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## ian linn, 10

By Dawn Ang

**Teacher, Author, Humorist, Wii Master, Future Scientist, Poker Player, Deadpan Comedian**

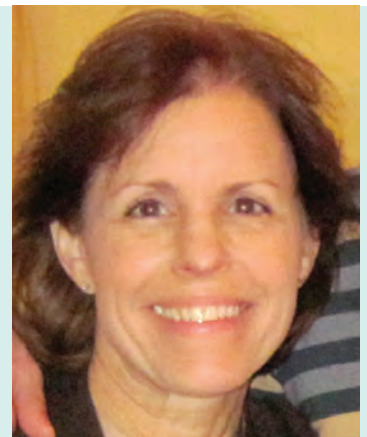
Everything happens for a reason, so I've come to believe.

Never in my wildest dreams could I have imagined as I share my 10-year story with you, that I would be a mother of two beautiful children, have a loving and devoted husband, and have left my beloved journalism profession. More important, that I would have learned so much about Moebius syndrome, a syndrome so rare there are only an estimated 1,000 documented cases in the country.

My son **Ian Linn**, who was born with Moebius syndrome, has led me on this tremendous educational journey.

Not enough is known about Moebius, which manifests itself primarily in facial paralysis. Many individuals with Moebius have additional challenges. Ian also has Poland syndrome.

see **ian**, page 10



## message from the development director

April 1, 2012, will mark my 10th anniversary as Development Director for CCA! Wow!

I came in thinking it would be easier than it was; I thought I would be able to bring in the funds we needed, no problem. But, it really is more difficult than it looks. No excuses, just fact.

Then the families entered my fundraising arena. The first "big" call from a family affected by a craniofacial condition wanting to help was from **Dede Dankelson**. She and her husband **Darin** wanted to hold a golf tournament to benefit CCA.

see **development director**, page 7



**m**iss **Brisa Dougan** is a first grader from north Texas whose favorite subject is recess. You'll find her at the playground swinging, hanging from monkey bars, scaling ladders and whooshing down the slides—a real girl on the go.

Outside of school, you'll see Brisa on the soccer field, playing for her team, the Celtics. And when she's not showing off her

fancy footwork, she likes playing on the computer, DSI and iPod.

As for music, she likes the song "Baby" by Justin Bieber as well as the hip-hop standard "Who Let the Dogs Out." Brisa also enjoys singing the children's songs at church. And as for TV, the *Fresh Beat Band* and *Extreme*



meet brisa dougan

ccakid



*Home Makeover* are her favorite shows. She also really likes the movie *Tangled* and even dressed up as Rapunzel Barbie for Halloween.

Brisa lives with her mom, dad, and **Bethany**, her 2-year-old sister. She has an older sister, **Hayley**. Although Hayley doesn't live with them, they do have a lot of fun playing with Barbies and playing outside when they do get together. Brisa also has a niece named **Aubreigh**, who is a year and a half old.

Brisa and her family attended the 2009 CCA

retreat in Grapevine, Texas—"the one with the inside pool." She didn't like the blue curvy slide so much because "it almost got my hair all wet and I almost slipped." Apart from that, she had a wonderful time.

Brisa was born with Apert syndrome and has had multiple major procedures so far and more to go. Still, she remains positive, flashing a smile and melting hearts wherever she goes. Her advice to other kids going through similar situations is to "be brave." Good advice, indeed.



# cca grad

## brittany stevens

By Harlena Morton

As the mother, I had the easy part, carrying a precious bundle of joy for nine months and delivering her. Miss Brittany has been living the unique part, the mysteries of Nager syndrome.

**Brittany Alexandra Stevens** turned 21 on August 23rd. She's had an amazing year: danced the night away at her senior prom, graduated from high school and was chosen as prom queen at summer camp. Princess Brittany (as she's affectionately known), deserved this wonderful series of events, especially since life hasn't always been a party.

Brittany was born at 5:36 a.m. on August 23rd, 1990, in a well-respected hospital in Philadelphia, Pennsylvania, after two long days of labor. The plan was to keep her in my hospital room, breastfeed her and take her home after a couple of days.

God had other plans. Brittany entered the world into special circumstances immediately! What was expected to be a glorious moment unexpectedly

became a confusing, frightening and blurred whirlwind. The doctors and nurses began to loudly yell commands and utterances of sheer disbelief. Someone was pushing on my belly. My husband was moved aside. Accusatory questions and comments were hurled our way. Brittany's father had a look of shock on his face as someone placed our daughter in my arms.

The next fifteen seconds were crucial, because I fell in love with the eyes, smell and soul of my 16-inch-long baby, whose head was only 11 inches around and filled with dark, shiny, curly hair. One picture was quickly taken and she was suddenly removed from my arms and whisked off to the NICU. My brand-new "mommy instincts" kicked in—I wanted to go where she was going!

As new parents, we were supposed to be on the telephone bragging to everyone that "the baby was here and she's so cute!" However, we were trying to explain to family and friends through tears and fear that she was kind



of "funny looking" and in ICU.

In her first hour of life, we were also devastated by hospital staff who accused us of doing something wrong during the pregnancy. We were told "she was a very bad baby" and they were going to let Brittany expire.

We had to go through legal challenges within two hours of her birth to keep her alive. Brittany was finally given IV nourishment at 5:00 p.m., after a judge agreed she had a right to life, even a challenging life. It would take five long years for Brittany to be diagnosed with Nager syndrome by a fellow at Children's Hospital of Philadelphia (CHOP).

