend the conference.

Although there was paperwork involved in getting reimbursed for my trip to the MAGIC Foundation Conference, the hardest part was finding out who to call to get financial help. We are already planning for next year's conference trip by making disabled dolls and guardian angel dolls to add to our craft collection. If any of you want to attend a national conference and don't have the money don't be afraid to ask questions. There is always a way.

## **New Offerings from the Blind Children's Fund (BCF)**

By Sherry Raynor, President, Blind Children's Fund

BCF is a 20 year old organization which represents a vast network of parents, professionals, and volunteers throughout the United States and the world, committed to providing what is needed to insure that children who are blind have optimum opportunity to live full lives.

When the BCF started there were only two books specific to the growth and development of a preschool child that was blind. The BCF has written, developed, and distributed 13 books, videotapes, and other resources to benefit parents and professionals in all 50 states, six territories, and more than 90 foreign countries. Two books, "Get A Wiggle On" and "Move It", have been translated into Spanish, French, Indonesian, Papamianto, German, Finnish, and Hebrew. Most recently, these two and another parent book, "Learning To Look", were translated into Slovak and Czech.

BCF is happy to announce two new books. The first is "Lessons" With a Child Who is Blind by Michael Brambring. This book presents an account of one family's experiences in rearing their daughter, Christina, who is congenitally blind. It is an outcome of their cooperation with the early interventionist who visited them regularly to help them with this task. The account is built around letters written to the parents after each early intervention visit. These provide a chronological account of their daughter's developmental path. The cost of this book is \$20 plus \$3 shipping and handling.

The second book is The Secret Code by Dana Meachen Rau. This is a long needed book for young children to understand Braille. This book was written for young children (4 to 8 years) so they can understand how blind children read Braille. In simple language and colorful illustrations it tells the story of how Oscar, a blind boy, teaches his friend Lucy how to read his Braille. This book costs \$5 for paperback or \$17 for hardcover plus \$3 shipping and handling.

For more information about these books, contact the Blind Children's Fund, 4740 Okemos Road, Okemos, MI 48864. Phone: (517)347-1357. E-mail: blindchfnd@aol.com.

Website: <<http://www.blindchildrensfund.org>>.

## **TCB Insight**

By Terrell I. Murphy, Executive Director, Texas Commission for the Blind

In December a large number of Texans who are blind came to Austin to testify about the Texas Commission for the Blind. Some testified about what the agency did for them years ago. Others testified about the services they are receiving now. Their messages were similar, regardless of the span of years. Almost every person testified that the agency helped shape their future in a positive way and that the agency is vital to the state and people with visual disabilities.

This past year has reinforced even more in my mind that being open to change has earned us so much support from people who are blind. As good as we were in the 1970s when I started with the agency, we are better now because we listened. We will make additional changes in the future if it means that Texans who are blind will receive the services they need to participate fully in all that life offers.

The latest change we've made to our Blind and Visually Impaired Children's Program is a revised system whereby parents and the Commission are partners in the true sense of the word. Our new family service plan has been completely redesigned. The new plan fosters greater communication between our caseworkers and parents of children who are permanently severely visually impaired. The plan sets in motion the important strategies parents agree are needed by their child in building skills toward personal independence and potential employment.

Rules and procedures have been rewritten to remove as many restrictions as possible, and we will soon be publishing a new informational brochure in English and Spanish that explains parental rights. Parents are now given 30 days advance written notice before we close a child's case, and we now will pay for a physical exam when it's needed for a child to participate in a beneficial activity. We have adopted procedures for providing respite care and child care to families. Parents choose their own caregivers because the parents know the child's needs better. The information we require from parents to determine whether the Commission can pay for a service has been greatly simplified.

All these changes are still in their infancy and we are looking to parents and our other partners to give us feedback on how the system's working.

The upcoming summer months are full of opportunities for children with special needs. Watching children participate in these activities is always one of the highlights of the year. Have a great summer!

## **Something to Do...**

By Phil Hatlen, Superintendent, Texas School for the Blind and Visually Impaired

Several years ago, I was asked by the Texas Commission for the Blind to give a presentation to a group of blind and visually impaired teenagers and their parents at a School-to-Work conference. I decided to talk to the students directly about my thoughts and feelings about the transition they were soon to make. What follows are my words to them on that occasion:

Many years ago, a friend of mine said something that I will never forget. She said that there are three things that every human being needs in life: someone to love, something to do, and something to look forward to. For some of you, this may be nothing more than another cute saying out of one of the many popular books of cute

sayings being sold now. But for me, these three things are the meaning of life.

