

ccanetwork



newsletter of the children's craniofacial association

Cher — honorary chairperson

summer 2005

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Brenna Johnston

brenna's story

by Robyn Johnston

nearly a decade ago, my husband Erin and I discovered we would soon be parents. Like all parents, we wanted to raise a child that was happy, healthy and well adjusted. On May 14, 1996, Brenna, the first of our three children, entered the world. She instantly was my little Sugarplum, such a sweet baby!

Her journey has not been easy, but you would never know it meeting her today. She knows that she's a typical kid who just happens to have been born with head and facial bones too small to function properly, and we try to keep her life as balanced as possible. Here's the typical part: Her favorite food is catsup, with hotdogs and hamburgers, no buns. The not-so-typical part: She had nearly 40 surgeries before she was eight years old. She was born with Crouzons Acanthosis Nigricans, a rare variation of Crouzons Syndrome.

Brenna has taught us so much in nine years, more than most people learn in a lifetime. She was born with a strong will and something to teach the world. Over the

see **brenna**, page 9



message from the chairman

In the spring issue of the newsletter Tim Ayers announced that he was stepping down as Chairman of the CCA Board of Directors. He has provided countless hours of his personal time to our mission and we will miss him as Chairman.

Tim is not going far as he will still be on the Board of Directors. He is especially committed to leading our advocacy efforts to get health insurance companies to cover craniofacial surgeries that today are classified as cosmetic or denied for other reasons. We know only too well that is not right. Tim, on behalf of your colleagues on the board and CCA friends – Thank you for

see **chair**, page 15

2006 Retreat Info

The 16th Annual Cher's Family Retreat will be at the Hershey Lodge in Hershey, PA, on June 22-25.

For more information, contact Annie Reeves at 800-535-3643 or ARees@ccakids.com.

cca teen

meet brittany stevens

fourteen-year-old **Brittany Stevens**, an outgoing girl from Philadelphia, PA, is this issue's featured CCA Teen. She was born with Nager Syndrome, a craniofacial condition that affects her learning ability, breathing, eating, speech and hearing. She has had 14 surgeries so far and has another one scheduled for this summer.

Brittany begins 10th grade this fall. When at school, she learns to count and build on her vocabulary. She also loves to color. Another activity at school is her life skills support class, where she learns how to cook, do laundry and take public transportation.

Outside of school, Brittany likes shopping, listening to music, seeing as many movies as she can and keeping up with the latest fashion trends.

Brittany also collects butterflies and hearts, two of her favorite things. And since she was a baby, she

began a bear collection, which, from what CCA has been told, is now quite extensive.

Brittany and her family heard about CCA through a contact at Children's Hospital in Philadelphia. Since they have been a part of CCA, they've been to quite a few retreats — Atlanta, GA, where she had the opportunity to meet Cher; Tempe, AZ; Washington, DC; St. Louis, MO and this summer's retreat in Nashville, TN.

Despite her physical and mental challenges, Brittany remains upbeat, strives to do everything everyone else does and has a great sense of humor. When you see her give the thumbs-up sign, she's telling you, "Good job, baby!"



Brittany Stevens

pick of the litter

thanks to all of the following CCA Families and Friends for recycling "litter" ... collections of discarded cell phones and empty computer and laser disk ink cartridges go for rebate points which have translated into over \$500 so far for our cause!

CCA Funding Factory Participants

Lee Ann Adams	Annie Reeves
Tim Ayers	Rose & Fred Seitz
Shirley Baptist	Shelley Shields
Covenant Medical Group	Amy Shackleton
Kristine Dale	Bill Sims
Tony Davis, DDS	Eberhard Struss
Jill Gorecki	Robert Vargas
Donna Gossett	Amber White
Heather Lermont-Pape	Robin Williamson
Alexis Menz	Stephen Wright
Dan Paulson	Wendy Zastrow

tiffany tells it like it is

my name is **Tiffany Kerchner**. I'm 16 years old and live in Pennsylvania in a small town called Fleetwood. I attend Fleetwood High School, where I'll begin 11th grade this fall.

When I was four years old, I was diagnosed with Moebius Syndrome, a rare birth defect caused by the absence of the sixth and seventh facial nerves.

