ccanetwork

newsletter of the children's craniofacial association   Cher — honorary chairperson   fall 2005

inside

Jylian Bilbow

jylian's story

by Kendall Bilbow

On March 17, 2002, we headed to the hospital to welcome our first baby daughter into the world. John and I always knew that raising a family was our first priority. I had been blessed with a happy healthy pregnancy, and my labor was to be induced on St. Patrick's Day! The pain caused by twelve hours of "natural" labor was almost unbearable for me, but John vividly remembers how the mood of anticipation in the room suddenly changed to that of worry. Jylian's heart rate was dropping drastically, and I was soon rushed to the operating room for an emergency C-section. John could only watch through a window in the operating room, but he recalls the reaction of the medical staff and the sense of urgency that filled the room. Jylian let out a faint cry but had to be immediately intubated. She

see **jylian,** page 9

lessons learned

The recent national tragedies caused by hurricanes Katrina and Rita have presented Americans with a few life lessons. People of all economic levels were forced out of their homes, some with greater haste than others. Some have already returned home, and some may never go back. Many affected will be able to adjust to the economic burden and psychological hurt that they have experienced; many will not.

As this panorama unfolded in the media I saw a parallel to CCA and the families affected by a craniofacial condition. First, there is an immediate impact on the family having a newborn with a craniofacial condition.

see **chair,** page 15

meet lexie adams

Lexie Adams and her mom

Introducing our latest CCA Kid, six-year-old **Lexie Adams** from Tacoma, WA.

Lexie started Kindergarten this year, where she draws, writes her ABCs, reads books, "does worksheets" and goes to the library. But her favorite school activities are riding the bus, having lunch, playing outside and attending movement class.

Speaking of movement, Lexie has been taking tap, ballet, jazz and gymnastics classes for the past two and a half years. She really enjoys her dance recitals. When asked if she likes performing on stage, she quickly replied, "I love to! I get to dress up really pretty."

She also spends a lot of time outdoors. Besides recess, she enjoys ice skating, roller blading and riding her bike. And there's always time for her pets: dog Patches; fish Onion; and hermit crabs Speedy and Molly.

Lexie is really creative and loves to color, cut and paint. In fact, she just finished making a lamb puppet. "She's always creating," her mom said. And it helps that she has three grandmothers who keep her well stocked with arts and crafts supplies!

Lexie and her family found out about CCA through a friend. Through CCA, Lexie has made a lot of friends. She and her family have attended the Tempe and Nashville retreats and plan to be in Hershey, PA, for next year's retreat.

She also had the opportunity to meet Cher backstage at one of her concerts. And, as all the CCA Kids interviewed would agree, Lexie thinks she's very nice.

Lexie has Crouzon syndrome. She has had three surgeries so far, and she's about to go to the doctor to find out how many more she has to have. Through all of the appointments, procedures and surgeries, she has been very brave, cooperative and strong. And that's her advice for other kids in her situation. "Doctors give you great care. Be brave and do what they tell you," she said.

Lexie dancing with her buddies at the 2005 Cher's Family Retreat

cca kid

meet casey deakins

Casey Deakins

Meet **Casey Deakins,** our newest CCA Grad. Casey, who lives in St. Augustine, Florida, graduated cum laude from Pedro Menendez High School last spring and is now enrolled in St. Johns River Community College, where she plans to pursue training to be a radiology technician.

Casey had a great senior year: She played percussion in the Falcon Regiment Marching Band, won a trophy for her multimedia presentation at the district Future Business Leaders of America, and looked beautiful for her senior prom!

She continues to take piano lessons and enjoys hanging out with friends and taking care of her nieces and nephew. She also enjoys horseback riding every chance she gets.

Casey, who has Apert Syndrome, enjoys life and is generally cheerful and enthusiastic. She has, of course, faced the same issues that most of CCA's kids have faced: facial differences, surgeries, teasing, and, sometimes, low self-esteem.

Her advice to the younger kids is to try to ignore stares and teasing and know in your heart that you are a worthy human being. She thanks God for all her friends, family and teachers who respected her as an individual and looked beneath the surface to get to know her and her capabilities.

She urges parents and others to allow each person with disabilities to be as independent and "normal" as possible and always to keep expectations for the person high! She says, "All we want is a chance to prove that we are capable people and have so much to give! Please give us that chance!"

We wish Casey best of luck as she pursues her college studies and look forward to seeing her at the retreat in Pennsylvania — her tenth one to attend!

Macey and Raven, two sisters having fun on the dancefloor

Mom, Raven and Macey at the 2005 Retreat

meet cca big sister, raven atkins

My name is **Raven Arielle Atkins.** I am 12 years old, and my birthday is October 4th. I attend Sacred Heart School, and I'm in the eighth grade.

