

Ashlin...

The birth of a new baby is an exciting time for a family. Ashlin was beautiful with blond hair and a smile so big it melted your heart.

For the Heng family, from Barnesville, the first several months were so exciting and filled with all the normal baby stuff. After several months, Tracy and Dave, Ashlin's parents, began to notice that Ashlin didn't seem to be experiencing normal baby milestones in the sequence or time frames one would expect. Ashlin is their second child, so things like rolling over, sitting up, crawling, standing and walking seemed delayed. They tried not to panic and told themselves some baby's progress slower than others... she'll get it. Ashlin had mastered eating with a utensil, waving "bye-bye" and saying words such as, "hi," "ba," for Barney, and "ju," for juice. Then Tracy and Dave noticed that Ashlin seemed to lose these skills overnight. One day she could do these things and the next day she didn't know how to do it. After a while, they began to think something might be terribly wrong.



*Ashlin, when she was
5 years old.*

They decided to pursue medical help. Initially, Ashlin was diagnosed with Autism. As most of us can only imagine, the point at which parents are given the news that their child has a disability can be frightening, uncharted territory. Imagine the shock of finding out your child who seemed perfect in every way has been diagnosed with a life-altering disability. For many, this can be a time of grieving and loss as the reality of all those parental dreams start to be second guessed. Naturally, it is the fear of the unknown.

Tracy and Dave quickly tried to learn everything they could about Autism. At 15 months-old, Ashlin started occupational, physical and speech therapy at MeritCare. After working with her occupational therapist one on one for some time, the therapist began to second guess the diagnosis of Autism and referred Ashlin to Dr. Welle, who immediately started testing for Rett Syndrome. Right before her fourth birthday, the Heng family got confirmation that Ashlin had Rett Syndrome. Once again, the emotional roller coaster began and Tracy and Dave had to start learning about this new diagnosis and what the future might be like for their daughter.

Tracy explained that Rett Syndrome is a chromosomal abnormality of the X chromosome that affects a person's neurological system. Because males only have one X chromosome and it only affects the X chromosome there are very few live male births. Females have two X chromosomes so they are more likely to live. It is rarely detected at birth and often misdiagnosed initially, because females

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have one affected X chromosome that can compensate for the other. Common misdiagnoses are Autism and Cerebral Palsy. At birth and potentially for the first few years everything seems fairly normal. A common diagnosis period is 18 months. Children with Rett Syndrome typically have lots of medical issues and can learn new skills and then, for no apparent reason, lose the skill quickly. Hence, constant repetition is essential for them to learn and maintain what they've learned.

Ashlin was only four years-old when she started receiving services from CCRI. Tracy said, "Within nine to twelve months, Ashlin went from only being able to sit at the table for five minutes to sitting for thirty to sixty minutes at a time and focusing on a project. This was a major improvement." The ability to focus for longer periods of time, made it possible for her to learn many new things.

As Ashlin got older, she started to exhibit behaviors such as hitting, biting, screaming, pulling hair and scratching. It was clear that these behaviors were due to frustration from her inability to communicate. According to Rachelle Staton her Residential Coordinator at CCRI, "She knew what she wanted, but couldn't communicate it verbally, so it was a guessing game that brought about much frustration for Ashlin." Rachelle said the frequency and intensity of these behaviors became so severe that Ashlin's team agreed to put her on an intense behavior modification program. The complexity of her care was further compounded by a seizure disorder that started at the age of seven. At first her seizures were very minor. However, as she has gotten older they have progressed to Grand Mal seizures that are very frightening to observe. CCRI team members receive extensive training about her seizure disorder, including how to keep her safe, and care for her during and after a seizure. Yet, the seizures can still be very intimidating.

"Ashlin just grabs your heart with her beautiful eyes and contagious smile and you want to do everything you can to make a difference in her life."

- Rachelle Staton, CCRI Residential Coordinator

Tracy knew her daughter was capable of telling people what she wanted or needed if they could just find a way for her to communicate. They started with a simple system in which Ashlin would point to a picture that indicated what she wanted. It provided Ashlin with the ability to communicate, but it was almost a full time job managing and organizing the pictures. You had to have pictures to communicate emotions, leisure activities, friends, family, food, places, etc. While it was an improvement, it didn't promote the independence they had envisioned because it was difficult to manage.

Tracy knew there had to be something easier. The Barnesville school that Ashlin attended started exploring various types of technology that might be available to help her communicate. They started with a small device that held eight pictures and allowed her to pick a picture of what she wanted and the device spoke for her. It too was limited in its capacity, but paved the way for another device, the V-Max.

Ashlin has been using the V-Max for 14 months. It is a computer that talks for her. Initially, Ashlin's progress was slow, but she is really advancing forward now. The school has worked with the family and CCRI professional caregivers to provide extensive training on how to use the device and how to teach Ashlin to use it. The V-Max has changed the Heng's life. With Ashlin's new found

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communication skills, her behaviors have subsided and the behavior program she was on for the past two and a half years has been discontinued. Consequently, the V-Max has brought about tremendous new found independence.

