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Natalie Wardlaw (right) and twin sister, Olivia Wardlaw (left)



message from the executive director

I wanted to take a moment to talk a little about the individuals and families Children's Craniofacial Association serves.

First, let me step back in time a little bit. This organization was founded in 1989 as International Craniofacial Foundation. In 1991 the board of directors decided to change the name to reflect the need to identify individuals with craniofacial anomalies at an early age. International

natalie's story

by Jennifer Wardlaw

I am proud to introduce my darling **Natalie Denise Wardlaw**, diagnosed with Pfeiffer's syndrome Type III, and her healthy twin sister Olivia Jean, mom Jennifer, dad Alex, her mimi, Denise, and many other family members and friends involved in Natalie's care circle. This little diva has endured many challenges and lots of pain, but she is still the sweetest baby on earth. I am pleased to share our journey with you.

Natalie and Olivia were born on July 9, 2004, and we are looking forward to their second birthday bash.

Natalie has been through 13 surgeries with multiple surgical procedures, and she has had a total of 25 hospitalizations. Most of these procedures took place by the time she was a year-and-a-half old. Her most recent

see **natalie**, page 8

see **e.d.**, page 15



Samantha Klinger



meet samantha klinger

Samantha Klinger from Convoy, OH, is an artist in the making. This talented and creative four-year-old loves to draw and cut paper into fun shapes. She also goes to school three days a week, where she creates lots of craft projects. This past Easter season, she painted Easter eggs.

When she's not busy completing her latest work of art, she plays outside — "any chance she gets," according to Mom. She loves riding her bike and also playing on the swings.

When indoors, she likes listening to music and is a big fan of the *Wiggles*, *Barney* and *Dora the Explorer*.

Samantha was diagnosed with Apert syndrome, and she has had at least 15 operations so far. Her doctors don't know how many more she may have to have, but the next major procedure, which includes a mid-face advancement, will probably occur when she is either six or eight. Throughout it all, she has been a real trooper.

Samantha's family surrounds her with love. She has an older sister, **Sarah**, who is nine. The two sisters are very close. Samantha is also very close to her grandpa, and she is 100 percent a Daddy's Girl.

Samantha and her family are relatively new to CCA.

They plan to go to this summer's retreat in Hershey, PA. This will be the first retreat for them to attend, and they look forward to meeting other families and making new friends.

cca kid

cca grad

meet erin ashley

Erin's mom is Debbie Oliver, of Cleft Advocate.
www.cleftadvocate.org



Erin Ashley

Erin Ashley, a 19-year-old with a gorgeous soul, was born March 2, 1987, with a bilateral cleft lip and palate. Although she came into this world with a facial difference, it did not stop her from making friends, achieving her goals and becoming the bright young woman she is today.

At an early age, Erin's two older brothers showed her how to be strong and stick up for herself when others tried to bring her down. Even before she was a toddler, children and

adults stared and made comments.

Middle school was tough for Erin. With her outgoing, comical personality, she made many friends, but the teasing escalated to an extreme.

She would go home and cry herself to sleep. She didn't even want to wake up to go to school, but she did because she knew she had to be strong.

As high school neared, Erin decided it was time to change not only her appearance — she tended to be a little tomboyish — but also her attitude about people. She reminded herself there is some bad in every good person and some good in every bad person.

She walked into her first class on the first day of high school and felt that everyone was staring at

her. Erin sat down, looked around and realized that no one really thought about who she was, what she looked like or even that she was 10 minutes late.

High school, it turned out, was the complete opposite of the madness of middle school. It seemed that most everyone grew up and minded their own business. The few that didn't were the ones who never would.

Erin decided to become more responsible and to handle things as an adult. She bought her first car herself and finished high school six months early with a better-than-3.0 GPA.

Only one week after graduating, Erin began college with hopes and dreams of becoming a pharmacist. In the meantime, she found a better job, making more

money, and decided to move out on her own.

Now, a young adult, Erin is more mature than most kids her age. She is the life of the party and never fails to make everyone laugh. She'll talk to anybody and everybody to make a new friend, and she will go out of her way just to make someone's day.

Erin realized the saying is true — what doesn't kill you only makes you stronger. She believes that the same people who treated her so poorly in the past really made her the amazing person she is today. They gave her the strength to be a better person, the courage to do anything she sets her mind to and, thankfully, the ability to talk to others who go through the same difficulties.





meet aaron guzzo

Scott Guzzo's Big Little Brother

If you're reading this, it's likely you know someone with craniofacial anomalies, so you may think me to be your typical, young American teenager who has a brother with disabilities. If you are reading this, it's also very likely you know my brother, **Scott Guzzo**, and you know that there is nothing typical about him — and that's fine with him. Why spend your life being typical when you can spend it turning everywhere you go into a party?