I'll skip something to do for the moment and come back to it. Someone to love—we all have people we love—our parents, our brothers and sisters, friends, relatives...and those we love most will change as we go through life. Many of you will some day marry, and find a depth of love and caring far greater than you can imagine. This little saying is correct—without someone to love, life is not very interesting. We all need other people in our lives that we can feel close to, can confide in, can be who we really are when we're around them.

Something to look forward to—can you imagine a life if you had nothing to look forward to? What each of us look forward to will be different. A pay raise, a better job, a promotion, a vacation, a special time with someone we love. I have known blind and visually impaired young people—recently graduated from high school who truly believed that they had nothing to look forward to. It was not easy getting a job, it took work to make friends in their community, it took effort to participate in recreational activities. I remember going to visit two former students of mine—two young men, totally blind, 22 years old, living together in an apartment. I showed up at their place about 1:30 in the afternoon. I waited a long time for them to answer their doorbell. When they did, it was obvious that I had awakened them. I asked them why they were sleeping through such a beautiful day. One of them said that they had no reason to get up, so they felt no motivation to get out of bed. No job, no friends, no hobbies, no interesting activities...nothing to look forward to. Always look beyond what you are doing, what you are thinking, where you are and what you're about—always have something to look forward to, and be willing to put forth the effort to make it happen.

Something to do—the person whom I heard use these words was referring to work. Paid work is what most of us do for five or more days each week. Most of us are pleased that we have something to do—that we do something productive, something that both we and someone else values. I'm sure that many of you have heard before that there are basically two kinds of workers. There are those who work to live, and those who live to work. Those of us who work to live perform a job and get paid for it. The pay allows us to live our lives with some level of satisfaction. We receive our enjoyment, enrichment, and our beautiful moments in life outside of our job. Perhaps the money we make allows us to pursue hobbies and recreational activities that become the pleasure in our lives. But we would not be likely to say that our pleasure comes from our job.

What about those of us who live to work? Yes, we are paid for what we do, but we also gain a great deal of pleasure and satisfaction from the work we do. Those who live to work receive two benefits from their job: they make money, and they get real pleasure from what they do. I fit this second category, and I consider myself truly blessed. I look forward to going to work. I get much pleasure and satisfaction from what I do. Perhaps this is because I am a lifelong learner. Every day I learn something new about my job, about how children and youth learn, how people act toward one another in the work place.

Winston Churchill once said, "Blessed are those whose work is their hobby, and whose hobby is their work." Regardless of whether you live to work or work to live, and most of us will fall somewhere in the middle, I wish for all of us a balance in life between joy and satisfaction. Joy for the life we're living, satisfaction for the good we're doing.

Yet, I know many people who work to live, and they, too, are truly blessed. They do their jobs, and gain great pleasure and satisfaction from other things going on in their lives.

I urge each of you to explore the world of work. Examine your own skills and what you enjoy doing. Compare these to jobs in the community. Participate fully in career education programs in your schools. My deepest hope for each of you is that you leave school with so much knowledge about who you are, what you are good at, and what you enjoy, that you will take charge of your own life. Use your vocational rehabilitation

counselor well, but don't let that person select your job. You must do that yourself. It is too easy to avoid making your own decisions about your future if there is always a professional around who is more than happy to make your decisions for you.

I wish for you the capacity to be the masters of your own life. I wish for you someone to love, something to do, and something to look forward to.

To Parents and Professionals:

The dignity of choice...isn't that what services with and for blind persons is all about? Should there be any higher priority for all of us than to encourage and enhance the ability of people to take charge of their own lives? I certainly don't want to choose a job for a blind person. I don't want to choose his friends...to choose where he lives...to dictate his life style...to impose my ethics on him. What education and rehabilitation should be doing is developing independent choice-makers, proud and productive people who know themselves well and will not let anyone else take charge of their lives.