Nager syndrome is extremely rare, affecting approximately 110 people in the world. Some of

the complicated features include a craniofacial anomaly, missing bones throughout the body, eating and breathing issues, possible mental retardation, bilateral hearing loss, etc. Many of the babies born with this syndrome don't survive infancy because of a very short chin, small mouth and weak palate, which makes it difficult for a baby to coordinate sucking, breathing and swallowing. The gene causing this syndrome has not yet been identified.

Brittany was 3 lbs., 14 ozs., and all eyes. Initial nourishment was provided through IV solution followed by NG tubes inserted into her nostrils, running down into her tiny stomach. Eventually, she received breast milk

see **brittany**, page 12

# ccasupersib

## meet quinn stevens

By Harlena Morton



Sometimes, when you're recovering from surgery, you feel better when you see a big, friendly smile! Brittany's younger brother, **Quinn Alexander Willoughby Stevens**, has a smile that can melt anyone's pain! Just ask big sister, **Brittany**, who has Nager syndrome.

Quinn was 2 years old when he attended his first FNMS Retreat in Chicago. Big sister Brittany was 5. He was cute, all smiles and had tons of energy. Most 2 year olds are energetic and inquisitive. However, Quinn didn't ask questions about the unique faces around

him. He simply saw children he could play with.

As the years progressed, Quinn became friends with a number of children in the CCA and FNMS families. **Elizabeth Hubbard** from CCA and **Kelson Vanderveer** from FNMS are two longtime friends. Despite the obvious craniofacial anomalies, Quinn never looked at them, or Brittany, in a peculiar manner. Instead, he's become a caring, sensitive individual, who has learned to value what is in a person's head and heart, not judging them for how they look. In fact, one

of his standard comments is "Don't judge!"

While growing up in Philadelphia and attending the public schools, Quinn became involved in various school activities, which helped him find his identity, other than just being Brittany's little brother. He began playing the drums, joined Cub Scouts, progressed in karate and focused on his academics.

By fourth grade Quinn was identified as mentally gifted, reading at a college level. He was assigned to rigorous academic programs, sometimes leaving Prince Hall

Elementary School to work with students in more challenging courses. This was a striking contrast to Brittany, identified as mentally retarded, and assigned to the Life Skills programs in school.

It was a blessing that Quinn had other things to focus on, because as a bright little boy, he was keenly aware of his sister's chronic illnesses. Every time Brittany was scheduled for surgery, Quinn would look into my eyes and ask, "Is Brittany going to die?" He would try to console her when he was present at appointments when



she had to give blood or be subjected to a painful procedure.

Quinn was too young to understand why Brittany always received lots of attention, but he wasn't too young to hurt or fear losing Brittany. Also, our extended family and friends did all they could to help make him feel just as special as Brittany.

Despite growing up in the shadow of big sister Brittany's rare syndrome, Quinn has become a humble superstar! He graduated number two in his elementary school class. At Hill-Freedman Middle School, he continued to perfect his percussion skills. He led the graduates into their graduation ceremony, playing the quad drums. He was also selected and performed with the Philadelphia All City Middle School Band and Orchestra.

High school was even more incredible! Quinn was accepted into the Northeast High

School Magnet and Aerospace Program. He played with the band, orchestra and jazz ensemble for four years, performing for more than 80 events each year. Quinn also had the distinguished honor of being selected to perform with the Philadelphia All City High School Band & Orchestra for his junior and senior years. His skills advanced to writing music.

At the end of each school year, Quinn always looked forward to going to the annual CCA retreats, reconnecting with old friends, making new ones and especially, dancing the night away at the dinner dance, with a bright smile directed toward his special friends!

As parents, Herb and I did our best to always let Quinn know he was just as special as Brittany. Additionally, many awesome teachers, neighbors and family members continually

encouraged his academic skills and musical talents—it takes a village!

Today, Quinn is on the full Prince Hall Academic Scholarship at

East Stroudsburg University in Pennsylvania, studying computer science, and is a member of the ESU Marching Band. He still plans to attend annual CCA and FNMS retreats and will continue to champion the needs of special people.



Finally, as a mother, I am painfully aware that smiles sometimes mask fear. There have been many times when Quinn was growing up, that family and friends have told him that he will have to take care of Brittany in the future—that's a heavy burden for a child to handle. I have instead told Quinn to live his life. He's an individual who has every right to shine in his own light! The loving bond that he and Brittany share is forever, clearly seen in his handsome smile, the smile that hugs the pain away!



## cca mugshot



### Send us your mugshots!

CCA donor and friend, Mario Adamo of Switzerland, "Behind me there is the river Limmat and part of the historic old town of Zürich."

**GO PAPERLESS** and view the newsletter online in FULL COLOR! Email [AReves@ccakids.com](mailto:AReves@ccakids.com) and let her know you want to save the environment and save money for CCA.