Scott Guzzo, age 22, of Evansville, Indiana, has Crane-Heise syndrome. To put it simply, Scott is about 3'3" tall and weighs about 38 pounds. He gets around in a wheelchair and he is

tube fed. He's always with the program mentally, but many people can't understand what he's saying. Because of his tongue, his speech is what English would sound like without consonants. He talks fast and he talks a lot because he has a lot to say. Being one of the few who speak "Scott," I feel his frustration when people don't understand him,

So what does it mean to be the only brother of the somewhat-famous Scott Guzzo?

Our lives aren't exactly your standard American Midwest lives, not because life is unbearable or hard

continued next page ⇨

having Scott around — it's not — but because everywhere we go, someone knows Scott. Whether in the mall, in the Grand Canyon or in the middle of the forest in Jamaica — it's happened in all three places — we go ahead and assume that we'll find a "Scott fan."

I think most people will agree: your life is a little different if you have an encounter with Scott Guzzo, even a brief one. I won't lie — sometimes it comes in handy.

Scott and I are closer than most brothers. Sure, sometimes I annoy him, and sometimes he runs over my foot with his 250-pound wheelchair, but I am very special to Scott for a very big reason: I am Scott's hook-up to the rest of the world. I do many of the things that he can't. He lives through me.

When I'm down, he's down with me, but he doesn't waste any time down there — he makes sure he's put me in a good mood within minutes. When I've had one of those rare moments where I do something cool, it's a victory for Scott, too. There's a connection between Scott and me that really no one knows about; not even my parents. (Well, now that this is published in a newsletter, I guess that takes care of that.)

Being Scott's brother means daily surprises; you never know what he'll do next. Being Scott's brother means frequent adventures. And being Scott's brother means there's never a shortage of true friends; the world loves Scott, and I strongly suspect many of the world's problems could be cleared up if we would stop and think about what Scott would do.

Scott has had more opportunities to die than most of us have. That's why he sees opportunities where everyone else sees a problem, sees love in people who maybe haven't laughed for months, and sees hope in people who have given up on themselves. I can think of more than a few times when the world was telling me to shut up and sit down, and my brother was the only one who told me it's okay, Aaron. I'm here for you, Aaron. You're NOT stupid, Aaron.

He lives simply. He has more joy than most able-bodied individuals have. Most important, he knows how to clear the dance



Aaron Guzzo

floor and burn out some tires when they play "Wipeout."

Aaron Guzzo is a 17-year-old junior at Signature School in Evansville, IN, where he is the class president. This summer, he'll compete in the National High School Forensics competition in Dallas, Texas. Aaron plays the piano and has

composed more than 20 songs. He has performed in numerous musicals, including Seussical the Musical and Beauty and the Beast. In December, Aaron became an Eagle Scout. He hopes to attend the University of Southern California and become a filmmaker and/or music composer. His heroes are Steven Spielberg, Stephen Schwartz, Stephen King and Andrew Lloyd Webber.

cca supersib

record-breaking attendance for the 2006 16th annual cher's family retreat!

More than 100 families will be attending the 2006 Cher's Family Retreat. Until this year, CCA has never had to turn a family away from attending the annual retreat.

We truly regret that more than 50 families who wished to go are not going to be able to attend. The reason is that the ballrooms where the events are being held at Hershey Lodge are at capacity. Fire codes prevent us from admitting anyone else into these rooms.

If Annie has not already received your registration form, you will not be able to

attend the events at Hershey Lodge. Even if you wanted to stop by, unfortunately CCA will not be allowed to permit you to attend.

We sincerely apologize to the families who will not be able to attend this year. We have already worked with the 2007 hotel in Salt Lake City, UT, so this type of dilemma will not recur.

We do, however, look forward to EVERYONE joining us in 2007. We encourage you to register early. Registration forms will be available July 1, 2006, and the deadline for SLC registration is May 18, 2007.

recipe regrets!

The publication of our *CCA Cookbook* is now slated to be ready for Craniofacial Acceptance Month in September, just in time to take orders for holiday gifts. We had hoped to pull it together in time for families to see the finished product at the annual retreat. However, only a handful of people have responded to our request for your favorite recipes. **We need more recipes from CCA families, board members, retreat attendees, donors, any and all of you!**

Please send your recipes to the CCA office or email to JGorecki@ccakids.com.