I am a cheerleader and a member of the Beta Club. I'm also in the choir. I played volleyball in sixth and seventh grade, and I'm trying out again this year. My favorite subject is math, but I still like my other classes. When I'm not at school I like to shop, go to the movies and go to my cousins' and friends' houses. I like going places and just having fun.

I have two brothers and my sister, **Macey.** Macey has a facial disorder called Pfieffer syndrome. When Macey was first born, I was curious and wanted to know all about her sickness. I really miss her when she is in the hospital and can't wait for her to come home.

When she's home, I help my parents by changing Macey's diapers, giving her a bath, feeding her and giving her breathing treatments.

I attended the last two CCA retreats, and the things I enjoyed most were the activities, pool party, dinner dance, going to the movies and shopping. And the resorts were really pretty.

Having Macey as a sister is different because I never knew anyone with a facial disorder. Even though she has one, I still love her. This also shows me not to judge others.

ccasupersib

ccabikernews

special insert to the newsletter of the children's craniofacial association Fall 2005

Cher — Honorary Chairperson

Jill Gorecki, Shari Green, Rob Gorecki and Marilyn Harrison; Shari and Marilyn are volunteers for CCA from First Gold Hotel.

ambassador's report

CCA's 2005 motorcycle raffle is over, and here's the report on the week of August 6 to13 in South Dakota! This year's raffle was a bit different because we had a custom bike built by **Porky's Chopper Co.** out of Dayton, OH. It is the first edition "Buffalo Chip" bike and was built live at the campground during the week.

When we arrived, we didn't expect the large semi-trailer "stage" that **Andy McCaslin** of Porky's was using to showcase the activity! It drew lots of spectators interested in seeing what the plan was. We set up our tent and sold raffle tickets with the help of **Greg Patterson, Deb Keith, Tammy Van Ness, Kevin Braden, Alan Gorecki, Theresa Rouse, Rhonda Hilliard, Marilyn Harrison, Shari Green, Randy Bush** and **Dawn Allen.** Andy's helpers, **Dean, Don, Harold, Tommy, Chopper Dave, Paul** and **Laney** helped talk up the charity to prospective ticket buyers as well.

There were lots of changes at the Buffalo Chip Campground, but our hosts, **Rod "Woody," Carol, Toni** and **Damon Woodruff** made sure we knew our way around. **Jeff Ice** and **Bonnie London,** her son **Donny,** his wife **Donna,** and **Brad Bruns**

see **ambassador,** page 6

Bike winner, Russ Narzinski (left) poses with Survivor favorite, Rupert Boneham

winners take the bike, and the art

Congratulations **Russ Narzinski** of St. Louis, MO. This lucky winner of the CCA WIN a BIKE 2005 raffle is the proud owner of a first-edition Buffalo Chip motorcycle, custom-built at the Buffalo Chip Campground by **Porky's Chopper Co.**

Russ bought one ticket at our booth at the Buffalo Chip Campground during rally week. The next day his cousin bought him one more, which was the ticket that won Russ the one-of-a-kind bike. Russ chose a Candy Tangerine color for the bike and will be presented with his prize in October during Biketoberfest in Daytona, FL.

see **winners,** page 6

ambassador, from page 5

assisted us with setting up our tent each day and running backstage with the bike wheels for the bands to autograph. Woody signed the bike and the week's headliners on the Chip's main stage also signed. Among them were **Shinedown, Dickie Betts, Tim McGraw, Keith Anderson, CCR, Toby Keith, Steve Miller, Queensryche** and **Disturbed.** Most all of them gave autographed items to boost ticket sales, too, thanks to **Brad Coombs** who was backstage and booked the acts for Woody. I'm always glad to visit our other friends, **Tom Kingsbury,** who puts CCA on the big screens, and **Steve Owen and his Crew,** who help us with our raffle drawing and everything else backstage.

Also boosting sales were visits by this year's **Miller Lite girl, Jenn Rose,** and from the **Hawaiian Tropic** modeling contest finalists, who also signed items for onlookers and ticket buyers. Each day, the bike looked better and better. Andy even let me fabricate some parts to be used! Our friend, **Terry Schmidt** contributed bandanas for us to hand out and **Mike Sanborn** scheduled daily radio spots on all the local stations to promote our fundraiser.

