

CHARGE Accounts



Winter 2006

A Quarterly Newsletter for Families and Friends

Vol. 16 No. 4

CHARGE Syndrome:
CHARGE has four major features - Coloboma, Choanal atresia, Cranial nerve abnormalities, and Characteristic ears
More information on website

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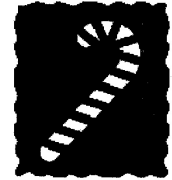
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Santa Claus
North Pole,
HOH OHO



Dear Santa,
Hi, how are you? Are you getting the toys ready? I would really love an Ariel Beauty Salon. I have been good all year.
I love you.

Love,
Kennedy Weir

Kennedy Weir, age 8, St. John, New Brunswick, Canada

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!!! Deadline for the Spring Issue - February 15 !!!
!!! Time to Renew Your Membership !!!

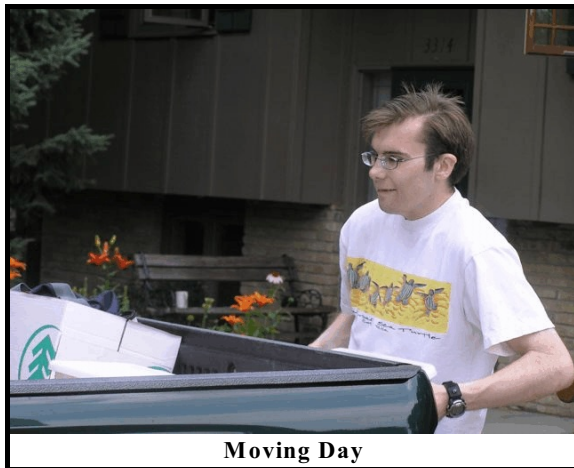
Independence Day: Our Story

by Mike and Sally Prouty

PERSONAL ACCOUNT

Andy was sitting at his computer as we left, absorbed in an internet conversation with his California buddies. He might have been describing his new digs. Maybe he was telling them about the fireworks he was going to see that night. Ironically, this was the 4th of July weekend, our Independence Day Holiday. Andy turned to wave a quick goodbye as we closed his apartment door. He never was much at multi-tasking.

As we drove our pickup home, the full impact of Andy's departure from "the nest" struck. In the weeks leading up to this day, we had been too busy packing boxes, setting up his computer, and buying last minute kitchen items to think much about the enormity of this day – Andy's latest and most significant "transition." But it all hit home on the short 3-mile drive home.



Moving Day

"This is something we've been dreaming about and working toward, for, oh I don't know, only about 25 years," I said. Sally was quiet. Her motherly hormones were raging and I knew she was processing multiple scenarios of what might go wrong – and her response – in the early minutes, hours, and days of Andy's new life outside the protection and security of our home.

"You're right," she said finally. We beamed at each other. A flood of conflicting feelings washed over us: worry, some doubt, guilt (were we abandoning our son?) but mostly happiness and pride for Andy and for us. No tears. This was, after all, a mutual thing. Andy wanted his independence as much as we wanted it for him.

Two significant events in the first year of Andy's life prepared us for this day.

Event 1: Week one

We were stunned young parents stumbling from specialist to specialist, reeling from bad news to more bad news: Your son has CHARGE. Your son is deaf. Your son is blind. Your son will need heart surgery. Your son will need growth hormone and is retarded. The onslaught was having an effect: after one grueling day of visits and bad news we were so physically and emotionally exhausted we crumpled to the floor of the elevator that took us up to our room near the hospital, and we were in such a state that we didn't even think it abnormal. Looking back, we shake our heads in disbelief.

Our first good news came when the Director of a large regional medical institution assured us he would synthesize and "connect the dots" of all the various specialists we had seen: cardiologists, audiologists, ophthalmologists, internal medicine specialists, epidemiologists, physical therapists, ENTs, geneticists, endocrinologists, to name a few. "I'll put a report together for you that will make sense of all this," this grandfatherly, genial administrator assured us. And then he left. That was the last we heard or saw of him. It was a hard but important lesson: *we would be Andy's only advocates*. We got tough. We got organized. We filled notebooks with data, reports, and forms. We got smart and strategic and figured out who we needed to know. We got second opinions. *We became informed advocates*.