Tracy talked extensively with heartfelt appreciation about CCRI and our caregivers. "Dave and I wouldn't both be able to work if we didn't have CCRI services and the quality of our family life would be very different. Ashlin is doing so much more than we could ever have helped her achieve on our own. The independence Ashlin has worked so hard to achieve has only been possible because of a "complete partnership" between home, school and CCRI all working together on the same goals over and over. This is the key to her success."

Because regression of skills is a characteristic of Rett Syndrome it takes a tremendous amount of repetition to teach Ashlin a new skill. One person would not have the time, nor in all reality, the patience required to teach her. Not to mention, as a family of five there are two other children that also need their parents love and attention. Thus, without assistance, some might say it would just be easier to do things for Ashlin rather than teach her to do them herself due to time constraints. Because of the partnerships in Ashlin's life, she is communicating, feeding herself, experiencing the community and learning new things every day. Her CCRI caregivers are there for her and to support her family.

Ashlin's future looks bright because of the many successful partnerships that have been built. Although this is the Heng's story, it is very similar to other families who have a child with a disability. Most of us take for granted that our children will progress as we expect. So we don't think about the added complexity a child with a disability adds to the family dynamics and responsibilities. This is why receiving services, such as CCRI provides, can really be a saving grace for families. Life for Dave and Tracy and other parent's of children with disabilities would look very different without this type of support.

The V-Max device costs about \$9500 and other adaptive items to help people communicate are expensive to purchase. Your donation to CCRI's service enhancement fund can help off-set some of the costs associated with purchasing various types of adaptive equipment or communication devices that can make a difference in the quality of life for a person with a disability.

~ Story by Rhonda King, Executive Director



Ashlin, now 11 years old, with her V-Max communication device, pictured with Alaina, one of her dedicated CCRI caregivers.

Now, more than ever, we need to band together to ensure that legislators and policy makers understand the necessity of these services and what they mean to families, our neighbors, just like the Heng's. If your services change as a result of funding cuts, make sure your voice is heard and contact your legislators. In 2010, it looks as if additional funding shortfalls could be a reality. Grassroots advocacy from families and caregivers will be our only chance to prevail against further cuts.

Volunteers Needed

Due to funding cuts from the 2009 legislative session, we've had to cut back in many ways. We are hoping to find volunteers to help with some of the following tasks.

CCRI has some great opportunities for you.

- a variety of clerical duties, filing
- photo copying
- help with the mail projects
- gardening and/or trimming bushes, weeding flower beds

We are looking for individuals who would be available to volunteer on an ongoing basis, approximately 4 - 6 hours per month.

We will provide all of the training needed for you to be successful.

Please contact Rhonda King
at 218-331-2002
for more information.

Employment at CCRI Can Impact Lives in Significant Ways

We were very touched to learn how much employment at CCRI meant to Jessica Rick, a former caregiver. We received a memorial along with a letter from her mother, stating that her daughter, Jessica, had died unexpectedly, in May from cardiac arrest, possibly due to a seizure.

Jessica worked at CCRI from 1999-2001 part time while working on her master's degree in School Psychology. Even though several years had passed and she had moved to another community, her mother said she still fondly remembered the people she met while working at CCRI.

Jessica told her mother about taking Bob to softball and his excitement when he won a trophy that year and attending Camp H.E.R.O. She said no matter how difficult a day she may have had, Bob always made her smile. Jessica's mother expressed her gratitude to CCRI, for being such an important part of Jessica's life.

Our deepest sympathy for the Rick family.

CCRI Receives \$75,000 Grant from Bremer

Earlier in the year, Jody Hudson, Development Director, applied for a grant through The Bremer Foundation that we hoped would preserve services for people receiving PCA (Personal Care Assistance) and ARMHS (Adult Rehabilitative Mental Health Services) at CCRI.

This two year grant from Bremer will allow us to continue providing these much needed services to the 80+ people who dearly need them.

Thank You, Bremer!

Softball...a Summer Tradition

Softball is one of the many unique programs offered by CCRI, and is open to anyone with disabilities in the Fargo-Moorhead area each summer.

If you want to make your day, attend and watch the fun and enthusiasm participants bring to the game. Please come and watch and cheer on the teams. The games begin at 6:30 each Sunday evening beginning June 14 - August 9th! *Note: no games on July 5th.*

The games are played at Centennial Field in north Moorhead on Hwy 75.

This year, there will be 8 teams. We'd like to thank our sponsors for their generosity to help cover the costs of uniforms and an awards banquet at the end of the season.

Our focus is on the value of the age-old adage: It's not whether we win or lose, it's how we played the game.



THANK YOU SPONSORS!



RICHARDS



TESORO



Angela Breckel Wins National Award

CCRI's ANGELA BRECKEL NAMED ANCOR
2009 MINNESOTA PROFESSIONAL CAREGIVER OF THE YEAR



Angela Breckel of CCRI, Inc. garnered the top honor for the state of Minnesota in the American Network of Community Options and Resources (ANCOR) 2009 Professional Caregiver Recognition Awards Program. She was nominated by Natalie Pieper, Jenn Nelson and Debby Moszer from CCRI, Inc. for her outstanding efforts.