Also, if you are interested in buying a sponsorship ad in the cookbook, please email JGorecki@ccakids.com.

fourth biennial cher convention to benefit cca

The first Cher Convention, an idea developed by Judy Didelot, Kim Werdman and Jody Cantwell, was held in 2000 as a one-time event to bring fans together, celebrate "Believe" hitting Number One on the Billboard charts and donate all proceeds to CCA.

However, with more than 700 attendees, worldwide press and countless emails for another convention, the Cher Convention has become a biennial event (even numbered years 2000, 2002, 2004...). It is a wonderful get-together of Cher fans from all over the world: Canada, Mexico, England, Germany, Italy, Australia and Russia, to name a few. Having held conventions in Chicago, IL, and Las Vegas, NV, **the conventions have raised more than \$100,000 for CCA programs and services.**

This year, the convention is moving to the Los Angeles area. Cher Convention 2006 will be held at the Warner Center Marriott Woodland Hills Hotel in Woodland Hills, CA on **July 7-9**. On Friday, the convention includes a silent auction of Cher memorabilia, dinner, and a **30th Anniversary**

Celebration of the Cher Show, starring Cher impersonators: Catherine Marie Carter, Chad Michaels, Wayne Smith, Amy Hohimer, and Mark Parry as well as special guests impersonating Gregg Allman, Lily Tomlin, Dolly Parton and Sonny Bono.

On Saturday, conventioners will enjoy 10,000 square feet of wall-to-wall Cher with non-stop entertainment, including Cher trivia, Cher Name That Tune, Cher Family Feud and much, much more! The day culminates with a dinner-dance and a Cher memorabilia live auction.

This year, a bus tour has been added on Sunday and will include many interesting places relating to Cher and to the area.

CCA is very grateful to the many Cher fan volunteers who dedicate countless hours, days and years to put on this convention that raises much needed funds to help our kids. Find out more about these wonderful people at **cherconvention.com/whowere.htm**.

If you are interested in attending this outstanding event, please register at **cherconvention.com**.

great news! from our families



"Pit Crew", Bob Beck (Grandpa), Freddie, Jonathan and Fred Seitz.

Freddie Seitz

Freddie placed Seventh in the Joe Lane Memorial Soap Box Derby Rally in Mineral Ridge, Ohio on April 23, 2006. He received a trophy and points for the Super Stock Division. (See photo above.)



Ryan Matney

Last August, 13-year-old Ryan Matney, of Berwind, West Virginia, was crowned the International Bowhunting Organization 2005 World Trophy Champion. Ryan took up archery when he was 10 years old and has competed on local as well as national levels, finally reaching the pinnacle of his sport by winning his first world title. Ryan was diagnosed with Craniosynostosis at birth and had his first surgery when he was four months old. "Lots of prayers and good Doctors helped me get better, the rest is up to me," Ryan says. God and hard work make anything possible, and Ryan is a perfect example that this is true.

Francis Smith

Francis Smith, of Garrett, Indiana, was born with Treacher Collins syndrome. Currently, he's in his second year at King's College in London, where he is studying anatomy, embryology, reproductive and developmental biology, psychology and medical genetics. He is also writing a paper on Treacher Collins syndrome for his head and neck anatomy class. Next year, he plans to do a laboratory research project at the college's Department of Craniofacial Development. "I'm so excited!" he said. "That's what I really want to do — research craniofacial development and anomalies, get a PhD and make a career of it."

Francis has also been involved with music, playing the piano for both his college and his church. He's even teaching himself to play the violin. Francis has attended the CCA retreats, and we consider him family. He is an outstanding young man.

Robbie and Erick Gorecki

Robbie Gorecki has moved from Wisconsin to Arizona where he is enrolled at Motorcycle Mechanics Institute in Phoenix, Arizona.

Meanwhile, his older brother, Erick Gorecki, upon graduation from UWM, has accepted a position with the Accounting firm of Ernst & Young, Milwaukee, Wisconsin.

national craniofacial
acceptance month

beyond the face is a heart

**CCA has declared
September "National
Craniofacial Acceptance
Month."**

CCA families, friends, volunteers and related support groups are encouraged to join this grassroots effort to widen the circle of acceptance throughout the United States. Our goal is to educate the public about living with a craniofacial difference and encourage them to look beyond the face to the heart within.

Help spread the message by joining this vital endeavor! Information packets are now available. These packets will guide you step-by-step. Included in the packet are press materials, print ads for local newspapers, CCA's brochure, information on the **Widening the Circle of Acceptance** fundraiser and detailed instructions on what you can do in your town.