Event 2: Two months later

A month or two out of the hospital, and still in shock by the arrival of a baby that had turned our world upside-down, some thoughtful professional suggested we visit a couple with a 27-something child who was deaf and blind, and still living at home, "to get some support." We expected to see a modern-day version of Helen Keller. We met a girl/child who was completely isolated from the world and who engaged in self-stimulation behavior in a corner. We absolutely were not prepared for that glimpse into what might be our possible future. Our depression after this visit turned quickly to determination. Our instincts screamed at us that we had to do *everything* possible – now – to create a different future for ourselves and our little baby boy. That ill-timed visit was in hindsight the best thing that could have happened. It was a rude awakening and it launched us on our journey.

We didn't really have a plan or a vision of what the future would hold. All we had was the conviction to try and set the bar high, to expect a lot from Andy and from ourselves. We practiced on doctors, and we refined our craft (as Sally says, to be respectfully demanding) with educators. We learned as we went. Here, in brief, is our story.

First: an important disclaimer

No two kids are alike. We set out intent on finding a class of "little Andys," and our plan was to move to wherever we found this place. Because Andy is profoundly deaf, we needed him to be among signing peers and signing adults. We learned very quickly no such classroom of Andys existed. Different levels of vision and hearing loss, different degrees of other conditions, to name only a few factors, makes each

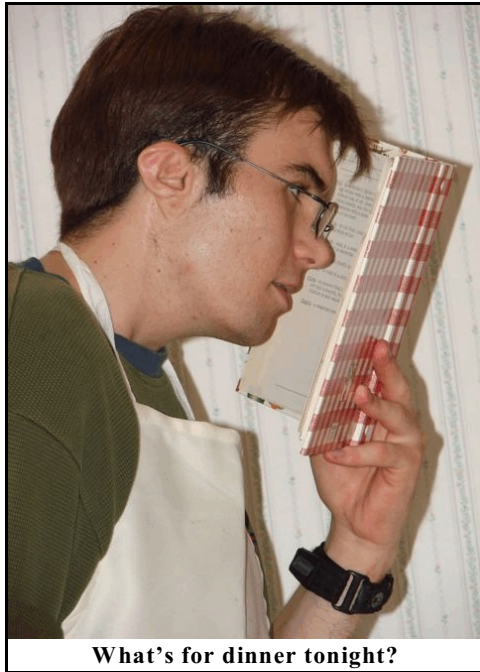
kid's and family's journey unique. *Everyone's story is different.*

Common Denominators

Are there some aspects of our experience that might have more universal application? Yes. First: make a plan, and then be flexible. Plan early and check it often. Bottom line: plan. We never wrote it down, but that's probably a good idea. Our goal was independence for Andy, and we tried to keep our eyes on that prize as we went on our way, knowing it might never happen. We admitted that this was in part a selfish goal, as much for us as it was for Andy. That's okay.

Second "rule:" set the bar high

We expected a lot from Andy. We tried to treat him like a normal little kid. His brother and sister went water skiing and snow-skiing so why not Andy? After Andy took out several tables at the bottom of the bunny hill, scattering skiers, drinks, and chips; we all decided maybe downhill skiing wasn't his thing. But water skiing was another matter. Andy was the talk of the lake as he perfected his 360-degree turns on the kneeboard. He skied on normal skis, but the kneeboard was his trick of choice.



Discipline

We expected a lot from Andy at home and in school. At home, Andy followed our rules like our other two kids. He learned his boundaries, and when he stepped over the line he learned the consequences of bad behavior. We didn't let his disabilities become an excuse for lack of discipline. He learned to respect. He learned "worthy home membership" as my father called it, meaning kids help around the house: cleaning the kitchen, taking trash out, and other duties as assigned. Work and rules came with the turf. After all, the world is full of rules and if he was given a pass at home, how could he cope when he was on his own?