When I was younger, the kids at school picked on me and teased me all the

time. I used to get so upset, so I had some plastic surgery done. I had eight surgeries total and don't regret any of them. Now, I can smile, and that's all that matters.

The kids at school have matured, and they don't bother me anymore. Actually, I've made so many friends. Still, there are a few people that will say some rude comments, but I don't let them get to me. My real friends love me for the person I am.

I've always been told that if I ever get made fun of, I should just smile at them. And I do. They hate that!

I have many hobbies. My main interest is music — *anything* relating to music. I started taking singing lessons when I was seven and have loved singing ever since. I also love playing instruments — piano, bells, xylophone, guitar, chimes and the vibes. I love Broadway plays and acting. I've been in a couple of plays, including *The Sound of Music*.

I love ice hockey, and I have season tickets for my favorite local team. Football, baseball and NASCAR are also some of my other favorite sports.

After I graduate from high school, I plan to go to college and study music. Since I love music, children and teaching, my goal is to



Tiffany Kerchner

become an elementary school music teacher.

In 1999, Diana Sweeney told my mother and me about CCA, and we've gone to every retreat since then. I used to think I had it so bad having all these surgeries, but when you get there and look into the eyes of some of the little kids, you know they've been through so much more than you. It makes you not want to feel even the least bit sorry for yourself.

I'm very glad that I have the opportunity to attend the retreats. Through CCA, I've made many friends and have so many good memories.



cca grad

ccasupersib

being gavin's sister

my name is **Lauren Trevino**. My parents are Tricia and Ruben Trevino, and my brother is Gavin.

It is hard to be Gavin's sister. Gavin has a trach and a hearing aid. Sometimes when we go places people stare at Gavin and me, and it makes me feel uncomfortable.

When my parents first told me that Gavin was getting a trach, I was nervous and scared. I didn't want Gavin to get hurt, but it had to be done.

Over the years Gavin has had four more surgeries. There were two main surgeries, not including the trach. Each time I was scared and nervous, but all of our prayers seemed to work.

We play soccer and we sometimes play baseball with our dad. Gavin can hit the ball far.

I am in the developmental soccer program for East Orange, a more difficult league. We won our last

tournament. Gavin plays on a soccer team, too.

I'm in the enrichment program at school, which I really like, and get straight A's and S's. I like to read all of the Harry Potter books, mysteries and Lizzie McGuire books. Gavin does well at school, too.

It's fun to have Gavin as a brother because he is funny and energetic. But like a lot of brothers, Gavin can sometimes be a pest. I love him all the same, though!



Lauren Trevino

denim days

Shelley Shields of Lubbock, Texas has been busy raising money for CCA.

Shelley, along with Deanna Moran and the entire staff at the Central Billing Office for Covenant Medical Group, put together a Denim Days Fundraiser with all proceeds benefiting CCA. During a Denim Day, employees donate to dress down for a day, wearing jeans or casual dress not otherwise allowed under their company dress code. It's a great way to raise funds! Not only did they raise \$122...they also collected 17 cell phones. A big THANK YOU goes out to all who participated at Covenant Medical Group!

2005 retreat recap

Instead of the usual write-up, the folks at CCA would like to give you a family's perspective of the retreat. Here's a letter from the Dankelsons, who just came back from this summer's retreat in Nashville, TN. It was their first one to attend, and they had a remarkable time.

Hello Family & Friends,

Our family had an amazing experience in Nashville, TN, last weekend. We attended our first family retreat held by Cher and Children's Craniofacial Association. The children and families that we met are nothing short of miraculous and amazing.

Many of you receive the CCA newsletter, which always profiles the children and families. Meeting them in person, however, was incredible — especially during such a fun event (no



Pete, Darin, Dede and Jacob Dankelson

hospitals, white coats or needles in sight!).

Our weekend started on Thursday evening at the annual ice cream social and was followed by lots of swimming on Friday with a group dinner at the Rainforest Cafe. Saturday dawned the annual pool/pizza party, which the hotel graciously allowed us to have in a not-yet-open spa facility and then the

dinner/dance bash on Saturday night. And, oh what a party it was! To see these kids in action is simply indescribable.