To receive an info packet call Annie Reeves in the CCA office, or email her at AReves@ccakids.com. **The deadline for requesting packets is July 31, 2006.**



natalie, from page 1

procedure, the third Chiari decompression in less than 10 months, took place last month.

The girls were induced and delivered by C-section at 36 weeks. Natalie was the bigger, older twin, which has become such an irony. Immediately following their births, Natalie went to NICU and Olivia went to the regular nursery. I knew when I initially saw Natalie in the operating room that something wasn't right, her eyes looked very big. I just thought, "Well she is a new baby who hasn't settled in just yet."

When I heard she went to the NICU for respiratory distress, I got a little

nervous but was told she was stable. Little did I know that my doctor would come into recovery to talk to me and verify my tri-screen results, which were in normal ranges. She told me she thought Natalie had Down's

syndrome or something similar.

My heart sank because I had so many ultrasounds. I told all my friends and family that my babies were healthy. What went wrong?

When I did go to the NICU the next day, it was shocking. Natalie looked very different than what I had expected, and the hospital staff couldn't tell me much about what was going on at this point. I just held her and cried. Here I have this healthy, "beautiful" baby in my arms one minute and the next minute I am holding my other child that is facially deformed, and hooked up to all kinds of tubes. One minute I wanted to be happy and rejoice and the next minute

all I can do is cry and ask "Why?"

After about four days, the Neonatologists came to tell me that they thought she had Crouzon's. The doctors informed us that with good medical attention and care, there was a chance that Natalie could go on to live a normal life, but that she appeared to be a more severe case. They even asked us if we wanted to keep her—of course, without any hesitation, we all agreed that yes, we were up to it. The biggest question in our hearts and the most important thing we wondered was will she feel the love we have for her and will she love back?

Once home, Natalie was having apneic episodes and turning blue from time to time. Here is this little three-week-old baby having respiratory distress and we were still left with many unclear answers. In the meantime, we were trying to take care of Olivia's normal baby needs.

We stayed up around the clock for months attending to both of the babies' normal needs and the apnea monitor constantly going off. One Sunday after Natalie had been vomiting and was cranky for several days, we ended up in the ER. We could only tell them that she had Crouzon's and educate the medical staff based on

what we knew and that the ENT thought she had hydrocephalus. This local hospital decided to send us into the Houston Med Center to Memorial Hermann Hospital. The specialists there operated on Natalie to do a shunt placement. She was seven weeks old.

In November 2004, we visited the genetics office. They told us that Natalie did not have Crouzon's but she had Pfeiffer syndrome Type III. I wasn't shocked; I had been reading on the Internet and predicted it was Pfeiffer's based on her symptoms. We were told that there are not very many documented cases of Pfeiffer's Type III and that the children usually die at an early age.

We were heartbroken. I cried a lot that day. All that we suspected was now confirmed. Somewhere, the lifespan past the age of three came up, and that sticks in my head. You feel like you are on a time limit. Although you try to convince yourself that life is not guaranteed for any of us it still stares you in the face every day of your life.

After numerous hospital stays and surgeries — several shunt revisions, shunt replacement, endoscopic cranial vault, traditional cranial vault, g-button placement, etc —

continued next page ⇨

natalie, from page 8

our family was battling a “no hope for Natalie approach” from some of our Houston doctors. We were devastated.

I found out about CCA from talking with other parents of craniofacial children. I felt like I had won the lottery when we were approved for a scholarship to attend the family retreat in Nashville, TN! We made so many new friends at the retreat, and it was so laid back. All of the folks were easy to talk with, and we felt like we had come across a bunch of old friends.

Alex and I bragged about how wonderful the trip was, and we told ourselves that we wanted to make the retreat our family summer vacation every year. While at the retreat, several families advised me to seek out a medical consultation from Dr. Fearon at Medical City in Dallas. I gave it a lot of thought and consideration.

Shortly after she turned one, Natalie was having sats in the 60s. Mimi took her to the ER. They admitted her, but wanted to discharge her 30 minutes later because there were no pediatric neurosurgeons in town until Friday — it was a Monday.