At school, one of our major goals was to have Andy master the English language to the point where his vision and hearing loss would be invisible if he were to communicate with the hearing world on a computer. We struggled with

some teachers who wanted to lower the bar and accept "deaf English" as a culturally acceptable and sensitive thing. But our compass – how would this play out in the hearing world? – told us to expect more.

We also knew teachers – whether they liked it or not – were a key part of our team. We worked to avoid being abrasive, rude, and "in-their-face," knowing that we might win a battle or two, but ultimately they had our kid in their class, and we always worried about having their attitude toward us rub off on how they treated Andy. So we cajoled, we informed, we played "good cop/bad cop" we got involved, we tried our best at being respectfully demanding. We knew like most things in life, relationships matter. So we fostered relationships when we could. We supported teachers, administrators, and schools when we could, and we in turn were supported by them. With his teachers' help and encouragement, Andy came to lead his own IEP meetings. Again, making him responsible, making him feel in control, gave him courage and self assurance so necessary in an independent lifestyle.

Act with the end game in mind

Perhaps more than anything, the vision of Andy living alone served as our compass and guided our behavior toward him. What skills would he need to live in an apartment? Paying his bills, washing his clothes, making his own food, figuring out transportation, making his own decisions and choices, being his own advocate. We knew Andy would need these key skills, and more, to live on his own. So we took every opportunity to develop them, even when he was a pre-teen. Did we think about, on a daily basis, him living in an apartment while he was 12 years old? Not explicitly, but the goal was there on the outer ring of our awareness. It was an unconscious, ever present guide. We put up with the added mess and time requirements with our guide in mind. And we grew in the process as well.

Shopping

Examples of putting this philosophy into practices are as many as there are tasks in a day. We took Andy grocery shopping with us, and allowed several hours to do so. We asked Andrew to cruise the aisles of the grocery store, reading the signs, to find the items on our food list; and once he found the peanut butter, for example, we expected him to decide between brands. We'd ask him why he chose one over the other, and point out cost comparisons when possible. In the process, we learned how difficult shopping is for a person with low vision! When we learned of on-line grocery shopping we knew Andy had found a valuable thing. Later, after he obtained a job but still lived at home, Andy was responsible for paying his "share" of living expenses by handling a significant portion of the grocery shopping, via on-line. He made the choices, he kept the list, and he paid the bills. Now that he's on his own, he shops at the local grocery store to save money. The hours spent years ago wandering in grocery stores is paying dividends now.

We let him cook. We never quite achieved our goal of him cooking a meal a week, but he became comfortable in the kitchen and we became comfortable with spilled flour and other collateral damage from a blind kid running blenders and mixing ingredients. The mess and broken bowls paid off: Andy came to enjoy cooking, even entertained the idea of becoming a trained cook. He found his niche with desserts (chocolate chip cookies and brownies) but could also make a mean fried egg and a helluva of a bologna sandwich. Somewhere along the line he also became the most fastidious kitchen cleaner in the house. When Andy was through cleaning the kitchen, it was spotless. But to get to this point required patience and flexibility. It required we let Andy experiment, make messes, and fail often.

Eating Out

This same attitude of “letting Andy do it” (because he’d have to someday) carried over to eating out. We let him choose from the menu and order his meal. If it was a fast-food restaurant, he learned to ask for a printed menu as a way to cope with the impossibility of reading off the sign behind the counter. We let him figure out how much tip to leave when eating at “sit-down” establishments. All this slowed everything down. Not a bad thing for everyone actually.

Travel

We knew early on Andy would never drive. So as early as preschool we worked with Orientation and Mobility specialists to begin to help him navigate in his environment and ultimately to help him become a savvy mass transit commuter. Throughout high school and post high-school programs, Andy worked with excellent O&M specialists and as a result of this work; he takes the bus regularly to and from work and the college campus where he attends night classes.