# calendar of events

date event contact

## 2011

Dec 3 **CCA Holiday Party—Midwest** [JPatterson@ccakids.com](mailto:JPatterson@ccakids.com)  
11:30a-2:30p Brat Stop/Parkway Chateau 214.570.9099  
Kenosha, WI 800.535.3643

Dec 10 **CCA Holiday Party—Dallas** [AReeses@ccakids.com](mailto:AReeses@ccakids.com)  
10a-Noon Southfork Ranch 214.570.9099  
Parker, TX 800.535.3643

Dec 10 **Ryan's Road for CCA 9-Pin** Nicole Gulich  
**No Tap Bowling Tournament** [ngulich@yahoo.com](mailto:ngulich@yahoo.com)  
1:30-4:30p Corning, NY

## 2012

Jun 28-Jul 1 **22nd Annual Cher's** [AReeses@ccakids.com](mailto:AReeses@ccakids.com)  
**Family Retreat** 214.570.9099  
Tempe, AZ 800.535.3643

Jul 13-15 **10th Moebius Syndrome** [www.moebiussyndrome.com](http://www.moebiussyndrome.com)  
**Conference** [dawnang@moebiussyndrome.com](mailto:dawnang@moebiussyndrome.com)  
Sheraton City Center Hotel 510.304.2302  
Philadelphia, PA 660.834.3406



## yoga for good

**a**nanda Yoga of Hadley, MA, held a "Do Yoga, Do Good" for CCA this past April. A kickoff party and prize raffle was held at the beginning of the month, with prizes donated by many generous local businesses and individuals. All the raffle ticket earnings were donated to CCA.

Throughout the month, all classes at Ananda Yoga were payable by donation, and the profits for the month were also donated to CCA. Ananda Yoga would like to especially thank **Elizabeth, Jason** and their CCA kid, **Nova**, for their support and inspiration for our fundraiser.

## a closer look

By Carmen Mickley

Please take a closer look at me,  
not what you see but what's beneath.

To you I may not look the same  
as others that have come your way,  
But my face does grin when I am glad  
and my eyes cry when I am sad,

I need comfort when I'm in pain,  
will you take a look again?

My heart beats the same as yours,  
can you try not to overlook  
that I am human just as you  
and I need love and acceptance too.

God creates each of his children,  
with no mistakes when sent from heaven.

So, before you point at me and laugh,  
take time to know the other half—

the part of me that doesn't show,  
you will change your mind I know.

My soul is gentle and I am kind,  
strength and faith I have inside.

I hope someday you will believe  
that we are not so different, see,

And at the end of every day,  
I close my eyes real tight and pray

that someday you won't turn your head,  
but get to know who I am instead.

I am more than just the face you see.  
Would you please take a closer look at me?



*Written for all the children  
whose only hope is to be  
accepted for who they are  
not for how they look.  
September is Craniofacial  
Awareness Month, I believe  
everyone deserves to be  
loved and accepted by  
others, no matter what.*

## development

**director**, from page 1

About a dozen years before, when my own kids were little, I remember receiving a letter, suggesting we help CCA raise funds by participating in the “2x2 Campaign.” The letter gave a whole list of fundraising ideas. I remember thinking, “What nerve they have asking us, the families! Why, we are the ones who need the help!” I was too overwhelmed with doctor appointments and everything else, and I had neither the energy nor the inclination to put our situation out there like that.

But Dede and Darin were part of a new movement, and thankfully things had changed. The Dankelsons started a trend, and a domino effect, that has literally kept CCA afloat during some difficult times.

I have the deepest respect for the Dankelsons’ bravery, and I am in awe of their energy and other families like them. It takes a lot of courage and stamina to put one’s “CCA kid” out there for the greater good, to help raise funds on behalf of all CCA kids and their families. Many do this because they have been helped and want to give back. But Dede’s family just wanted to help. Dede and Darin held their “Pete’s Scramble” golf tournament for four years before they even met us in person or came to their first retreat—the very program

their efforts were helping fund.

Happily, as I said, other families followed suit. The **Dales**, whom you’ll read about in this issue, featured as our “Donors in the Spotlight,” have just completed their 7th annual Friends of Jeremy golf tournament. Since then, **Links of Love for CCA** and the **Hartley Company Golf Outing** tournaments started up and **Fore Ava’s Friends** is in the planning stages.

A **Walk-A-Thon** held by then-volunteer, now-board member, **Donna Gossett**, at the elementary school where she worked, led to a happy parade of alliteration—**Seth’s Stride, Ryan’s Road, Raegan’s Rally, Nibblin’ with NattyCakes, Alexa’s Appeal, Friends of Freddie** and **Trevor’s Trip to Triumph**, which begat **Henry’s March, the Chocolate Festival, Little Fire, Big Heart, Lily’s Dinner, Jaci’s Country Dance Bash** and **Texas Moms’ 5K for CCA**. Then there was every “a-thon” one can think of: the **Denim Days**, the **Cash Collections** in honor of a CCA kid such as **Be Brody’s Angel**, catalog sales and home parties when the hostesses give CCA their credit or the consultant, their commission. And, of course the donations of all the discarded cell phones as well as empty ink cartridge collections—**Cash for Trash**. Families have held these events and many more over

the years, efforts of every kind, too numerous to mention them all, but I just had to name a few!

These family fundraisers set Children’s Craniofacial Association apart as an organization whose families help contribute **up to 42 percent** of the income budget. In fact, much of the corporate giving that comes into our organization comes through the fundraisers as well. Those funds allow us to provide much-needed programs and services to all families affected by craniofacial differences. Aside from a nice warm feeling about giving back and devotion and loyalty, it makes a statement that gives other donors and prospective donors, considerable comfort and satisfaction that this charity

and its mission is so valued by the people it serves.

So, yes, I have found out during the past (almost) ten years, that fundraising has many dimensions. But the loyalty, devotion and dedication of every family who holds a fundraiser has made a huge impact. We appreciate all the time and effort our families dedicate to their fundraisers, and I personally thank each and every one from the bottom of my heart.

Thanks so very much and holiday blessings to all!

Jill Patterson  
CCA Development Director

If you would like to talk about holding a fundraiser, give me a call at 800.535.3643 or email [jpatterson@ccakids.com](mailto:jpatterson@ccakids.com).