## **Jim Gatteys Heads Up NFBT, TCB, TSBVI Collaboration**

By Jim Durkel, Statewide Staff Development Coordinator, TSBVI, Outreach

Welcome to the newest member of the Outreach program, Jim Gatteys, Family Workshop Coordinator. Jim was born in Dallas with ROP (though it was called RLF back then) and is blind as a result. Jim has a younger brother who also has ROP, and his parents were part of the group that established Dallas Services for the Blind. Jim went to public schools and remembers wanting to attend TSBVI (though he never did) in order to participate in sports. He is a braille reader who claims that "if there is a piece of technology out there, I have used it!"

Jim graduated from Texas Tech University with a Bachelor's in psychology and a minor in horticulture. He has worked for TCB as a rehab teacher, transition counselor, and technology trainer. Jim explained that his mother taught him how to be a rehabilitation teacher. "She was sneaky," he said. First she would call home in the afternoon and say, "I am running late, the meatloaf is in the metal pan in the refrigerator, the oven is set at 350, just put the pan in the oven and turn on the oven." After a while, she would call home and say, "I did not have time to make the meatloaf, but the pan is on the counter, the tomato sauce is in the can next to the pan, the dry ingredients next to that, the ground meat in the refrigerator. Set the oven at 350." Even later she would just call home and say, "Would you fix dinner?"

Jim has also worked as a teaching assistant in a resource room for students with visual impairments, been a braille proofreader, and played piano at a supper club. He is also a registered massage therapist.

Jim's new position as Family Workshop Coordinator was created as the result of a cooperative effort between NFBT, TCB, and TSBVI. Jim will work with the families of children between ages 6 and 16 who are visually impaired and mostly on grade level in their schoolwork. Jim will be supporting opportunities for those students and their families to meet and interact with each other. Jim will also be coordinating the "Through Your Child's Eyes" workshop that is offered in five different locations each year around the state. This workshop gives basic information about visual impairments, programming and resources. It is done in collaboration with other agencies or organizations such as Texas Commission for the Blind, the regional Education Service Centers, parent support groups, and others.

If you would like to learn more about Jim's program, or request that he bring one of these training opportunities to your part of the state, please call him at (512) 206-9440 or e-mail him at [gatteys\\_j@tsb1.tsbvi.edu](mailto:gatteys_j@tsb1.tsbvi.edu).

## **Sunglasses Offer UV Protection Beyond Summer's Dog Days**

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*Editor's note: This reprint was written just after summer, so references to snow may seem a bit out of place this time of year. But since exposure to ultraviolet radiation increases the chances for cataracts and macular degeneration later in life, this information is important as we enter summer.*

ST. LOUIS, August 25, 1998 — Labor Day is just around the corner, but that doesn't mean people should retire their sunglasses like they do their summer whites, says the American Optometric Association (AOA).

That's just one of several myths that may keep people from protecting their eyes year-round from harmful ultraviolet (UV) radiation. Here are a few other facts about sunglasses and UV protection from Michael D. Jones, O.D., AOA executive director:

Good UV protection doesn't have to be expensive. AOA recommends that sunglasses which offer 99-100 percent UV protection. These levels can be found all along the price spectrum. Look for sunglasses with the AOA's Seal of Acceptance or have the UV level tested by an optometrist.

UV damage is cumulative. Children should be encouraged to wear sunglasses beginning in infancy whenever they are out in the sun. Their eyes are most susceptible to UV damage because the eye's lens has not yet begun to cloud.

Wondering what color lenses to choose? Gray lenses don't modify colors. Green and brown are also good choices.

Ask for a UV coating on your glasses. Some brands of contact lenses also offer some degree of UV protection, but they won't fully protect your eyes. Wear sunglasses over them.

Give yourself additional protection and style by wearing a broad-brimmed hat to block out even more UV radiation, which is present year-round and can be reflected off winter snow as well as summer sidewalks.

Light eyes have less pigmentation and are thus more susceptible to the harmful effects of UV radiation just as lighter skin is.

Two appearance-related appeals: High-fashion frames can be fitted with lenses that offer adequate UV protection. Also, wearing sunglasses not only keeps the sun from damaging the skin around your eyes, it cuts down on squinting, which helps stave off fine lines and wrinkles around the eyes.

Visit the American Optometric Association's website at <<http://www.aoanet.org>> for more information on eye health and eye care from the 32,000-member organization representing the nation's primary eye care practitioners.