Community

We sadly realized that while we could help Andy in many ways, by both advocating and teaching him to advocate for himself, we could not with a wave of our hands create friends or community for him. To us, having a community was an important ingredient to a fulfilling and independent life. While we couldn’t “create a friend,” we could look for community. With that in mind, we seized on Andy’s interest and skill in pottery, demonstrated in high school. We signed up for classes at a local non-profit pottery organization, “Northern Clay Center” where Andy could enjoy a sense of community. We recognized church was another place for community, so we attended a church for the deaf for 10 years. As Andy’s networks grew, opportunity followed. He worked at a YMCA deaf day camp. He was asked to help teach pottery to deaf elementary school students.

Finances

We worked toward making Andy fiscally responsible. Like everything else, it was a slow process. First came a state ID card (in place of a driver’s license). Then we opened a checking account and Sally spent hours teaching Andy how to balance his account. (I still can’t balance a checkbook.) Finally, Andy applied for a credit card, and with that came the responsibility of paying his bill on time. Grocery shopping became an on-line exercise, with a monthly bill. His monthly phone bills for his “Blackberry” PDA had to get paid. We stressed the importance of paying bills on time. In short, like most people, Andy’s life became more complicated – a good thing, we thought. But we worked to introduce these changes in a controlled and slower way that was manageable for him. Throughout the process Andy figured out this was all necessary if he was going to live on his own.

Medical

Andy’s biggest challenge is and will continue to be becoming an informed advocate for himself in the area of medical care. He still doesn’t quite understand all the nuances of his medically complex condition, or the ins and outs of negotiating the medical world. But we started with little steps. We ask him to call to set up medical appointments and request interpreters. Andy uses the CHARGE notebook form to prepare for doctors’ appointments by writing down his questions or concerns and then using this same form to capture doctors’ comments and test results. This same notebook contains background information on Andy’s various conditions. We still have a way to go, but we’re making progress.



Andy Settles into his New Home

Through all of this, did we ever lapse? Of course! We failed early and often and sometimes for days and months at a time. We became impatient, tired, angry, and frustrated. We took the easy way out and did things for Andy when we should have let him struggle. But we always tried to get back on the path, and we never beat each other up when we would stray. Life is messy. Life is not black and white but rather, a symphony of gray. We learned to set the bar high, but to compromise, be flexible, and be realistic. We learned to lean on each other and play to each other’s strengths to cover our individual weaknesses. We learned to step in when the other was at

his/her wits end. We learned incredible respect for single parents!

We also benefitted from an incredible array of gifted and committed teachers, interpreters, interveners, specialists and special programs. We needed all the help we could get. Andy could not have achieved independence without them. We often told them they were part of the team, and yet we can't overstate their importance. Fortunately for Andy, we have lived in places where these resources exist, and we were able to make the fullest use of the talents of the people involved.

Andy still has a lot to learn! We're not sure he's eating the healthiest of meals. He still calls us with absurdly mundane questions: such as "how much water should I add to the frozen spinach?" He still needs to find a stronger knit community and a more robust social life. He gets overwhelmed by medical appointments and information. He struggles figuring out how to advance in his job and what courses to take.

To celebrate our 30th anniversary, we recently spent 3 weeks in Italy. At 3 AM, fast asleep in our villa in Tuscany, we were wakened by a text message from Andy. Sally jumped out of bed fearing the worse. "Where's the spaghetti sauce?" was the question. Andy hasn't figured out time zones either.

Note: Other articles of Andy's experiences growing up with CHARGE have been printed in previous issues of CHARGE Accounts. One of those articles was in the Fall 2005 issue and can be found in the archives on our web site (www.chargesyndrome.org). We thank Mike and Sally for sharing Andy's story with us and wish Andy continued success with his "independence."

On a Saturday morning just before "the move" Andy and I were eating breakfast in a restaurant prior to pottery class. I asked him if he was worried about the move. "Yes," he replied. "About what?" I asked. He ticked off three questions in rapid fire: "Who will fix my Blackberry if it breaks?" "Who will cut my hair?" "Who will help me with doctor appointments?"