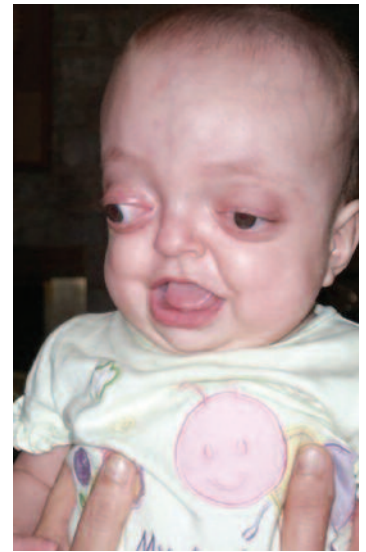
We felt lost again. I sent Dr. Fearon an email expressing our desperate need for assistance and help in determining where we go from here with Natalie. I also called CCA and asked for financial assistance to get to and stay in Dallas. Without a hesitation, CCA supported our last-minute trip to Dallas and made me feel like everything was going to be okay. Dr. Fearon wrote me back the same day; his immediate opinion was that Natalie had too many surgical procedures and she needed to be seen by him and his colleagues. He told me if we wanted to bring her to Dallas, he would make sure his staff was ready for us.

We headed to Dallas as fast as we could. Dr. Fearon kept his word, and we were welcomed with open arms. He said that Natalie needed to have another traditional cranial vault. He also advised us that Natalie had to have a trach. The Dallas ENT didn't feel it was high risk and that placing a trach would be simple and problem free. We were relieved.

Drs. Fearon, Sacco and Trone all performed their magic on the day of the surgery. I remember their reassuring me that she would be okay. We waited in that little surgery room for about eight hours. When Natalie went to PICU, they warned us several times that she was going to look really bad. When we first saw her, she was swollen up as large as an average balloon. The first thing I noticed were her eyes — they no longer bulged. She also had the trach protruding from her neck. As the days went on, she swelled even more and more. She looked worse before she looked better.

For the most part, the surgeries went well. She had a beautiful forehead and nice bridge for her nose. Overall, she did well. We learned to take care of the trach in the midst of all of the chaos.

Dallas medical professionals and CCA were a blessing. I think God



took us there when he knew we needed to go. Natalie has done amazingly well since we went to Dallas. She has had a couple bouts of trachitis, completed her third Chiari decompression, had a stint placed in her spine to drain the “syrinx” fluid and had a permanent Broviac catheter placed. However, she has recovered better than ever!!

I also want to say that without a family unit, none of this would have been possible. Mimi has dedicated her life to my children and helping us. Without her, I think I would have been lost, and Natalie may not have recovered as well.

We have all learned through Natalie that she has a spirit about her that attracts anyone that walks past us. We all worried there would be a lot of negativity as a result of her looking different.



see **natalie**, page 10

natalie, from page 1

Another wonderful experience I must share was from a co-worker. His family and Bible study group adopted our family for Christmas 2005. When he told me two weeks before Christmas that they were doing this, I cried and I could not believe that our life moved them so much to do something this special. Our Christmas was completely taken care of, and our living room was full of gifts. This brought such joy to us when we weren't even sure if we would be able to afford gifts. Kind acts like this seem to happen to our family all of the time, and I feel blessed and thankful for every little thought, prayer or gift we receive in Natalie's honor.

Natalie has really improved greatly and now weighs 20 pounds. She says "Mama, Dada, bye and ba (for a bottle)." She likes to sing through her trach, is doing several signs and dances with her arms—it's so cute because it resembles the "chicken dance." Natalie does not crawl or walk, she still drinks out of a bottle and gets fed through the g-button.

Natalie is so loving, trusting and happy. She loves every person who walks by. Natalie has a mind of her own, and I often tell people that no

one gives her credit for how smart she really is. Olivia is a healthy, smart young child who loves her sister without any preconceived notion that Natalie is not healthy. The beauty of watching Olivia love her sister is a joy. Olivia has tried to be patient and take care of her sister, like running to check on her when her monitor goes off to silence it or wipe Natalie's nose. She is a good helper, and I think God blessed me with both babies for a reason. The ironic thing is when I want to feel calm and peaceful, I run to hold Natalie and when I want to laugh and play really hard, Olivia is there and ready.

As hard as our life has been this past 20 months, I have found myself fascinated with all of the knowledge I have gained through this experience and all of the good people we have met. I think we all live in our "own little worlds" until something significant happens to us to show us another light, a light we may have never seen. It's all accredited to Natalie and the blessing that she is to our friends and family. We look forward to making wonderful memories with everyone at the Hershey 2006 retreat. Blessings to all!

congress considering insurance rights for craniofacial patients:

Make Yourself Heard

Representative Mike Ross of Arkansas recently introduced legislation in the US Congress to guarantee insurance coverage for craniofacial patients. This legislation (HR 4022) was proposed because insurance companies often label needed reconstructive care as "cosmetic" and deny coverage for this or other reasons. The Reconstructive Surgery Act of 2005 seeks to guarantee that insurance companies meet their obligations to cover medically necessary care.