## Have you included CCA in your estate arrangements with a planned gift?

### financial assistance

do you travel to receive quality medical care? If you do, and need financial help, CCA has a financial assistance program that will help with food, travel and/or lodging. Call CCA for an application at **800.535.3643**. All we ask is that you **apply at least four to six weeks prior** to your next appointment.



# craniofacial acceptance month

This year marked the seventh year CCA observed September as Craniofacial Acceptance Month across the nation. CCA families, friends, volunteers and related support groups widened the circle of acceptance for individuals with facial differences. The goal is to create awareness that beyond the face is a heart and the true person within.

Many of our CCA families were able to get their local newspapers to feature them in the paper. Radio stations also ran PSAs throughout the month of September. And, for the fourth year, CCA held National Picnic Day in September as part of Craniofacial Acceptance Month. CCA families across the nation held picnics in Florida, Indiana, Minnesota, Nebraska, Ohio, Utah, Virginia and 3 in Texas!

CCA thanks everyone for all of their hard work in making Craniofacial Acceptance Month another great success!



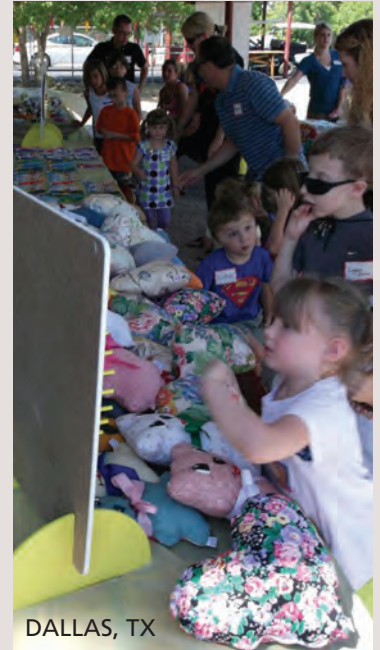
BELLMead, TX (WACO AREA)



DALLAS, TX



BELLMead, TX (WACO AREA)



DALLAS, TX



BELLMead, TX (WACO AREA)



COLUMBUS, NE



ROUND ROCK, TX (AUSTIN AREA)





NEW HAVEN, IN



FARMINGTON, MN



FARMINGTON, MN



COLUMBUS, OH



FARMINGTON, MN



MIDLOTHIAN, VA



COLUMBUS, OH



SANDY, UT



MIDLOTHIAN, VA



ORLANDO, FL



SANDY, UT



MIDLOTHIAN, VA



ORLANDO, FL



SANDY, UT



MIDLOTHIAN, VA





So, in Ian's case, he does not smile the way we do, he does not frown, and he does not have lateral eye movement. Articulation is difficult, because with the paralysis, words that begin with B, P, and M are hard to form. He was also born without his left pectoral muscle, and has a smaller left hand. He has overall low muscle tone.

In a world where appearances seem to matter so much, where we respond to the slightest smile, wink, frown, it was terrifying to new parents like me and my husband, Emmet, that we could not tell if our baby was happy or sad or angry.

So we adopted the philosophy that he was happy, and we would smile at him all the time. We began to recognize the cries of frustration and anger. We managed.

When Ian was born, we were living in Philadelphia. We could not have been at a better place.

## Hecho en Argentina—Made in Argentina

That's what we like to tell Ian.

It was October 2000. Emmet and I were living in Buenos Aires, where he was a financial journalist. The local economy was in shambles. In the few months we were there, we had experienced two attempted pocket-pickings. Emmet had been mugged, and many of our friends had been held up at gunpoint and robbed. I was sick as a dog, and ended up in the hospital, where we were told I was pregnant.

It was time to cut our losses and return home to Philadelphia.

I spent the remaining six months of my pregnancy planning for our future as a family. Aside from being really, really sick in my first three months, the pregnancy was uneventful. I planned to stay home for six months after the birth,

and then return to work as a journalist.

Inexperienced as I was, I walked to the oldest hospital in the country, Pennsylvania Hospital, three times, pillow tucked under my arm, thinking each time I was in labor. Ha! When labor truly began, I was in no position to walk those four blocks to the hospital. My total labor and delivery took about five hours.

Ian was anxious to join us.

When they placed this 6lb 9oz baby on me, I noticed his left hand was webbed and his index finger had no nail. No one else had noticed it. I asked Emmet to point it out to the doctor. I recalled the science classes I was in as a child, where the tadpoles' tail and webbed feet eventually evolved. I thought maybe as Ian grew, the webbing would go away.

I wasn't even worried when our pediatrician came into the delivery room to tell us that Ian had Poland syndrome. We were told it was merely cosmetic, that it wouldn't really affect his functioning. No biggie.

In the course of the morning, I attempted to bond with Ian, to nurse him periodically. Each time I did, he would gag, and I would call the nurses over. After about three times, a nurse came in and told me they wanted to take him to the NICU to observe him.

By mid-afternoon, a team of doctors descended on our room and delivered the news. They thought Ian had Moebius syndrome. They wanted to send him over to Children's Hospital of Philadelphia, less than three miles away.

That's where we spent our first week.

We took turns to stay with Ian, wanting him to see one of us every time he opened his eyes. We held him as much as we could. We learned to intubate him. We were trained in CPR.

We were terrified. In the research we had done, much of what we learned portrayed the more severe cases of Moebius syndrome.

We already knew that without surgery, he would never be able to smile. What else? Would he be able to eat normally? Would he walk? Would he talk? What were his cognitive skills going to be like?