I smiled at these questions. They were so ordinary, so natural, and for the most part, so easy. "Okay," I replied, "There are many people around to help with the Blackberry if it breaks. Your mom can continue to cut your hair, if you're nice to her, and we will continue to work with you on the medical stuff." That seemed to satisfy Andy.

We had a thornier discussion recently. "I'll never find a girl friend," Andy said. "Hmmm, well you've got to get out more to meet people before you can find a girl-friend," I replied. "I've got to find someone who can sign, a deaf girl," Andy said. "OK, let's make a plan," I said. The adventure continues.



*Thank You to Everyone for Your Generous Support of the
CHARGE Syndrome Foundation*

Especially to the . . .

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The Callanan Group Unlimited TX
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The Erika Josephson Foundation NY
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PRESIDENT'S NOTE

Neal Stanger

Hello everyone,

I can't believe that another year has come and gone. From my family to yours, I wish everybody a happy and a healthy new year. As I reflect back on the previous year with the Foundation, I realize that we had the following innovative and new changes:

- Our website (www.chargeyndrome.org) was updated early in the year. It is now quite user friendly. Back issues of *CHARGE Accounts* are now online for everyone to access.

- Later in the year, "CHARGE Syndrome, a Management Manual for Parents" was uploaded onto the website. It is in pdf format, and anyone (families and professionals) can download individual sections or the entire manual at absolutely no charge.

- We have come out with an exciting new fundraiser that you can easily host in your own home with proceeds going towards the Foundation. For more information on this, please email me (neal@chargesyndrome.org) or the Fundraising chair, Dennis O'Toole (dennis@chargesyndrome.org).

- We have made arrangements to move the administrative headquarters of the CHARGE Syndrome Foundation to an office on the campus of the Helen Keller National Center (HKNC) in Sands Point, New York. In the near future, we hope to hire an Administrative Director to run the day-to-day business of the Foundation out of the new office. Marion Norbury (our current Executive Director) will continue to devote her time to working directly with families from her home office in Columbia, Missouri.

In the year ahead the major tasks will be to add even more publications to our website and host the 8th International CHARGE Syndrome Conference in Orange County, California in July. Marilyn Ogan (marilyn@chargesyndrome.org) and Jim Thelin (jim@chargesyndrome.org) are busy making sure this will be the best and most informative conference yet and I personally hope to see all of you there. If there is anything you need or anything you would like to see happen within the Foundation, please feel free to call or email me and once again, HAPPY NEW YEAR!!



CALENDAR 2007

January	Time to renew your membership for 2007
February 1	Deadline for Scholarship Applications for 2007 Costa Mesa Conference
February 15	Deadline for Articles in the SPRING Issue of CHARGE Accounts
February/March	Conference Registration Forms in the mail
March 15	SPRING Issue of CHARGE Accounts in the mail
July 27 - 29	8th International CHARGE Syndrome Conference, Hilton Orange County/Costa Mesa in Costa Mesa, California. More details: in future issues of CHARGE Accounts
September 25-30	Deafblind International Fourteenth World Conference, Burswood International Resort Convention Centre, Perth, Western Australia. More details: www.dbiconference2007.asn.au/



FOUNDATION ACCOUNT

COMMITTEES

For a description of what each committee is responsible for, please go to www.chargesyndrome.org or contact the chairperson or the Foundation Office.

Conference Committee
Chairperson: Marilyn Ogan

Fundraising Committee
Chairperson: Dennis O'Toole

Medical/Research Committee
Chairperson: Meg Hefner

Family Services Committee
Chairperson: Marion Norbury

Adult Services Committee
Chairperson: Bonnie Haggerty

Education Committee
Chairperson: Susy Morales

Collaboration Committee
Chairperson: Neal Stanger

Public Awareness Committee
Chairperson: John Wynne

All board members have a special email address: [\(firstname@chargesyndrome.org\)](mailto:(firstname@chargesyndrome.org))

The CHARGE Accounts newsletter is intended for general information only. Medical or treatment information and/or opinions are not necessarily endorsed nor recommended by CHARGE Syndrome Foundation, Inc. or its officers. Readers are reminded that the best source of medical advice is always their physician.