On Friday, we took some time to scope out (ride) possibilities for next year's events. We visited our friends at **First Gold Casino** in Deadwood and picked up stubs and funds for raffle tickets they had sold there. A special donation of a canvas-transfer art print was made to CCA by Harley Davidson commissioned artist, **David Uhl.** Chances to win the print were given to all who purchased 30 tickets for $100 while out at the Buffalo Chip Campground. We stopped by the gallery in downtown Deadwood so I could personally thank David.

Back at the Chip, the bike could not be painted and chromed on the premises, so Andy decided the winner would get to choose the base color! Just before our raffle drawing I cut off the long pony tail of **Bruce Tyrell,** because he promised to get it cut off on stage at an event in July that raised more than $1,000 for CCA. After that, **Russ Narzinski** from St. Louis, MO, won the bike (I just found out he picked out a "Candy Tangerine" orange color for the bike!), and **Randy Merrill** of Ft. Worth, TX, won the print! The weather held out for us most all the week, except for storms on Wednesday night — what a week!

I'm off to MMI this November, (Motorcycle Mechanics Institute), and there's no summer break at that school, but if CCA goes to Sturgis in 2006, I hope to be there to report for you once again!

CCA Ambassador, Rob Gorecki

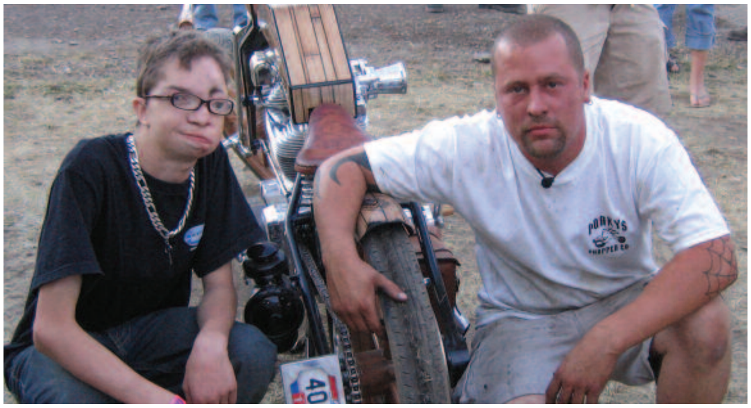
winners, from page 5

Bear Merrill, winner of the art print

And another congrats goes to **Randy "Bear" Merrill** of Ft. Worth, TX. He's the winner of a beautiful canvas-transfer art print that was donated to CCA by Harley Davidson commissioned artist, **David Uhl.** Chances to win the print were given to all who purchased 30 tickets for $100 for our bike raffle while out at the Buffalo Chip Campground.

Way to go winners! And on behalf of all CCA kids and their families, thank you to all who participated in the raffle!

Rob Gorecki thanks artist David Uhl



who built that custom bike?

Andy McCaslin, a young entrepreneur in the custom bike world who runs **Porky's Chopper Co.** in Dayton, OH, was enlisted by **Rod "Woody" Woodruff** to build the first-edition Buffalo Chip custom motorcycle.

Andy's brainchild was to build the bike live on the grounds for all to see. Together, Andy and Woody decided that the project should benefit CCA.

Andy pounded the pavement for support and found help from the industry in Ohio, South Dakota and parts beyond. The following businesses donated or discounted parts for building the bike:

- A to Z Painting
- Aesthetic Finishers
- American Industrial Maintenance
- Arlen Ness
- Avon Tire
- Baker Drivetrane
- Blair LLC
- Carl's Speed Shop
- Crane Cams
- Custom Gunsmithing and Engraving
- Designs Now
- Headwinds Headlights
- Hog Halter Inc.
- J&P Cycles
- Jim's Body Shop
- Karyacan
- Lincoln Electric
- Mayhabs Hot Rods
- Mr. Lucky Seats
- Porky's Chopper Co.
- Russell Fittings
- Showride Images
- Spyke Starters
- Tower Machine
- Vance & Hines Racing

Andy, Dean and Porky's Chopper Co. would also like to thank everybody at the Buffalo Chip, staff and vendors, as well as **Mike Breeding, Tommy Cooper, Harold Clifton, Paul Dicory, Mike Mahab, Tom Manshine, Tim** and **Colleen Marsh, Elton Parrish, Don Strouth** and **Taiwan Tommy.**

And thanks to the many others who we were fortunate enough to meet but just didn't get their name!

more friends become family

In July, prior to Rally week in Sturgis, our good friend **Mike Sanborn,** held a Charity Dart Tournament at **The Clock Tower Lounge** in Rapid City to boost raffle ticket sales.