What did our future hold? More important, what was in store for Ian's future?

It broke my heart – still does – to think of the challenges Ian will face throughout his life.

But humor can break through many barriers, right?

So maybe his facial paralysis will serve him well – future poker player, or better yet, perhaps he could give deadpan comedian Steven Wright a run for his money.





That is why meeting so many of you at this past June's retreat made such an impression on me. Your resilience inspires me.

Our personal journey has been one of triumph, perseverance, exasperation, exhilaration, frustration, sadness, joy and, sometimes, anger.

I am angry with anyone who dares to limit Ian's abilities. I am angry with bureaucracy—with individuals who favor job preservation over the developmental progress of any child with identified needs.



Ian has worked hard to be where he is today. At 10, he is a straight-A student and has entered the most prestigious public middle school in Philadelphia—Julia R. Masterman School. Besides working hard at school, he still has two sessions each of occupational therapy, physical therapy, and speech therapy a week. He also takes swimming and karate. He continues to see a wonderful team of doctors at Children's Hospital of Philadelphia.

We celebrate his successes: At age 2, he took his first steps; at age 3, he was humming Beethoven's Ode to Joy; at age 8, he read a book on the periodic table of elements and decided his favorite element is beryllium; at age 9, he read Homer's *The Odyssey*, unabridged. Ian has also decided he enjoys the music of *Electric Light Orchestra*.

Don't get me wrong—he's still a kid who enjoys tormenting his little brother. Lego *Harry Potter* and *Star Wars* on the Wii are his first choice for fun activities. Cookies and cream is his ice cream flavor *du jour*.

We continue to work on overcoming his visual and physical limitations. We also

continue to wrack our brains to understand and forgive the bullies who exist in our world. At this point, that is our greatest challenge.

It is amazing how the ignorance of these cowards can so easily strip a child of self-esteem.

"Ian, it's not you, it's them," we have said repeatedly.

I continue to struggle to overcome this anger and focus on the positive.

So much is possible.

We do what little we can to educate the public about Moebius syndrome and craniofacial challenges.

I work to surround our family with friends who continually champion Ian's accomplishments.

The support we have from friends, from the Moebius syndrome community and, now, from CCA have been invaluable. As much as it can sometimes feel like it, we know we are not alone. We felt that at the CCA retreat and we feel it with each Moebius Syndrome Foundation Conference. (Emmet and I are hosting the next Moebius conference in Philadelphia in July 2012, and expect 500 people to attend.)

Everyone goes through challenges. Ours is just a little different. Ian has come a long way, and for that, we are grateful.

Thank you.

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children's  
craniofacial  
association

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**brittany**, from page 3



through small tube bottles. It took her an hour and a half to drink a few ounces.

For 41 long days after she was born, I would sit in the NICU from 7 a.m. to 7:30 p.m. and tend to her basic needs right along with the nurses. The doctors wracked their brains to try and figure out why she turned out the way she did. Finally, at 4 pounds and 14 ounces, we took her home on a heart and respiration monitor, infant CPR training under our belts, and lots of prayers and well wishes from the NICU Team.



The journey from the hospital to today has been incredible! Brittany has had 33 operations, including a C1-C2 spinal fusion, two major oral surgeries, bone added to both feet,

knee restructured, her chin lengthened and 13 sets of ear tubes.

She's endured lots of pain over the years, but she is living a life that some doctors said would never be possible! We were told she would never walk, talk, run or even know she was in the world. We were told she would live in an institution and be a drain on the state! We were told she was a very bad baby and would not live long!

Despite a very low APGAR score at birth, Princess Brittany is one of the most dynamic young women I know! She first spoke at age 5, and boy does she talk now! She first walked at age 2, and now she runs, dances and walks on a treadmill daily! But more than these miracles, Brittany knows she's in the world and tells everyone important to her that she loves them daily! She's a practical joker, loves a good movie and knows how to party! She's caring, empathetic and always helpful. Doctors don't know everything—at least not in this case.

We learned about Nager syndrome through **NORD** (National Organization for Rare Diseases) when Brittany was 5. Having a name for her syndrome led us to **Margaret Hogan**, founder of the **Foundation for Nager and Miller Syndromes** (FNMS), an

international support organization. Additionally, **Diana Sweeney** of **Children's Hospital of Philadelphia** (CHOP) told us about Children's Craniofacial Association (CCA).

These incredible organizations have become family to me and my little family. Over the past 16 years, they have provided priceless information through medical professionals and parents, which has helped our entire family and family doctors better understand Brittany's medical needs. **Dr. Wendy Ingersoll**, Brittany's longtime pediatrician, has been instrumental in helping her receive all of the medical support she's required during this journey. In fact, her staff has become involved with the **Pennsylvania Home Health Initiative**, a movement designed to be proactive with special children and adults. In other words, it takes a village to help a family! Also, the various specialists at CHOP who helped get Brittany to where she is today include **Dr. Scott Bartlett**, plastic surgery; **Dr. Steven Handler**, ENT; and Dr. Bernard Horn,

orthopedics. These doctors represent a small fraction of the large team of doctors who worked diligently to give Brittany a wonderful quality of life. They are forever in our grace!

Brittany will begin working at an adult



workshop soon. Her brother, **Quinn**, recently began college. Brittany lost her father, **Herbert L. Stevens Jr.**, to cancer two years ago.

As for me, I will continue to work with several organizations on behalf of special children and adults, especially those living with Nager syndrome.