EXECUTIVE DIRECTOR'S NOTE

Marion Norbury

FOUNDATION ACCOUNT

Time to Renew Your Membership

It is time again to renew your membership in the Foundation. All membership terms are on a calendar year - due in January and running out the following December. Check your mailing label or your membership card. If it says 2006, your 2007 membership fee is now due. You may use the membership form that is included with this newsletter. A self-addressed envelope is enclosed for your use. Please renew early. Remember to make note of any changes in your address, phone numbers, or email. If this was your first year as a member, you were credited for the year 2006. So whether you joined in January 2006 or July 2006, you need to renew now for 2007. **Membership renewals are due by March 1 to receive the Spring Issue of CHARGE Accounts.**

Fundraising Drive

A letter announcing our Annual Fundraising Drive was mailed in early December. We hope you will consider making a contribution and will share the sample letter that was enclosed with your family and friends.

Have you considered using the "Fundraising in A Box" that we have available now?. All the materials you need to do this activity are in the box. For more information, contact Dennis O'Toole, Fundraising Chair at dennis@chargesyndrome.org or Neal Stanger at neal@chargesyndrome.org.

Lee E. Norbury Memorial Scholarship Application Deadline February 1, 2007

The Lee E. Norbury Scholarships is intended to support individuals with CHARGE and/or their families attend their first conference. The deadline for the scholarship application is February 1, 2007. The application was mailed out with the Fall issue of CHARGE Accounts. If you have any questions or need more information, please contact me at 800-442-7604 or marion@chargesyndrome.org.

2007 Conference Information

The Registration Form for the 8th International CHARGE Syndrome Conference in Costa Mesa, California, July 27-29, 2007 will be mailed to all members in the Spring. Our Target Date is late February for mailing.

General information about the conference to help you plan your trip is included with this issue of Accounts. It is available now on our web site. We look forward to meeting many of you in Costa Mesa, California in July 2007.

Board of Directors Elections Coming Soon -

It is time to ask for applicants for the Foundation Board of Directors. The board has 12 members each serving a four year term. Six members to serve four year terms (2007-2011) will be elected in the Spring of 2007 (current members are eligible to be re-elected).

If you are interested in serving on the Foundation Board of Directors, please write or call the Foundation office for an application. All applications must be returned by March 1, 2007. A ballot will be included in the Spring issue of CHARGE Accounts and the results will be announced in the Summer issue.

What does it mean to serve on the Board of Directors? This is a working board. Every member has a responsibility for some facet of the Foundation's program.

- Each Board member is the chair or member of a committee (see p. 6). Some committees are very busy, others have a more limited role.

- The Board usually has a face to face meeting once a year.

- Conference calls are scheduled when the Board needs to speak together on issues (may do this 1-2 times a year)

- Email is used regularly to keep in touch and to provide for efficient discussion of issues

If you have questions, please contact Neal Stanger at neal@chargesyndrome.org or 914-793-8330 or Marion Norbury at marion@chargesyndrome.org or 800-442-7604.

Other News

In the Fall Issue I mentioned the **Texas Retreat** that Cathy Springer had organized. They met on October 7 with 21 families present and had such a good time, they are planning to repeat it next year. Congratulations, Cathy, and thank you for all your work planning a great event.

The **ASHA Leader**, published by the American Speech-Language-Hearing Association, has several articles on CHARGE syndrome in their October 17, 2006 issue. We have a limited supply of copies available for \$5.00 each (includes postage). It is listed on the order form enclosed with this issue of Accounts.