## **Texas Reading Club Provides Summer Fun**

By Carmen Keltner, Public Awareness Coordinator, Talking Book Program

Up with the curtain! Lights the lights! The annual Texas Reading Club will explore the magical world of theatrical productions with its 1999 theme, "Open a Book, on with the Show!" Texas children, from toddlers

to teens, are encouraged to read books about all aspects of theatre in the annual reading program sponsored by the Texas State Library and Archives Commission (TSLAC) and your local public library.

“This year’s Texas Reading Club offers young readers all over the state the chance to learn about the exciting world of theatrical productions,” said Jenifer O. Flaxbart, director of the Talking Book Program. “The Talking Book Program is here to support young readers with disabilities in getting involved with local libraries and other kids, to make this a summer of reading fun.”

The Texas Reading Club helps young readers maintain their reading level over the summer break from school and encourages students to read as an important and fun summer activity. Local public libraries all over Texas will sponsor activities such as contests, story hours, demonstrations, and puppet shows centered around the theatrical theme. Participating readers set goals and keep logs of the number of books they read, or how many hours or minutes they read.

Young readers with visual disabilities can participate in their local public library’s Summer Reading activities, borrowing the books they choose to read in cassette, Braille and large-print formats from TSLAC’s Talking Book Program. Contact a children’s librarian at the local public library to enroll your student in the Texas Reading Club and ask for a reading log. Let the librarian know about any accommodations your young reader may need to participate in activities at the library, and explain that your child will be provided with books in alternative media in order to participate.

If your young reader is already using the Talking Book Program, you can begin making plans to borrow books. Usually, libraries participating in the Texas Reading Club will count any books (they don’t have to be library books) on any topic as entries in your young reader’s Reading Club log. The Talking Book Program’s Reader Consultants can help kids find Talking Books or books in other formats to read as part of their Texas Reading Club activities.

Young readers not currently set up with Talking Books may obtain an application form from teachers or local librarians. (Librarians and teachers may certify applications for Texans with visual and physical disabilities; a medical doctor or doctor of osteopathy must sign applications for people with learning disabilities.) Or you can contact the Talking Book Program directly to request an application form by calling (800) 252-9605 or by sending an e-mail to [tbp.services@tsl.state.tx.us](mailto:tbp.services@tsl.state.tx.us).

For further information about the Talking Book Program and the Texas Reading Club, please contact a Reader Consultant at (800) 252-9605 (toll-free from anywhere in Texas) or (512) 463-5458; or send an e-mail to [tbp.services@tsl.state.tx.us](mailto:tbp.services@tsl.state.tx.us). (The phone lines are often busy, so be sure to leave a message if you call after business hours or on weekends.)

## **Some News Items from AVIT**

By Jim Durkel, Statewide Staff Development Specialist, TSBVI Outreach

THE VIP PROGRAM is a preparation program for training education professionals in the field of visual impairment. TEA recognized the need for continuing specialized personnel preparation for VI teachers and O&M instructors. A \$3 million grant was awarded in January, 1998 to Region 11 for a project by ESCs, TSBVI, and universities, to develop new collaborative programs in personnel prep that address the continued shortage of VI professionals in Texas. This program includes in part: distance learning through video conferencing, professional mentoring, and curriculum review. There is no continued funding at TEA beyond December, 2001 (beyond the current \$3 million). Continued funding is doubtful unless some action is taken.

It was suggested that AVIT work with the State Board of Educator Certification (SBEC) to develop a proposal for the next legislative session. AVIT members have begun meeting with legislators to request permanent state funding for personnel prep of VI professionals. There is a continuing need for more VI teachers, especially in light of an aging teacher population and the lack of younger teachers to replace them.

**ELECTRONIC TEXTBOOKS:** Jim Allan updated the group on the status of the State's consideration of electronic materials, including texts, by students in Texas. A report completed and sent to legislators contained recommendations regarding the use of electronic textbooks in Texas. The report ("Computer Network Study Project") is available at the TEA website, with hardcopies available from Chuck Mayo in the Textbook Division of TEA. There is a concern that CD roms, interactive media, and electronic texts be made accessible. The report recommended specific actions to achieve accessibility. A change in the textbook adoption process would have to go through the State Board of Education. It was proposed that a letter be sent to the Commissioner of Education, asking him to require accessibility of textbooks as an administrative action by the Commissioner.