Darin and I are extremely impressed with CCA, especially the organization and thought that goes into this annual retreat. The organization provided virtually all our meals and entertainment for the entire weekend. They only charged \$50 per family to register, and every year they give about 20 "scholarships" to children and families who would otherwise not be able to afford the travel and hotel expenses.

Cher sent each child as well as their siblings very nice "goody bags" with gifts, and some included GameBoys and iPod Shuffles (depending on age). What impressed us the most was how everything was focused on the

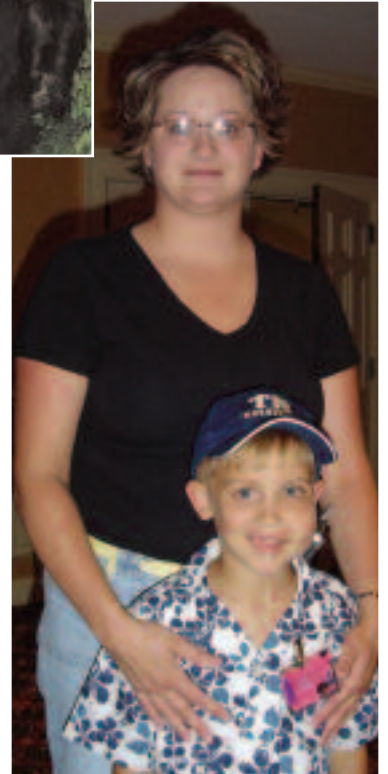
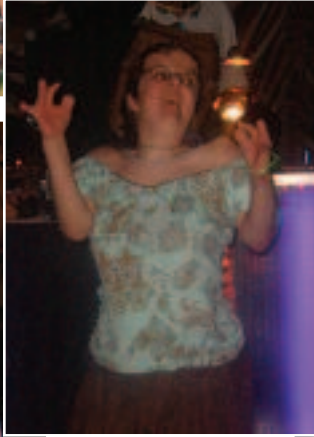
kids — from the entertainment and activities to the food that was served and gifts that were generously given.

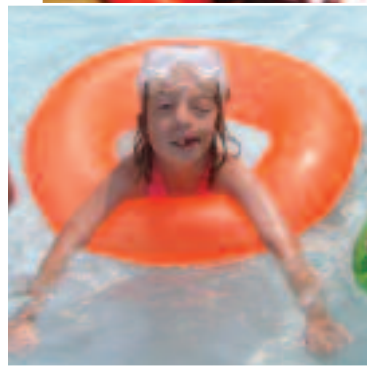
The retreat is the one weekend a year that these kids get to be in a "majority" group, be with others who understand how they feel and simply "let their hair down." Many of these kids have attended several retreats and you could just see the joy in their faces all weekend long. Also keep in mind the severity and frequency of surgeries these kids endure in addition to their facial difference, so you can imagine how they must look forward to this event. Our family is already looking forward to attending next year's retreat in Hershey, PA.

Thanks for letting us share our awesome weekend with you!

The Dankelsons
Darin, Dede, Peter & Jacob







your fair share

Did you know...

When the United Way Campaign at work asks you to contribute your fair share or any amount, you can designate that the funds go to Children's Craniofacial Association. CCA is not a United Way beneficiary agency but directed donations may be made to any 501(c)3 nonprofit organization you request. That way you will be helping your workplace meet their campaign goals as well as this important cause! Thank you!

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 trip.

what's cookin'?

We're compiling a CCA Cookbook for sale to raise funds and awareness!

If you have not yet contributed your favorite recipes, please email to recipes@ccakids.com or mail to the CCA office (see back of newsletter for the address).

The Cookbook project will be launched in 2006 with families taking pre-orders in the Spring. We will also make it available to the general public through our Web store.

The books will include some informative pages about your charity and photos of retreat fun, not to mention recipes contributed by our CCA families. These will make great gifts – especially if your recipe is in there!

The project will raise awareness for craniofacial conditions, CCA's mission and vision, and of course, \$\$\$.

focus on a \$1,000 bonus!

that's right, help CCA zero in on a \$1,000 bonus by participating in the 2005 Schoolpop 20/20 promotion!