## testimonial



**L**ivie was born on September 25, 2010, after a very long and difficult delivery. She was bruised badly from her nose up, and her head was not exactly round after her delivery. Because of complications with her delivery, we were back at the doctor's office frequently after she was born. At two weeks old I noticed that her head was not rounding out. It was

then that we started making our trips to the Mayo Clinic in Rochester, MN.

We were told that Livie was born with craniosynostosis, and the only way to fix this was through surgery. If left untreated it could cause a whole new list of problems. Two days after we found out about Livie, my husband, **Mike**, lost his job. What felt like a horrible nightmare at the time, I can actually say was a blessing in disguise. Mike was there and was my rock for my entire maternity leave. It also gave us the opportunity to have our other two girls home with us as well.

I want to thank CCA's Financial Assistance Program, Annie Reeves and all of those involved in the program. What you have done for my family and all of those you have helped along the way is truly amazing. Without CCA I have no idea what we would have done during such a difficult time in our lives.

I can never repay you for the peace of mind you gave me knowing that our hotel accommodations were being paid for while we were in Rochester for Livie's surgery, but we can pay it forward. Our family is working on paying it forward and hope to make a difference to other families along the way.

Thank you again for all of your support and for always being there.

Mike, Jennie, Addie, Bella and Livie Rutter~Farmington, MN

## donors in the spotlight

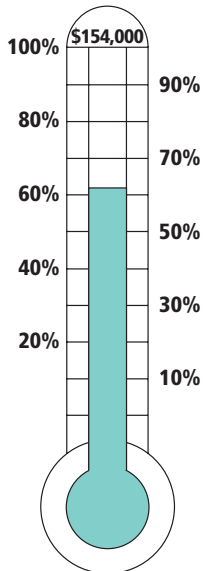
**T**his issue we wish to highlight **George and Kristine Dale**, a couple who've been part of our CCA family since 2003, when they attended their first family retreat in Washington, DC. The Dales became a part of the CCA family because of their son, **Jeremy**, who has Goldenhar syndrome. Jeremy just turned 12 years old and has made some really great friends through CCA.

After years of serving on various CCA committees between them, George took on the role of chairman of the board for CCA and held the position for a full two years before stepping into the vice chair position. Kristine and her mom most recently named CCA the beneficiary of a memorial fund for her dad in honor of Jeremy. They have hosted the annual Friends of Jeremy Golf Tournament, which has raised awareness in their community and **more than \$150,000 for CCA** over the years. For almost a decade, they've let us give no fanfare for their generosity and altruism. Finally, they've let us highlight them here. Thank you, on behalf of all CCA kids, George and Kristine, our Fall 2011 Donors in the Spotlight!



Click on "**Donate**" at [ccakids.org](http://ccakids.org)

## 2011 FAMILY FUNDRAISER GOAL THERMOMETER



**SHOP FOR THE HOLIDAYS!  
GO TO [WWW.PROMOTES.ME/CCA](http://WWW.PROMOTES.ME/CCA)**

# hydrocephalus

By Jennifer Rhodes, MD and Gary Tye, MD

**h**ydrocephalus is a condition where there is buildup of fluid around the brain. While many people think this fluid is water, or a condition sometimes known as “water on the brain,” the fluid is actually cerebrospinal fluid (CSF). Too much CSF accumulating in the areas around the brain, known as ventricles, can place harmful pressure on the tissues of the brain.

In children with craniofacial conditions, hydrocephalus is most often caused by blockage to the flow of CSF. It may be present at birth or develop later. Other causes of hydrocephalus may include poor absorption of CSF or overproduction of CSF. An excess of CSF leads to enlargement of the ventricles which in turn may cause an increase of pressure in the head. This may cause damage to surrounding brain tissue resulting in neurological problems. With some craniofacial conditions, up to 80% of children develop hydrocephalus.

## Symptoms

Children with hydrocephalus can present with a wide range of signs and symptoms. Infants’ heads may appear larger and show an increase in head circumference. The most common complaints include nausea and vomiting, headache, irritability, tiredness, double vision, and seizures. Older children may also complain of inability to hold their urine. Additional findings can include swollen optic nerves, weakness, and developmental delay. The diagnosis can be confirmed on an MRI scan.

## Treatment

The goal of treatment is to improve the flow of CSF out of the ventricles. This can be done by the placement of a device called a shunt or by a procedure called a third ventriculostomy.

A shunt is a silastic tube that consists of 3 parts: An intraventricular part which goes inside the brain, a valve to control flow of spinal fluid, and distal tubing which may be placed in the abdomen, heart or chest cavity. The surgery typically takes about 30-45 minutes and the child will stay overnight in the hospital. A shunt may be the preferred treatment in children with outflow obstructions at the skull base, which is seen in certain craniofacial syndromes.

A third Ventriculostomy involves using an endoscope to enter the ventricular system where the spinal fluid is made. A hole is made creating a connection between different areas of the drainage system. The child is watched overnight in the Intensive Care Unit and may have an external drain. A third ventriculostomy can only be performed in certain cases based on the anatomy found on the MRI scan.

The neurosurgeon on the team will review the MRI and determine the appropriate treatment for hydrocephalus.



On the 10th anniversary of the publication of *Fearless*, we are proud to announce the publication of an anniversary eBook edition, now available on Amazon. All of us at CCA wish to thank our good friends, author **Bradley Harding** and illustrator, **Dan Gremminger** for making this possible. Their generosity and dedication to CCA is heartwarming!



# hartley golf outing

By Nancy Michael

## The 3rd Annual Hartley Company Golf Outing

was held on August 9. With more than 80 golfers and about 20 volunteers we raised **\$27,239.74** for CCA! Our volunteers all wore CCA T-shirts (purchased from CCA), and every person attending got a CCA wristband to help spread awareness. Plus, CCA provided golf towels for all the golfers.