The American Medical Association has developed clear and simple guidelines regarding the differences between cosmetic and reconstructive. The legislation proposed by Congressman Ross incorporates the AMA definitions. The legislation also is virtually identical to the language in federal law requiring coverage for reconstruction after mastectomies.

To make this proposal the law of the land, however, depends on support from citizens—and that's easy to do. Just go to www.aica-advocates.blogspot.com/ scroll down the right side of the page, type in your zip code and you will have the information you need for contacting your senators and representative by email, by phone, or by postal mail. Your message to them should be simple and to the point: "Please support HR 4022, the Reconstructive Surgery Act of 2005. This legislation simply requires insurance companies to meet their obligations. It's a matter of fairness." That's all you have to say. If you want to include some details about your personal situation, that's even better—but keep it simple and to the point. Ask your friends, relatives, and neighbors, church groups, community organizations, school classes, bowling leagues, and anyone else you can think of to do the same.

gifts to cca

You may notice a change in our listing of donor gifts.

We are now publishing a list of our donors quarterly (in every newsletter) with levels of giving indicated for total donations to date, so you will have a better indication of your donor level.

Also, we have resumed insertion of donor envelopes in our newsletter for your convenience. As always, your gift may be made "in honor" or "in memory."

Check for the donor lists on www.ccakids.org as well!

regional volunteers

Public awareness about craniofacial conditions is important on several levels.

It's important that families find quality medical care, that healthcare professionals are aware of the special medical and emotional needs of children and adults with facial differences, that the public understands and accepts facial differences and that individuals with facial difference are accepted.

CCA has formed a network of regional volunteers across the country who have banded together in an effort to educate and inform the public. The regional volunteers and CCA will now turn to local areas to recruit volunteers who will distribute educational materials throughout their communities.

If you would like to help educate your community and take part in this national awareness effort, call or email CCA Program Director, Annie Reeves at 800-535-3643 or AReves@CCAKids.com.

donors, january 1 – march 31, 2006*

Gifts from Individuals

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none to report first quarter, 2006

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Greg Luetkemeyer

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Kathy & Steven Hubbard, in honor of Elizabeth Hubbard from Mom & Dad
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Daniel & JoAnn Kopshinsky, in honor of Robbie Gorecki
Bruce & Diane LaRue, in honor of Scott Guzzo from the LaRue Family
Greg Luetkemeyer, in honor of mother, Betty Luetkemeyer
Ellen McPadden, in honor of Jeremy Dale from Aunt Ellen
MaryAnn Pallante, in honor of Freddy Seitz
Harry H. Porter, Jr., in honor of the marriage of Marybeth Ayres & Jim King
Carol Schatt, in honor of the marriage of Marybeth Ayres & Jim King
Elizabeth Vitez-Bainbridge in honor of son, Thomas Vitez from Elizabeth J. Vitez
John & April Wharton, in honor of Jake Wharton

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

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Prudential Foundation (Employee Giving/Matching Gifts)
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Wellpoint Foundation (Employee Giving/Matching Funds Management)
Wells Fargo (Employee Giving)

CCA Corporate / Foundation Sponsors (\$1,000-\$5,000)

A grant from the Dallas Jewish Community Foundation, recommended by Mr. & Mrs. Gerald Frankel
Guyuron Family Foundation, Inc.
A grant from the David & Shirley Hubers Family Fund of The Minneapolis Foundation, recommended by Travis & Christa Rymal
Wal-Mart

CCA Corporate / Foundation Partners (\$5,000 or more)

none to report first quarter, 2006

* Listed are First Quarter 2006 Monetary Donations. We are extremely grateful for these and all prior donations, raffle ticket purchases, fundraisers and in-kind donations not recorded here.