It's easy! When 20 Supporters sign up, register, and use a new Schoolpop VISA card and 20 Supporters (any 20 Supporters!) make at least one online purchase through <http://schoolpop.p01.com/u.d?MEpJ2VfonU9d5toR=14201> between **4/1/2005** and **12/31/2005**, CCA earns a \$1,000 BONUS!

And that's not all. The 20/20 Promotion has other benefits that will help you earn even more for your charity:

- Every time you shop at <http://schoolpop.p01.com/u.d?EEpJ2VfonU9d5txc=15331>, the merchant contributes a percentage of each purchase back to CCA.
- CCA earns a one-time **\$20 Activation Bonus** for every Schoolpop VISA cardholder who activates their new card.
- **Every purchase** you make with the Schoolpop VISA card earns an additional 1% contribution.

It's easy to help us earn the \$1000 bonus – and start earning contributions all year round! Here's how you can help:

- 1** Simply **apply** for the Schoolpop VISA card online at <http://schoolpop.p01.com/u.d?WkpJ2VfonU9d5txb=15341> or by calling 1-800-297-1286.
- 2** After you receive your Schoolpop VISA card, **register** it at <http://schoolpop.p01.com/u.d?RkpJ2VfonU9d5txW=15351> (in the MY Card – My Account section).
- 3** **Activate the card** by making a purchase at any store or online merchant.
- 4** **Shop through Schoolpop.com** and "double dip." Earn the merchant contribution for our charity and qualify as a Supporter toward the \$1000 bonus.

For complete program details or more information, contact Jill Gorecki at JGorecki@ccakids.com or call the office at 800.535.3643.

Remember – your participation will help CCA earn a \$1000 bonus – and your everyday purchases will continue to benefit CCA all year 'round!

brenna, from page 1

years, we have figured out, she doesn't follow any textbooks when it comes to medical procedures. Her little body writes its own rules, much to her doctors' dismay at times.

Brenna's first year was difficult, but with lots of help from uncountable sources, and our own determination, we slowly put the pieces together. I firmly believe each of us can choose to make the best of each situation, or not. Most things are in God's hands, not ours. We have chosen to keep a positive attitude and have the determination to work through issues constructively, even the tough ones. It really does make a difference. Also, we strongly believe in the "village raising the child" approach. Her success is a result of the many people who have been involved in her life.

Brenna's breathing has been an issue we have

sleep apnea constantly affected her daily functioning, because she rarely had a restful sleep. She started using oxygen at night when she was four. She got by without a tracheotomy, but she did suffer due to her apnea. As a family we wanted her to have more freedom to live without restrictions — if we could make it work.

Some of her cranial bones were fused, so she had her first major craniofacial surgery at six months to expand and reshape her forehead and release the pressure on her brain.

Several complications occurred which would plague us later on. Her bones were weaker and more brittle than suspected. We knew immediately post-op that things weren't right. As it turned out, the frontal advancement would have to be redone at some point. For this, we were referred to doctors out of state.

In the meantime, I had to fight our insurance compa-

ny to let us go out of state and obtain the expertise we so desperately needed. We found our team of doctors in Seattle, a team with whom we could easily communicate and trust. By then, Brenna had just turned two. Already she was a charmer, always smiling and teasing her doctors with her spunky-but-sweet attitude. They decided to let her bones grow and mature for a while, as they were still very thin and fragile.

At this point, Erin and I realized Brenna needed a playmate, another child who would love her through thick and thin. Caden, the first of Brenna's two brothers, was born.

The day after her fourth birthday, Brenna went back to Seattle to have her frontal skull bones reconstructed. Unfortunately, a screw from her original surgery had migrated, sharp-end down, into the right frontal lobe of her brain, the speech center. It had to be removed. She also had undetected hydrocephalus,



Perry, Erin, Caden, Robyn and Brenna at this year's retreat.

which caused her cerebral spinal fluid (CSF) to leak uncontrollably. Brenna ended up with meningitis and several other infections, including one on her new, beautifully shaped forehead bones. After several surgeries, extremely aggressive antibiotic treatments, a few temporary shunts and finally a permanent VP shunt to divert the CSF pressure, she unfortunately lost her new forehead to the infection. She was finally released to go home in August. We didn't know if she would walk or talk again, but she did, with time.