The next AVIT meeting will be held at Criss Cole Rehabilitation Center in Austin, on Thursday, July 22, 1999 from 10 - 3; the fall meeting will be held on November 18, 1999. Anyone interested is invited to attend.

## **The Alliance of and for Visually Impaired Texans (AVIT)**

AVIT is an interorganizational coalition committed to speak on behalf of Texas's children and adults with visual impairments for:

- the advancement and protection of their human and civil rights,
- the improvement of their social welfare and economic conditions,
- the education of the public with respect to their special concerns,
- the promotion of interorganizational cooperation, support, and communication on issues affecting them.

AVIT's mission is to:

- Provide a forum for discussion for those with a common interest in the quality of life for children and adults with visual impairments.
- Maintain a communication "Network Alert System."
- Collect and distribute information to member organizations and individuals regarding legislative and other issues.
- Provide information to public policy makers concerning important issues related to improving the quality of life of persons with visual impairments.
- Promote growth and awareness among member organizations.
- Prepare and distribute a Master Calendar listing meetings, conferences, hearings, seminars, and special events that are sponsored by or are of interest to Alliance members.

If your organization wants to join AVIT and become part of the "Network Alert System" please contact: Mary Ann Siller, Treasurer, at [siller@afb.org](mailto:siller@afb.org), American Foundation for the Blind, 260 Treadway Plaza, Exchange Park, Dallas, Texas 75235; phone (214) 352-7222. Organizational memberships (\$50/year) and associate memberships (\$10/year) are available. For additional information about AVIT's activities, contact Dr. Karen Wolffe, Chairperson AVIT, P.O. Box 341, Manchaca, Texas 78652; phone: (512) 707-0525; e-mail: [75254.2250@compuserve.com](mailto:75254.2250@compuserve.com).

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# CLASSIFIED

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Mail or e-mail your new classifieds to Jim Durkel at:  
TSBVI Outreach, 1100 West 45th St., Austin, TX 78756, or [durkel\\_j@tsb1.tsbvi.edu](mailto:durkel_j@tsb1.tsbvi.edu).  
An up-to-date Statewide Staff Development Calendar is posted on TSBVI's website at [www.tsbvi.edu](http://www.tsbvi.edu).

## **Usher Syndrome Family Retreat**

June 11 - 13, 1999  
The Four Points Hotel  
Austin, TX

Parents, brothers, sisters, and especially children who have Usher Syndrome are invited. We hope to bring these families together for learning, sharing, and lots of fun!

William Kimberling, Ph.D., a geneticist with the Usher Syndrome Project at Boys Town, will speak and be available to meet individually with families.

We are offering Texas families stipends to help with the cost of travel. To learn more about this retreat, please contact Connie Miles at (281) 298-6157, or e-mail [cmiles@flex.net](mailto:cmiles@flex.net).

## **"CHARGE Into The New Millennium" The 4th International CHARGE Syndrome Conference**

Sheraton Crown Hotel  
15700 John F. Kennedy Blvd., Houston, TX  
July 23 - 25, 1999

Limited travel stipends are available to all Texas families by contacting:  
Connie Miles at (281) 298-6157  
or e-mail to [cmiles@flex.net](mailto:cmiles@flex.net).

Families outside of Texas should contact:  
CHARGE Syndrome Foundation Inc.,  
2004 Parkade Blvd.  
Columbia, MO 65202-3121  
e-mail [marion@chargesyndrome.org](mailto:marion@chargesyndrome.org)  
phone (800) 442-7604  
or (573) 499-4694

## **Cornelia de Lange Syndrome 20th Annual Conference for Families**

June 24 - 27, 1999  
Doubletree Hotel  
Dallas, Texas

For more information contact:  
CdLS Foundation  
(800) 223-8355

## **Texas Focus**

June 16 - 18, 1999  
Corpus Christi, TX

**Registration deadline is May 10 !!!**

Families needing stipends for travel and child care can contact Jean Robinson at (512) 206-9418, or Kate Moss at (512) 206-9224.