donors, 2005 total giving*

Gifts from Individuals

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Sharon Allbright
Linda Anderson
Marcy Anderson
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Angelic Bruns, in honor of Cher
Megan Marie Brassier, in honor of Anna Macon Hawse
Carol Bassett, in honor of Sophie's birthday
Jana Butera, in honor of Jimmy Butera's birthday
Jim & Beverly Butera, in honor of Lily Salvato's birthday
Larry Carpenter, in honor of Cher
Cher's Birthday Bash, in honor of Cher
William Conrad, in honor of Michelle Perkins
Dede & Darin Dankelson, in memory
Gerald & Ruth Dankelson, in memory of Agnes Miller
Cristen DeRonja, in memory of Mecon Hawse
Elizabeth Effa, in honor of Sophie's birthday
Mary Evanich, in memory of daughter, Ann Jaeger
Jeffrey Fearon, MD in honor of his Colleagues
Jeanette Fraizer, in honor of Jake Fraizer
Roger L. Gilbertson, in honor of Emily Paulson from Roger & Joey Gilbertson
Joseph Haas, in honor of Freddie Seitz from Aunt Betti & Uncle Joe
John & Arleen Heirty, in memory and in honor from Jim & Arleen
Hillcrest Plymouth, LLC in honor of Meeka Rowat
Paul & Patricia John, in honor of Maria Hogya
Helen Johnston, in the name of John Johnston
Kathryn W. Kemp, in memory of James Kemp
Jeffrey Kremers, in honor of Ann Ranfranz from Jeff Kremers
Katherine May, in honor of Sophie's birthday
Peggy McDannel, in honor of Cher

Laurie Monnier, in honor of Jeremy Dale from the Monniers
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 Colleen Orso & James Sullivan in honor of Maureen & Larry Sullivan
 Elizabeth (Liz) Prince, in memory of Daniel Prince III from The Prince Children
 Ronald & Tracy Prizant, in honor of Mr. Freddie Seitz from Dr. and Mrs. Prizant
 Tommy & Annie Reeves, in memory of Grandpa
 JoAnne Roosevelt, in honor of Dr. David Genecov from The Roosevelt Family
 Michael Saucedo, in honor of Marc Anthony Saucedo from Mike Saucedo, Jr.
 Solange Skyer, in memory of Richard Skyer Jr. from his wife
 Deborah Slosser, in honor of Fred Seitz, from Deb Slosser
 Smiley Face Campaign, in honor of Cher
 Mary Ann Smith, in honor of Father Mark, Jack & Donna Smith
 Susan & Oyvind Solvang, in honor of Meeka Rowat
 Patricia & Harold Timmer, in honor of Kara Butterly from The Timmers
 Richard S. Ward Lumber Co., in honor of Kathy & Elizabeth (Lizzy) Hubbard
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Dell USA (Employee Giving)
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Corporate / Foundation Gifts

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

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A grant from Biedenharn Foundation
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 A grant from Edmond & Alice Opler Foundation
 A grant from Wells Fargo, secured by employee, Stephen Wright

Fundraising Events

Up to \$1,000

Bonner's Pub Fundraiser / Robert Muller, CCA Volunteer
 Border's Charity Giftwrap Fundraiser / Margaret Jenna, CCA Volunteer
 Covenant Medical Group Denim Days Fundraiser / Shelley Shields, Organizer
 Crawford Walk for CCA Fundraiser / Lisa Crawford, CCA Volunteer
 Evening of Giving Fundraiser / Rose Seitz, CCA Volunteer
 Highland Elementary School Denim Days Fundraiser / Justin Prince
 SBC Employee Sloppy Joe Luncheon/Denim Days Fundraiser / Wendi Borges, Organizer
 Smiley Face Campaign / Peggy McDannel, CCA Volunteer
 Katz' Deli Fundraiser / Jennifer Guerra, CCA Volunteer

\$1,000-\$5,000

Independent Order of Odd Fellows—Century Lodge No. 492 Fundraisers / Doc Remer, Organizer
 Salon D Cut-A-Thon for CCA / Jana Butera, CCA Volunteer, Organizer

\$5,000 or more

CCA Win A Bike 2005 Raffle
 East Elementary Walk-A-Thon for CCA / Donna Gosset, CCA Volunteer
 First Annual Friends of Jeremy Golf Tournament / George & Kristine Dale, CCA Volunteers
 Third Annual Pete's Scramble for CCA / Darin & Dede Dankelson, CCA Volunteers

matching gifts

Many companies offer a matching gift program, and will match your gifts, the gift of a spouse or retired employee. This could double or even triple your gift to Children's Craniofacial Association! For a matching gift form or more information, please contact your Human Resources office.

* Listed are Monetary Gifts to CCA during 2005. Also listed are fundraising event titles. We are extremely grateful for these and all prior donations, raffle ticket purchases, fundraisers and in-kind donations not recorded here.

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.

cca annual giving campaign

by now you've received our annual funds appeal letter* and have read the amazing story of **John Moulton** and the struggles his family dealt with as he grew up with Apert syndrome in a time when CCA was not around. Today, Children's Craniofacial Association is making a difference for many children and their families and through your donation, you can too. Please think about contributing to the best of your ability. Gifts of cash, stocks, real estate, trusts and annuities will allow CCA to continue to provide programs and services and will allow you a tax advantage.