Brenna started kindergarten that year, but was now required to wear a helmet during physical activity, since her forehead bone was now missing. We let her decorate the helmet

[Brenna] was born with a strong will and something to teach the world.

struggled with until just this year. She required nasal stents at four months, and then again before age two. We had to use a special feeder so she could get enough calories to gain weight. She burned more calories breathing than she could consume. She had to have her tonsils and adenoids out. Her

with stickers to make it her own. She knew that she needed to wear it because she was missing some bones. She didn't want to, but she understood.

After that summer, I became pregnant with our third child, Perry. It was so hard on Caden to have me

see **brenna**, page 10

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gone all the time, for medical purposes, that I wanted him to have a sibling who could stay home with him.

That fall, Brenna's doctors discovered that she had a moderate case of Arnold Chiari malformation, where the base of the hindbrain slips down through the base of the skull and impedes the flow of CSF down the spinal column. She developed a syrinx (fluid bubble) in her spine, which affected her motor coordination, endurance and control. Her energy level sank even more. She had headaches and her feet were numb and tingly. She struggled in school. Her breathing was still marginal, and the pressure in her brain was rising again.

Brenna underwent her first Chiari decompression

surgery the following spring. The goal was to alleviate some pressure in her hindbrain and spinal chord. Since she had no forehead bone, they had to design a special spongy apparatus to do the posterior surgery. That summer, her doctors reconstructed her forehead using rib graphs and synthetic bony material made of coralline structure over a titanium mesh. It was one of the first big surgery's that went perfectly.

Last summer, eight years and many surgeries later, Brenna finally reached the phase in her medical plan where she could finally

get her mid-facial bones advanced via the RED device. This experience was bittersweet. It was a challenging summer, but it has made all the difference in the world for her. Unfortunately, early on in the eight-week procedure, she caught a very resistant staph infection, MRSA. So we spent most of the summer in and out of the hospitals fighting this infection while dealing with the RED. Fortunately we qualified for a wonderful program called Angel Flight. Very generous pilots donated their time, airplanes and resources to transport us weekly between Seattle and home. It was a huge blessing!

Brenna now has tons of energy. She is slowly and steadily catching up in school and has a real zest for life. She also knows that if anyone has a problem with the way she looks that it's "their" problem, not hers.

She also received awesome news — no more surgery for a while! We enjoyed this summer to its fullest. We attended the CCA retreat in Nashville. Brenna, Caden and I went two years ago in Washington, DC. At that time, our budget wouldn't

allow for us to fly across the nation, but thanks to CCA, who helped with our travel, we were able to go.

I am SO glad we went. It made such a huge difference for our family. The retreat has really helped Brenna realize she's not alone. It also enlightened her brother Caden. He got to see firsthand that lots of people are born a little different, just like his sister. It helped him realize they are just kids too!

Once again, I want to thank the CCA for all they do and have done. The Cher concerts, the financial help and just being there. We feel honored to share our story here in order to help others understand they're not alone.

We have learned so much in the last nine years. Our path has not been easy, but there've been so many rewards. We've tried to keep everything in perspective and retain some normalcy and balance in our lives throughout the medical craziness. Our strong faith has also helped us get through the rough times. I know God has big plans for Brenna in the future.

Watch www.ccakids.org for our affiliates' link page and visit there before shopping, especially for the upcoming holidays!

cca programs

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

download the newsletter

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

U.S. Congressman Mike Ross of Arkansas plans to re-introduce his **Reconstructive Surgery Act** when Congress reconvenes in September. This important piece of legislation seeks to guarantee medical insurance coverage for craniofacial surgery and health care. The next edition of this newsletter and personal emails will provide families with more information on the legislation and how you can help.

2005 calendar of events

date	event	contact
September	Craniofacial Acceptance Month	www.CCAKids.com 800.535.3643
November 1	Deadline for recipe submission for inclusion in CCA's cookbook	www.CCAKids.com 800.535.3643

inside...
a **special message**
from **Cher**



Cher, CCA's Honorary Chairperson, with CCAKid, Elizabeth



children's craniofacial association
empowering and giving hope to facially disfigured individuals and their families

www.ccakids.org

a special message from cher

We have a number of CDs from our Cher fund appeal, "A Special Message from Cher" available for distribution to all your friends and family. Please consider handing some out where you live or work (with permission) during the month of September for CCA's Craniofacial Acceptance month and help us spread awareness about craniofacial conditions while raising funds.