And **Bruce Tyrrell,** longhaired friend of CCA, challenged the crowd to raise more than $1,000 in ticket sales. If they did, he'd let someone cut his hair on stage before the bike drawing. They did — in fact **they raised $3,064 for CCA!**

CCA Ambassador to Sturgis, **Rob Gorecki** did the honors, cutting off Bruce's long ponytail, which was later donated to **Locks of Love.** (Bruce has known Rob for years, having met him while working backstage at the Chip.) Bruce is quite a guy!

Thank you to all who supported and participated in the effort, including Bruce, Mike, The Clock Tower Lounge, **The Legendary Buffalo Chip, Fisher Beverage, Eagle Beverage, Black Hills Harley Davidson, Ramada Inn,** and **Cheers Hills Vending.** Welcome to the family!

back-to-back leading the pack

Once again, the **Dale family** of Horseheads, NY, led the pack of CCA families and friends selling raffle tickets. **They sold almost 400 tickets and raised about $2,000!**

Tim McGraw, one of the headliners at the Chip, where the raffle drawing took place, autographed a CD, which was sent to the Dales for their repeat accomplishment. Thanks again **Kristine, George, Jeremy** and **Tommy Dale,** and to all of our families and friends who helped sell!

sturgis 2005

Jylian, from page 1

could not breathe on her own. John touched her chest briefly, and she was rushed to the NICU. Our family and friends waited anxiously in the hall, but as the tiny bed rushed by, everyone knew something was not right.

I soon woke from sedation, and I was informed that Jylian was born with a multitude of "anomalies." The situation was surreal, and we were so sad and confused. The next few days were touch and go, and the doctors knew that Jylian's condition was extremely rare. Jylian's jaw was recessed, and it was blocking her airway. Her skull was abnormally shaped, her fingers and toes were very long and thin, and there were concerns about her heart and vertebrae as well. We were not able to hold Jylian. We knew practically nothing about medical procedures, and we desperately wanted to be told that there was an easy way to "fix" all of Jylian's abnormalities. We were emotionally exhausted, yet hopeful and so proud of our precious girl. In one week, I felt as if one hundred years had passed. I was in a new world, and I was instantaneously a different person.

Jylian was transported to Cook Children's Hospital soon after her birth. She needed a tracheostomy in order to be able to breathe on her own. On the scheduled day of her surgery, her surgeons discovered a tear in Jylian's intestine. She underwent emergency exploratory surgery, and she needed a temporary colostomy. We felt as if we had been knocked to the ground again, but we pushed on and immediately learned how to care for the colostomy. At just under one month old, Jylian was able to have the tracheostomy procedure we had been waiting for. I was able to HOLD my sweet baby for the very first time.

John, Kendall and Jylian Bilbow

Jylian was now able to leave the NICU, and we moved upstairs to the Transitional Care Unit. John and I literally lived in the tiny room with Jylian, and we learned how to care for her trach. We were instantly comfortable with our new responsibilities as her (medical) caregivers, and we even amazed each other. Looking back, we know that God was carrying us through this time. We also relied on each other for the emotional strength to make it through each day. Jylian had another abdominal surgery at 8 weeks old to close her colostomy, and she was given a G-button for feeding at this time (she is still fed through the G-tube today).

Finally, on May 20, 2002, we were able to bring Jylian Shay home! We had already made arrangements to meet with Dr. Kenneth Salyer for Jylian's initial craniofacial visit and skull scans on May 23. We had begun to research craniofacial conditions and treatments while we were staying in the hospital and were confident that Dr. Salyer's craniofacial team at Medical City Dallas would be able to give us help and hope.

Jylian's abnormally shaped skull was officially diagnosed as craniosynostosis, and on September 13, 2002 her first cranial surgery was performed in Dallas. Because of Jylian's upper spinal anomalies, her surgeons removed much of the base of her skull and part of her C-1 (cervical spine). She lost a lot of

see **Jylian,** page 10

Jylian, from page 9

blood, and she was in the PICU for about six days. We felt relief to know that they had given her brain plenty of room to grow. Four months later, Jylian's second skull surgery was done. This time, her surgeons worked on the front of her skull, including her brow-line. We began to learn just how strong-willed our sweet Jylian was. Her little eyes swelled shut, but she learned to stretch her mouth open very wide in order to "pull" her eyes open. We would laugh because it was so cute, and our giggles made her laugh until her eyes closed again! It was precious.

Our next step was the jaw distraction. This procedure would advance Jylian's lower jaw, so that she would no longer require the trach. We had yet to hear Jylian's sweet laughs (and cries), and we were looking forward to the possibility of life without the trach. The external jaw devices were cumbersome, but she adapted as if they weren't even there. John and I turned the devices everyday, eventually advancing her lower jaw significantly. She would wear the devices for almost six months.