*If you did not receive our letter, please see it on our web site, www.CCAkids.org and hear John play the piano.

planned giving plans

about half of what you leave behind at death goes for estate tax. It pays to plan in advance. When you consult an attorney or investment professional regarding your wishes for distribution of your assets in your will, consider a provision for CCA.

Help enable the charity you have embraced to continue good works in your name.

Your planned gift in the form of an endowment will live on after you.

trash to treasure!

please save your old cell phones for CCA as well as empty laser disk and ink cartridges from your computer printers. CCA can turn those in for rebates! Send them to us or if you think you can fill a whole box, call us and we will send you out a collection box...it's all ready to go, labeled and the UPS shipping is pre-paid.

Thanks for participating!

calendar of events

date	event	contact
June 22-25	16th Annual Cher's Family Retreat Hershey, PA	AReeves@CCAKids.com 214.570.9099 800.535.3643
July 23-26	2006 North American Craniofacial Family Conference Alexis Park Resort Las Vegas, NV	debbie@cleftadvocate.org 888.486.1209
July 28-30	Genetic Alliance Bethesda North Marriott Bethesda, MD	www.geneticalliance.org
August 6	Wendelyn's "Course of Dreams" Golf Challenge Country Club of Arkansas Maumelle, AR	wendelynyvonne@hotmail.com
September	Craniofacial Acceptance Month	AReeves@CCAKids.com 214.570.9099 800.535.3643
October 14	Second Annual Friends of Jeremy Golf Event Willowcreek Golf Club Big Flats, NY	gdale@stny.rr.com

ccaprograms

and services in the spotlight

Families of craniofacial patients often call CCA to seek emotional support, discuss problems and identify resources. Through our database, we are able to network families with support groups and/or others who have similar conditions and experiences. We also keep a list of helpful resources and are always willing to listen and offer emotional support to family members who need a shoulder upon which to lean. For further assistance or information call Annie Reeves at 800-535-3643 or email AReves@ccakids.com

programs we offer

- Toll-free hotline
- List of qualified physicians
- Information and support
- Educational booklets
- Financial assistance
- CCA Network, a quarterly newsletter
- www.ccakids.com Web site
- Annual Cher's Family Retreats
- Public awareness
- Family networking
- Advocacy

now open

Our new online Web store is now open. Look at all the great items featuring our logo which you can purchase to help spread awareness of CCA! How about a cap for Dad?

www.ccakids.org or
www.ccakids.com

download the newsletter

If you are currently receiving the newsletter by mail, but would rather download it from CCAKids.org, let us know by sending your email to KSilverman@ccakids.com. The online version is in full color!

e.d., from page 1

Craniofacial Foundation had a very institutional sound and didn't seem to be capturing the attention of families.

Today, as in the past, CCA is a support organization for all individuals with craniofacial conditions, young and old. I believe this demographic is reflected in the people who attend the annual Family Retreat. Yes, we have many affected children, but we also have many affected adults. Some of them have grown up with CCA, and others have just discovered us. CCA endeavors to provide services for all ages, so if you're on the fence about contacting CCA because you thought we were for kids, call or email us now and become part of a caring, sharing community.

On another note, CCA has designated September **Craniofacial Acceptance Month**, and there will be opportunities for your family to be involved. We

have planned activities to spread awareness and acceptance during the month, which will be posted on ccakids.com.

Please check it out and join us in the effort.

One last thing — the battle isn't over; it's just begun! We still need lots of help getting the

Reconstructive Surgery Act (HR4022) passed!

Doing something as simple as copying a letter from www.aica-advocates.com

then mailing or emailing can make a huge impact. You don't have to be an affected family member. If you are reading this newsletter you can help, so please be a part of this important effort. For more information read the article on page 10 of this issue of *ccanetwork*.

Char Smith

Executive Director

3cheers

for volunteers!

CCA would like to thank **Miranda Williamson** (daughter of Board member Robin Williamson), **Madison Cantu, Dani Wofford, Briana Nelson,** and **Erinn Lopez** for volunteering their time to help with our Annual Campaign mailing. The schools which these 7th graders attend, require that they do a certain amount of volunteer hours per semester. Aside from volunteering, these girls enjoy things such as sports, scrapbooking, drawing, music, singing, shopping, eating, dancing, sleeping...and of course, hanging out with their friends.



Madison Cantu



Erinn Lopez



Briana Nelson



Miranda Williamson



Dani Wofford

children's craniofacial association

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If you know of someone who would like to be placed on the mailing list please forward to us their name and address.