Children's Craniofacial Association envisions a world where people are accepted for who they are, not how they look.

Your help is most appreciated. Thank you!

Be one of the first 100 people to donate \$100 or more and receive a copy of the 20th Anniversary DVD, *Mask*, starring Cher! To find out more, go to our Web site at www.ccakids.com!



prosthetic ears: what you need to know

having a child who is born without an ear is very serious and upsetting. When this occurs it is important to know the treatment options. This condition, known as microtia is most commonly seen in hemifacial microsomia. The term “micro” means small and “otia” means ear. Translated literally microtia means small ear. For children or adults, microtia may appear in varying degrees. They may have no presence of an ear, as little as a small bump or they may have a partially formed ear. One would think a person would be unable to hear from a microtic ear. However, in most cases, there is only an

approximate 40% reduction in hearing due to the sound being conducted through the temporal bone to the inner ear.

Individuals with microtia have the option of no intervention, surgical ear reconstruction or prosthetic construction. In this article we are going to explore the steps involved in obtaining a prosthetic ear.

A prosthesis is constructed in four steps and the patient may only need to be present for three painless appointments.

In step one, an impression is made to duplicate the natural anatomy. Next a clay sculpture recreates the appearance of the natural anatomy. In step three

the sculpture is molded and an elastic material is cast to replicate the image. Finally, the prosthesis is hand painted and tinted to visually blend with the surrounding anatomy.

On average, the process requires three office visits and is painless. The cost of the prostheses varies according to the complexity of the product. While the patient is responsible for payment, medical insurance may help cover costs. It is important to check with your insurance company before making a decision.

One main advantage of prosthetic ears is not having to endure surgical intervention. It is important to completely research the options to be sure you will be satisfied with the result. The advantage of surgical intervention is the fact that the ear doesn't need to be replaced periodically, can't be lost and is less sensitive to outside factors such as makeup and hair products. After considering all of the options individuals can make the educated decision to most effectively meet their needs

This article is intended for information only and is not a recommendation for treatment.

check out our syndrome booklets

have you seen the new and updated CCA syndrome booklets? Four booklets in the original series of seven have been updated, and three booklets on additional topics have been written. Each is written in an easy-to-understand format and is ready for downloading. Simply visit www.ccakids.org and click on Syndromes, then Booklets.

CCA is extremely grateful to craniofacial reconstructive surgeons Dr. Davinder Singh, Dr. Barbara Honnebier and Dr. David Low for donating their time and expertise to write these booklets, which are valuable resources for CCA families.

(See page 7 of the spring edition of CCANetwork for additional booklet authors.)

ticket to ride

thanks to all of our CCA Families and Friends selling tickets to our annual motorcycle raffle!

As of the deadline for this printing, the following folks were on board helping sell chances to win this year's "ride":

Stacey Atkins
Kendall Bilbow
Tami Bowers-Feinstein
Kevin Braden
Alex Chambers
Lisa Crofton
George & Kris Dale
Dede Dankelson
Sandy Deakins
Billy & Karla Dean
Beverly Grim
Casey Gore
Alan Gorecki
Rob Gorecki
Jodi Klemann
Mary Lytle
Molly Lytle
Andy McCaslin / Porkys
Chopper Co
Wendy Niemi-Zastrow
Karin Perry
Mike Sanborn / Buffalo
Chip Campground
Nicole Saylor
Elizabeth Schlecter
Laura Thonnesen
Tammy Van Ness
Muriel Walker

north american craniofacial conference recap

The North American Craniofacial Conference was packed with three days of education, sharing resources and fun. CCA was proud to be the Leadership Sponsor of this important event conducted by Cleft Advocate and AboutFace USA. Children with craniofacial conditions and their moms, dads and siblings attended workshops especially designed for their needs and interests.

Workshops for parents were designed to answer their most pressing questions and provide them with a road map for their child's future. Topics included research and access to information, early intervention services and how to jump insurance hurdles.

Adult sessions centered around other important issues, including employment and ADA law, insurance and legislation, and secondary surgery and treatment.