Angela Breckel was chosen as Minnesota's top Professional Caregiver. Energy, enthusiasm and laughter are qualities Angela shares with everyone she meets. She has used these qualities to influence the lives of many people she has worked with in this field. Angela is not one to shy away from adventure. Whether its coaching an adaptive softball team, coordinating acts for a talent show, planning an accessible trip across the country, or her many other activities, Angela has influenced the lives of those she serves.

"We are extremely proud of Angela. Her hard work and devotion to improving the lives and well being of others in our community is inspiring and humbling. I am proud to have Angela as part of the CCRI team." said Rhonda King, Executive Director.

Angela is the second CCRI employee to be honored with this award. In 2007, Duane Hickel was also honored at the national level by ANCOR.

CCRI Honors Dedicated Caregivers

Twelve professional caregivers were recognized for their outstanding contributions, creative, innovative proactive approaches in providing care and their successful results at CCRI, Inc. over the past year. *Pictured, back row, left to right; Wayne Zitzow, Grace Lopez, Teneil Hoepfner, Tara Selzler, Diana Weil, Amier Hamed; Front row, left to right, Janet Nordby, Corrine Lidenberg, Andrew Hilliker, Angela Breckel, Jenny Thompson, and Debra Schillinger.*



*We commend you for doing more, doing it better
and always exceeding our expectations.*

Camp H.E.R.O.

Another successful year of camp has come and gone. Over 50 campers and 30 staff members visited Lake George for a few days of fun. This year the weather cooperated. While it wasn't too hot, it wasn't too cold...and *most importantly* it didn't rain.

Many activities and choices were offered to campers. Some of the craft activities included making faux fossils, camp journals, necklaces, making a mask for the masquerade ball / dance, and tie-dyeing a t-shirt.

For those who didn't like crafts, the waterfront was one of the favorite areas to hang out. Some of the waterfront activities included pontoon rides/tours around Lake George, paddle boats, and canoeing. A few brave individuals used the swimming area and naturally reported to those not in the water that it wasn't cold at all. Needless to say, they struggled to convince their friends to get in the lake. A few fish were also caught, mostly small fish but no one seemed to mind.

Two groups took day trips to Itasca State Park to visit the Headwaters of the Mississippi. Most enjoyed the short hike and a few individuals crossed the rocks of the Headwaters.

Almost all of the campers participated in the Masquerade Ball and danced to their favorite songs.

Others enjoyed spending time around the campfire roasting marshmallows. Dan Nelson brought his acoustic guitar and got everyone involved in a campfire sing-along before the night ended.

Gregg, at the masquerade ball. He is an avid dancer and refers to dancing as "Burning up his shoes!"



A huge thank you to the CCRI team, Camp Courage team, the campers and for all of our generous donors and sponsors for making Camp H.E.R.O. 2009 a success!

Memorials

In memory of

LaVon Olson

Yvonne Norgren
Sue Severson

Heather Kazemba

Kathrine Grover
Michael & Paula Keeping
B. Lynn Bennett
Jane Duncan
Ronald & Lynnette Dotseth

Liz Utke

Jennifer & Phil Behrens

Erma Fredrickson

Jack & Kelly Borgen

Jessica Rick

Valerie & Charles Rick

While every effort is made to ensure the accuracy of donor records, errors occasionally occur. If your name has been omitted, or misspelled, please accept our apologies and contact Jody at 218-331-2024.



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The mission of CCRI is to enhance and enrich the lives and learning of people with disabilities.

The vision of CCRI is to provide an environment where people of all abilities may experience life's possibilities.

CCRI LEADERSHIP TEAM

CCRI Board of Directors

Jim Danielson - *President*
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CCRI Sr. Leadership

Rhonda King, Executive Director	20 Years
Lynette Weber, Options Director	17 Years
Shannon Bock, Director of Programs	14 Years
Sue Lopez, SLS Director	12 Years
Carolyn Cossette, Medical Services	11 Years
Jody Hudson, Development Director	10 years
Mark McGuigan, Business Manager	8 years
Carmel Froemke, ARMHS Director	6 years
Andrea Ryan, HR Director	3 years

Save the Date

CCRI's Annual
 Walk & Roll-a-thon Fundraiser & Picnic
 Saturday, September 12th
 beginning at 10:30 a.m. at Moorhead's
 Gooseberry Park Large Shelter.

The Walk & Roll-a-thon begins in Gooseberry Park and follows the walking paths in the park and surrounding streets. It'll be a shorter walk than in previous years. Afterwards, we'll enjoy a CCRI picnic and listen to the fun music of the Groove Tones!

All walk participants that raise over \$300 in donations will be eligible to be entered into a random drawing for two free round trip airline tickets for travel to any destination within the U.S. (a \$1000 value!)

Donation pledge forms are available
 at www.creativecare.org

It'll be a fun event, we hope to see you there!