Before the golfing event, we held a raffle. **Hunt Brothers Pizza** donated the top prize of two NASCAR Hot Passes, which created a lot of sales. The day started with rain, but soon we were golfing under beautiful blue skies. We held a 50/50 drawing, and all winners donated back their winnings to CCA. Other prizes were awarded to golfers at the

games we held at special holes.

After golfing, the group moved indoors to enjoy a wonderful dinner. **Raegan Daughtery's family** joined us at the event to say a few words regarding CCA and their daughter. During dinner, we held an auction, continuing the raffle



sales and creating a lot of activity. All of the gifts for the auction were donated by our suppliers and local businesses.

The auction—and the entire event, for that matter—was great fun. Music, food, and support for CCA were flowing. Thank you, CCA, for helping make the event such a success. Next year at our 4th Annual Golf Outing, we strive to raise even more for CCA kids!



## wiggles in dallas!

On July 8th, Dallas-area CCA families were treated to the **Wiggles** in concert by Phoenix nonprofit, **Ear Candy Charity**, which provides youth access to music education. Their interest was in giving tickets to a children's organization in Dallas, and CCA was happy to oblige! A great time was had by all. Thanks, Ear Candy and Wiggles!



# cca's newest resource for craniofacial families:



**ccakidsblog.org**  
support. experience. inspiration. empowerment.

## Not familiar with the "blogosphere"? Let us explain...

**Blog** [blawg, blog] –noun  
a website containing a writer's or group of writers' own experiences, observations, opinions, etc., and often having links to other websites.

The CCAKids Blog was developed by CCA families and staff to give those affected by craniofacial conditions a place to find support, inspiration and insight into the experiences of others on a similar journey. With important documents, useful tools and frequently updated blog posts, it is CCA's hope that this becomes a go-to spot for craniofacial families.

We welcome and encourage feedback about this new endeavor! So check it out and let us know what you think.

[www.ccakidsblog.org](http://www.ccakidsblog.org)

Find us on Facebook – CCA Kids Blog



## good news

Thanks, **Melanie Dunn** at **Lime Punch** of Rocky River, Ohio, for sending custom hair ribbons and bows to give as get-well gifts to

CCA girls undergoing surgery. She and her own CCA kid, **Phoebe**, also provided a number of their special goodies for both our family retreat raffle and our next holiday party. In Phoebe's own words, "Make the girls feel special and put a smile on their face." Thank you!

There's a beautiful likeness of CCA kid, **Avery Lytle** hanging at **CHOP** (Children's Hospital of Philadelphia) painted by artist, **Robin Frey**. A grant enabled Robin to paint portraits of 8 kids who frequent the hospital. Congratulations to all!



## reagan's rally

On September 3rd, we held our **2nd Annual Reagan's Rally** at **Deerassic Park** in Cambridge, Ohio. We had so much success with the first Rally that we had our expectations set pretty high for this year's event, and it did not disappoint. We incorporated a 5K this year in addition to our walk and auction.

Our day began with registration for the 5K and walk at 9 a.m. The course that had been mapped out for the runners was challenging. Some people came to run the 5K, while others came just to take a nice walk around the beautiful park. We had around 50 participants for the walk/run. It was a very hot day, but everyone really seemed to enjoy themselves!

Following the race, the runners and walkers headed inside the lodge to join everyone for the auction and snacks. We had more than 70 items donated! Some of the items were Ohio State football tickets, Mosser Glass, Scentsy Products,



several hair product baskets and offers, homemade pies, hunting items, gas cards, oil changes, car washes, pizza gift cards, Thirty-One products, and the list goes on and on!

Family and friends made baked goods, **Deerassic Park** donated drinks, and **Food Distributors** donated hot dogs. All of these items were available for a donation. We also had a 50/50 raffle that raised \$400.

We were blessed with another beautiful day for our event this year. It was truly amazing to see the response from our community, family and friends to help organize and make this event so successful. We were able to raise **over \$8,000** this year for CCA. This is more than we raised last year, a trend we hope will keep repeating!

## 2012 annual cher's family retreat announced

**June 28-July 1 in Tempe, AZ**

For more information, please contact Annie Reeves,  
[ARees@ccakids.com](mailto:ARees@ccakids.com)

We hope to see you there!



# links of love for cca

The 4th annual Links of Love golf tournament to benefit Children's Craniofacial Association took place on September 30, raising more than **\$12,000**. This year's event featured local CCA kids on each of the 18 tee signs who represented all our kids as well as informed golfers about the numerous craniofacial challenges our families face. These kids included:

- **Jylian Bilbow**
- **Elizabeth Dalton**
- **Samantha & Brendon Collins**
- **Leigh Ann Howington**
- **Phoebe Butler**
- **Ryan Holliday**
- **Avary Mitchell**
- **Sadie Bono**
- **John Gorman**
- **Aiden Skees**
- **Luke Bowen**
- **Caroline Dale**
- **Andrew Davis**

- **Sam Greer**
- **Joshua Helton**
- **Manning Conley**
- **Brooklyn Nicholl**
- **Guerin Bell**

Golfers teed off out in Wylie, Texas, at beautiful **Woodbridge Golf Club** after morning coffee and snacks from **Starbucks** and box lunches from **Corner Bakery**.