Teen sessions focused on the challenges transitions can present. Workshops to help them with setting goals, developing social skills and staying caught up with school when treatment takes them away from the classroom provided insightful and valuable tools. Image enhancement and

behavioral skills rounded out the fun, interesting and educational activities.

The explorers' club for kids with craniofacial differences and their siblings aged 7 to 11 featured games and activities with education and fun in mind! Workshops included how to answer questions about your facial difference when your parents aren't around, dealing with bullies and understanding your trip to the doctor.

In order for parents to benefit most effectively from the experience, childcare for the little ones was provided, but they weren't left out of the fun.

Children aged 0 to 6 participated in activities and games, watched videos and just had a great time.

One of the highlights of the conference was keynote speaker Major Daniel J. Wattendorf M.D., who spoke on the importance of knowing family medical history. Dr. Wattendorf is a clinical geneticist with joint appointments at the National Human Genome Research Institute and the Armed Forces Institute of Pathology. In his presentation, Dr. Wattendorf stressed knowing family history as

a powerful guide to understanding risk for disease. With this important information, an individual and his healthcare professionals can individualize care to prevent and screen for conditions for which one may be at higher risk. (To help gather this important information, visit www.hhs.gov/familyhistory/.)

Special guest Barbara Kammerer Quayle spoke to the group with a delightful, uplifting spirit. Her message — It's TOOL time: Turn Social Challenges into Social Success by Practicing NEW Behavioral Skills to Increase Confidence — motivated everyone.

Another special guest, humorist David Roche, inspired and entertained the group with his personal story. Speaking on issues of self-esteem, diversity, disability and facing change, David transformed the lessons of lifelong facial disfigurement into a compelling message.

CCA congratulates Debbie Oliver of CleftAdvocate.org and Rickie Gill, executive director of AboutFace USA, for a conference that made great strides in empowering those with craniofacial difference and their families.



new staff member

When you call the office in the morning, you will be greeted by the friendly voice of **Kelly Silverman**, our new Administrative Assistant. Having experience in both a nonprofit and corporate environment, Kelly will be maintaining our database of families, donors and volunteers, as well as sending out packets of information. Not only does Kelly bring a positive attitude to CCA, she also brings her adorable Baltimore accent as well. Kelly and her husband moved to Texas from Baltimore about a year and a half ago. Kelly lives in Las Colinas with her husband, Josh.

3 cheers for volunteers!

Every year CCA retreat attendees anxiously anticipate the reveal of the retreat logo design, and each year attendees are surprised and excited about the results. For the past eight years, the retreat logo has been created pro-bono by an extremely talented artist in the Dallas area. And it just so happens this talented artist is the husband of CCA board member, Robin Williamson. **Bruce** and **Robin**, the duo of **Williamson Creative Services** of Carrollton, TX, have thrilled attendees with interesting, whimsical and even provocative retreat designs.

The 2005 retreat design, "Nashville Cats," was a huge hit. As a matter of fact, several families were approached in the Opry Mills Mall and asked where they could buy the shirt!

After Bruce puts his creative spin on the design, Robin takes it and creates the annual retreat program that allows attendees to stay in touch through listed email addresses, gives them the retreat schedule

and allows them to make notes during the weekend.

In addition to the retreat work, Bruce and Robin volunteer in other capacities. Robin has designed and produced CCA's brochures, quarterly newsletters and syndrome booklets. She designed the CCAKids.org website and designs numerous printed materials for special events.

Bruce designed CCA's logo, was a regular volunteer at Our Children's Store and steps up to the plate any time CCA needs his help. And now, the next generation of the Williamson family volunteers has entered the scene as 13-year-old **Miranda** along with her friend, **Erinn Lopez**, recently helped CCA staff prepare for the 2005 family retreat.

Three Cheers for Bruce, Robin and Miranda Williamson, CCA super volunteers – talented and generous!

Watch for more of Bruce's talented work in the soon-to-open CCAKids.org Web store.



(above) Robin, Bruce and Miranda Williamson. (below) Here are just a few of Bruce's t-shirt designs you may have in your wardrobe...



2005 Retreat design



2002 Retreat design



2004 Retreat design



2001 Retreat design



2003 Retreat design



1998 Retreat design

september is children's craniofacial acceptance month

Knowing the reason, accepting the difference.