Contact: Jim Durkel, TSBVI (512) 206-9270 or e-mail [durkel\\_j@tsb1.tsbvi.edu](mailto:durkel_j@tsb1.tsbvi.edu)

## **Six Day INSITE Training**

Austin, Texas  
June 7 - 12, 1999

For more information, contact Gigi Newton at (512) 206-9272, or [newton\\_g@tsb1.tsbvi.edu](mailto:newton_g@tsb1.tsbvi.edu)

**American Council of the Blind (ACB)  
National Convention**

Cosponsored by  
**National Association for Parents  
of the Visually Impaired (NAPVI)**

July 3 - 9, 1999

at the Airport Westin Hotel  
5400 W. Century Blvd., Los Angeles, CA

For further information call Barbara Hayes  
in the ACB national office at (202) 467-5081 or  
(800) 424-8666, 2:30 - 5:30 p.m. Eastern time,  
or check out ACB's website at  
<[www.acb.org](http://www.acb.org)>.

**The MAGIC Foundation Conference**

July 22 - 25, 1999

The Marriott Oak Brook Hotel  
Chicago, Illinois

The Magic Foundation is a nonprofit organization  
providing support and education regarding growth  
disorders in children and related adult disorders.

Registration fees for the conference are \$45 per  
family for members, and \$60 for nonmembers.  
For more information about this conference, con-  
tact the MAGIC Foundation at (708) 383-0808, or  
visit their website at:  
<<http://www.magicfoundation.org/default.htm>>.

**Did you know?**

**Applications for Fall 1999 VI training  
are due June 16th!**

The TSBVI website, <[www.tsbvi.edu](http://www.tsbvi.edu)>, has a job  
bank and information about financial aid in the  
"Professional Preparation" section;

For more information, contact KC Dignan.  
phone: (512) 206-9156;  
e-mail: [dignan\\_k@tsb1.tsbvi.edu](mailto:dignan_k@tsb1.tsbvi.edu)

**Summer Institute on Technology**

July 26 - 29, 1999

TSBVI  
Austin, TX

Summer technology training for teachers of the  
visually impaired will be offered on the campus  
of the Texas School for the Blind and Visually  
Impaired, on July, 26 - 29, 1999. The proposed  
schedule can be found at <[http://www.tsbvi.edu/  
EDUCATION/summer.htm](http://www.tsbvi.edu/EDUCATION/summer.htm)>.

On July 26, 10:30 a.m. to 4:00 p.m., a vendor dis-  
play will feature specialized software and hard-  
ware devices for individuals who are blind or vi-  
sually impaired. Admission to the vendor display  
will be \$10.

For registration information, please visit the  
TSBVI website at <[www.tsbvi.edu](http://www.tsbvi.edu)>.

**Mentor Training**

July 22 and 23, 1999

A summer mentor training will be held at a resort  
or conference center in the Austin/San Antonio  
area. If you are an O&M specialist with at least 3  
years of experience or a VI teacher with 4 or more  
years of experience and would like to mentor a  
new VI professional, please contact Ruth Ann  
Marsh at (512) 206-9203, or e-mail  
[marsh\\_ra@tsb1.tsbvi.edu](mailto:marsh_ra@tsb1.tsbvi.edu).

The **TSBVI Website** at <[www.tsbvi.edu](http://www.tsbvi.edu)> is con-  
stantly being updated. Check it out today for new  
information about teaching children with visual  
and multiple impairments, adaptive technology  
resources, registration information for Space  
Camp for Interested Visually Impaired Students,  
and lots more!

# SEE/HEAR

published quarterly: February, May, August, and November

Contributions to the newsletter are always welcome.  
Articles can be mailed or e-mailed to section editors at:

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Austin, TX 78756

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**PROGRAMMING** - Ann Rash (512) 206-9269; rash\_a@tsb1.tsbvi.edu  
**SYNDROMES/CONDITIONS** - Gigi Newton (512) 206-9272; newton\_g@tsb1.tsbvi.edu  
**NEWS & VIEWS** - Jim Durkel (512) 206-9270; durkel\_j@tsb1.tsbvi.edu

**Deadlines for articles are:**  
**December 2nd for the February edition**  
**March 3rd for the May edition**  
**June 3rd for the August edition**  
**September 3rd for the November edition**

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**The audio version of SEE/HEAR is provided by  
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**SEE/HEAR is available in Spanish and English on TSBVI's website at <www.tsbvi.edu>.**

**If you no longer wish to receive this newsletter, please call (512) 206-9314.**

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