Volunteers, **Judi Freeman, Tracy Thomas, Beverly Butera, RaeGene Munglioli, Cinde Keller, Cheryl Moore, Amy Abernathy, and Emily Harwood** made the day go smoothly from registration and selling games/contests/raffles to photo-taking and distributing refreshments on the course.

The day was rounded off with a great dinner catered by **Spring Creek Barbeque**, auctions, raffles and awards. The festivities were emceed earlier in the day by **Ryan** and at the end of the day by **Nate**, from **JACK FM**, who both donated valuable air time as well as posted the



event on their website and calendar.

We wish to thank our sponsors, both in-kind and monetary:

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- And special thanks to our auction donors:
- **Geoff & Lori Gunn**
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- **Thee Viron Roe of Nieman Marcus Salon, downtown Dallas**



We are extremely grateful, as always, to all who had a hand in our planning, participation, fun and success this year. We extend a warm invitation to everyone to come out and join us next year for the 5th annual Links of Love golf event to benefit CCA kids! Thank you, all!



# donors, january 1 – september 30, 2011\*

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CCA Chance Raffle / Annual Family Retreat Attendee Participants  
 Do Yoga, Do Good in honor of Nova Cox / Ananda Yoga, Justine Budhram  
 Friends of Freddie / Frederick Seitz Fundraising Effort  
 Rick's Raffle / Raffle Ticket Sales / Established by Ann & Doug Burgin  
 Torey's Distraction Screening / Nick Wiese

### \$5,000 or more

Lily's Dinner / Tasha, Nathan, Lily, Tanner, Nick & Josey Walker  
 Raegan's Rally / Ashley, Boz, Raegan, & Drew Daugherty  
 Nick Wiese fundraising effort

### \$10,000 or more

Chocolate Festival / Chef Rick Chiavari  
 Links of Love Golf Tournament

### \$20,000 or more

Friends of Jeremy Golf Tournament / Kristine, George, Jeremy, Tommy & Cody Dale  
 Hartley Co. Golf Tournament in honor of Raegan Daugherty / Eric Johnson  
 Henry's March / Rachel, TJ, Lauryn & Henry Johnson

### \$30,000 or more



# Jaci's Country Dance Bash

By Jaci Samhammer

Despite Hurricane Irene coming in that weekend, **Jaci's Country Dance Bash II** went off without a hitch on Saturday, August 27, at the **Elks Lodge 2023** in Morrisville, PA. We had an awesome turnout and raised **\$2,700** for Children's Craniofacial Association!

Everyone who joined us had a lot of fun participating in different raffles and a dance contest, which was very popular! The day was filled with great food, dancing and lots of laugh. Thanks to all who showed up, and a special thanks to my friends who surprised me by bringing another CCA family—their friends, the **Lytle family**.

Some of our supporters were **The Fairless Hills Elks Lodge 2023, VFW Post 6393, American Legion Pos 317, James J. Doughtry Funeral Home, Giant, Shoprite, Amtrak, Trenton Thunder, Sesame Place, Curves, Philadelphia Flyers, Centre Fruit, W.E. Krewson Inc., Country Music Fever, Cold Springs Beverages, and Pure Romance.**

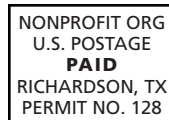
I would also like to thank my helpers, **Elizabeth Xibos** and **Trish Hallam** for selling tickets, **Harry Beerhalter** of **Country Dancing Feet for Djing, Christy** for driving me to pick up donations, and **Mickey McAllister** and **Kenny Kotnarowski** for bartending. And thanks to **Lydia Devlin** and the entire **Elks staff** for making all of the food and **Jeffrey Lippincott** for being our cameraman.

See you all in the summer 2013 at Jaci's Country Dance Bash III!

## Corporate/ Foundation Gifts

### CCA Corporate/ Foundation Friends up to \$1,000

American Express Charitable Fund (employee giving)  
 AT&T (United Way Employee Giving Campaign)  
 Bank of America (United Way Campaign employee giving)  
 Black Sheep Organization of the West Side  
 Cameron Manufacturing & Design  
 Chubb & Son, Division of Federal Insurance Company (matched gift of Jeffrey M. Brown)  
 Combined Federal Campaign / Local Creative Growth Counseling & Coaching  
 Hargrove Oil Company, LLC



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## tony stewart gives the nod to cca



Two-time NASCAR Sprint Cup Series champion **Tony Stewart**—owner of Tony Stewart Racing, co-owner of Stewart-Haas Racing, a highly competitive driver, and a tireless advocate of auto racing in its many forms—and, increasingly, Tony is also well-known as a dedicated philanthropist. Like his racing style, Tony Stewart pushes the limits to help others through his Foundation.

The Tony Stewart Foundation just announced the winners for

its “Tony’s Grant Accelerator” competition. Children’s Craniofacial Association has been selected as 1 of 40 charities from throughout the United States to be known as an Accelerator Charity and receive a monetary grant. More than 300 nominations were reviewed by the foundation and 72 organizations were invited to submit the full grant application.

“We created this competition to uncover terrific charities that are serving children and animals in innovative ways,” remarked Stewart. “The result is a collection of charities—large and small—with a common denominator of having a

strong volunteer network and a dedicated staff to deliver programs.”

The TSF Grant Accelerator Award of \$5,000 will be used for updating and improving the delivery system of information through the CCA Website and social media resources.

Since 2004, the Tony Stewart Foundation has awarded more than \$5 million in grants to organizations serving children, animals and drivers. Complete information about the foundation plus photos & stories of the 40 Grant Accelerator Charities are available at [TonyStewartFoundation.org](http://TonyStewartFoundation.org)