Join the effort by spreading awareness in your community. Watch for details in your email or call the CCA office before September 1st for information on how you might participate

help wanted!

We invite and encourage all CCA families and friends to hold fundraisers during September for CCA's Craniofacial Acceptance month! The easiest to do are the **Denim Days** (or PJ Day or Hat Day etc.) at your company or school for a small donation of say, \$1 – \$5. Let's see how everyone dressing down can add up! Contact Jill Gorecki for information on how to set up a fundraiser.

chair, from page 1

your leadership and for all that you do!

Tim has left a big role to fill, but as the newly-elected Chairman I am very committed to CCA's mission. My immediate goals are to work closely with the board members to fully utilize their skills, talents and community connections that each brings to the table. I am also working with CCA Executive Director Char Smith to continue with our plans for making our programs and services fully functional to our families.

By the time this newsletter is printed and distributed our Family Retreat in Nashville will be a thing of the past. I do hope, however, that I will have met many of you in Nashville as I plan to be there. I am anxious to hear from you and learn how CCA can continue to be a source of support. Comments and input from you can be emailed to me at robtvargas@hotmail.com.

Robert Vargas, *Chairman*
Board of Directors

getting to know the new cca chairman

robert vargas, cfre

Robert has been in public education and human services all of his professional life. He has an extensive background in nonprofit management, including program development and organizational leadership. While most of his professional experiences have been with agencies affiliated with national organizations, Robert is equally adaptive at working with small "grass roots" organizations.

Robert is the president/CEO of Disability Resources, Inc., located in Abilene, TX and is adjunct faculty at Collin County Community College in Plano, Texas where he teaches English as a Second Language. Robert served as executive director of the Epilepsy Foundation of Greater North Texas from 1999 until 2004. The Epilepsy Foundation affiliate provided individual and family support, employment services and advocacy for persons with epilepsy.

From 1985 to 1997, Robert served as executive director of United Cerebral Palsy of Metropolitan Dallas, Inc. Prior to that, he served as the administrator of mental retardation services at the El Paso State Center. Both of these organizations underwent significant program expansion in residential and rehabilitative services during his tenure. He is past president of the Variety Club Care Van Program, an organization that provides vans to nonprofit agencies. He is a Certified Fund Raising Executive and is a member of the Association of Fundraising Professionals (AFP). Robert is also past president of the AFP Dallas Chapter and served on the national board of AFP.

He earned an undergraduate degree in psychology from the University of Texas at El Paso and a graduate degree in teaching from Oakland University in Rochester, Michigan. He resides in Abilene, Texas.

coming soon

Our new online Web store will be available soon on our Web site. Watch for lots of great ideas for holiday gift giving which will also serve to spread awareness of CCA!

www.ccakids.org

a senior moment

baby Boomers (folks born from 1946 – 1964) are fast approaching retirement years and, with growing families, are drafting wills and trusts as well as estate planning.

Please remember CCA when making those plans!

Contact us if you'd like ideas which could have a tax advantage for you and your loved ones. It will have a profound and positive affect on our future!

third annual pete's scramble

Pete's Third Annual Scramble for CCA was held May 21, 2005, at Beacon Hill Golf Course in



Commerce Township (Detroit), MI. Hosted once again by the Dankelson family, the outing was another big success, raising over \$7,800 in direct donations to CCA.

Fifty-two players enjoyed a beautiful day of golf and fun, ending at the "19th hole" for raffles, prizes, a silent auction and Cher's special message. Everyone who golfed got a "Pete's Scramble for CCA" T-shirt to help spread awareness and acceptance of people with facial differences.

Word spread far about this year's outing, thanks to an article about Peter in the local newspaper and a story published in *Children's Hospital of Michigan* quarterly magazine. A "kick-off" party the night before was also added to this year's festivities.

The Dankelsons wish to send their thanks and gratitude to all of Pete's generous individual and corporate supporters as well as several PGA and NASCAR professionals who graciously donated memorabilia for the silent auction and raffles.

Mark your calendars for next year's outing on May 20, 2006, at Beacon Hill. All levels of golfers and support are encouraged to attend!



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Cher

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The views and opinions expressed in this newsletter are not necessarily those of CCA.

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