Help with Grant Writing - Ruth Schwartz (whose grandson, Danny, has CHARGE) has volunteered to assist with some grant writing for the Foundation and the conference. If anyone works for a large corporation, they can speak to the corporation's foundation representative to find out if a grant of \$1,000 or more is a good possibility. (Some grants are limited to "local" uses only; some have stipulations about what types of materials or events they will fund; etc.) If it is a feasible grant, they can call Ruth at 805-642-5583 and mail her the grant application. This will be time consuming, so please respond only if there is a real possibility of obtaining funds. Often individuals don't feel they know how to apply for the funding/grant. Ruth has done a large number of grant proposals, so knows how to get them filled out and submitted appropriately. Thank you, Ruth for volunteering!

For many years, the CHARGE Syndrome Foundation operated independently of other organizations and during that period developed its own character and goals. More recently, the Foundation has made specific efforts to interact with organizations that have similar objectives and can assist us in serving the needs of our families. As a result, we have established formal communications with the National Technical Assistance Consortium for Children and Youth with Deaf-Blindness (NTAC) and with the National Family Association for Deaf-Blind (NFADB). The Foundation has also joined a coalition of organizations who are advocating an increase in the federal funding for deaf-blind programs. Deafblind program funding has not been granted increases in well over a decade.

Foundation Office Move

In the last issue of CHARGE Accounts, Neal Stanger announced the upcoming move of the CHARGE Syndrome Foundation office to the campus of Helen Keller National Center in Sands Point, New York. Although the Foundation will remain completely independent of HKNC, we hope that the proximity to HKNC and the offices of NFADB will facilitate additional cooperation among the organizations in the future

NTAC becomes NCDB

NTAC has recently undergone a major reorganization. Many of you know of DB-LINK, the information services and dissemination division of NTAC. Both are funded through the US Department of Education. They are run by the Teaching Research Institute at Western Oregon University. The new organization is called the National Consortium on Deaf-Blindness (NCDB), and combines the resources and expertise of three organizations: the Teaching Research Institute at Western Oregon University (NTAC and DB-LINK), the Helen Keller National Center, and the Hilton/Perkins Program (Deafblind program) at Perkins School for the Blind. You can view the website at <http://www.ncdbtad.org/>

Nancy Steele is the NCDB Technical Assistance Coordinator for the southeast region of the United States. I am very pleased to announce that her office is now located near my office in the Department of Audiology and Speech Pathology at the University of Tennessee.

Cochlear Implant Grant

The Cochlear Implant grant was funded to determine the degree to which cochlear implantation affects positive communication, language, and speech outcomes in children with deaf-blindness. The study is seeking participants who are under 13 years of age who have cochlear implants or who are planning to be implanted. The following states are participating in this study: CA, FL, IL, IN, KS, KY, MA, MD, MN, MO, NY, NJ, OH, OR, PA, and TX. If you live in one of these states and you would like to have your child participate in this study, please contact your state deaf-blind project or Ella Taylor at taylor@wou.edu.

Advisory Boards of NCDB and Cochlear Implants for Children who are Deaf-Blind

I was very pleased to be invited to serve on the advisory boards for NCDB and for the study on Cochlear Implants for Children who are Deaf-Blind. Meetings were held in Portland, Oregon in early November to discuss plans and objectives for both groups. NCDB provides technical assistance to deaf-blind projects in every state and some territories. In brief, NCDB is pursuing an ambitious plan to expand the scope and monitor the quality of services offered nationally – and this includes children with CHARGE who now represent the largest group with genetically-caused congenital deaf-blindness.

A Comment on Deaf-Blindness and CHARGE

In the process of interacting with organizations that serve the deaf-blind, parents often remark, “My child has some hearing and vision impairment, but is not deaf-blind.” The term “deaf-blind” is perhaps an unfortunate one because the majority of the individuals classified as deafblind have some hearing and/or some vision. Although the dual sensory impairments are not totally disabling, they affect the lives of the individuals in terms of their ability to communicate, learn, and socialize in ways that are unique. The needs of individuals who are deafblind cannot be adequately met by experts in low vision or hard of hearing: they need services by experts in deafblindness. It is my observation that the specialists in deafblindness are the educators who have the best ability to understand the challenges faced by children with CHARGE syndrome.

Time to Renew Your Membership for 2007