Jylian's first year was filled with surgeries, but throughout this time, we were hopeful that we would see her gain strength. Her physical progress was very slow. We were beginning to learn that Jylian's syndrome was more severe than we had hoped, and it affected much more than her craniofacial bones alone. John and I have remained hopeful and positive from day one. There were (and are) situations in which one or both of us "break down," but we have always been able to see the greatness and the miracles in Jylian's life. At this particular time, as we were coming to realize how significantly Jylian's hypotonia (low muscle tone) was affecting her life, our hearts were heavy. Jylian's sweet spirit and bubbly personality carried us through!

Surgeries became less frequent, and we had more time to realize the need for networking with other families and raising awareness of craniofacial conditions. We also felt called to use our resources to help raise money for children who do not have access to craniofacial surgeons and quality care. I truly believe that Jylian has touched lives, and we are committed to helping her make a difference. I created Jylian's website (www.jylian.com), which has helped share her story and information about her surgeons and the craniofacial organizations that mean so much to us.

Jylian's third cranial surgery was done just after her second birthday, and she recovered quickly. Home therapy resumed, Jylian was doing well, and we were anxiously preparing for our very first CCA Retreat. At the 2004 Tempe CCA Retreat, John and I felt a sense of peace and normalcy that we had never experienced. We were able to let go of our burdens and simply have fun with other families who knew exactly what those burdens were all about. It was an amazing time, and we knew we never wanted to miss a CCA Retreat!

Jylian's jaw devices had been off for more than six months, and we began to "cap" her trach. We had to go through several sleep studies and failed attempts to remove the trach. We had always been comfortable with the trach, and we knew that we couldn't let this difficult part of our journey lower our spirits. In God's time, when we were least expecting it, Jylian's trach came out successfully! This was a huge step for Jylian!

Our time of celebration became short-lived. We have learned to "expect the unexpected," and we were knocked off of our feet again when we learned that Jylian's spinal anomalies were severe, and her spinal cord was potentially at risk. Jylian needed surgery to fuse her two upper vertebrae to the base of her skull. This would require that she wear a halo for three to four months. We had our brief moment of disappointment, and then we began to look forward to the surgery that would hopefully bring stability to our baby girl.

We learned that Jylian has an extremely rare *Marfanoid Craniosynostosis* syndrome, which is a connective tissue as well as a craniofacial disorder. There are only about 20 other people in the entire world that have been diagnosed with this particular syndrome. We now know more about treatment for

> “At the 2004 Tempe CCA Retreat, John and I felt a sense of peace and normalcy that we had never experienced. We were able to let go of our burdens and simply have fun with other families who knew exactly what those burdens were all about. It was an amazing time, and we knew we never wanted to miss a CCA Retreat!”

Jylian’s heart anomalies, and we’re grateful for our new information.

Although much of this year has been a waiting period for the spinal fusion, Jylian’s made some huge strides. She began homebound pre-school, and it’s absolutely amazing to watch her learn. She LOVES school, and she is so bright! Jylian loves the “Wiggles,” and she doesn’t need to be on her feet to do the moves to EVERY “Wiggles” song! She loves her dolls, music and her new “princess” room! Through the miracle of adoption, our Jilly Bean will also be a big sister in the months to come. We can’t wait!

Jylian’s spinal fusion will take place soon, and we are prepared. We have been blessed with an amazing support system, including friends, family and our church family. Jylian inspires us everyday, and I don’t know who I would be without her. When we began to plan our family, I never would have imagined that we would be faced with so much adversity. Life is a gift, and it’s not easy. God has given us peace and joy in the face of the adversity. Jylian is not her fragile body. She is the essence of strength and determination. We look at Jylian and see what life is really all about.

2006 Retreat Info

Registration is open for the 2006 Cher’s Annual Family Retreat to be held in **Hershey, Pennsylvania June 22–25th.** Contact **Annie Reeves** at 800-535-3643 or email her at AReeves@CCAKids.com for a registration form and reservation information. Due to space restrictions at the hotel, rooms will be limited to immediate family members (parents/siblings) of a child or adult with a craniofacial condition. If you have additional family members who wish to attend, contact Annie for details.

donors, april 1, 2005 through september 30, 2005*

Gifts from Individuals

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(up to $100)

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*Listed are monetary donations since last September. We are extremely grateful for these and all prior donations, raffle ticket purchases, fundraisers and in-kind donations not recorded here.

We do our best to accurately recognize donors. If you notice an error, please let us know.

save those cells!

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! Just send them to us. If you think you can fill a whole box, call us and we will send you a labeled, UPS pre-paid collection box. It's that easy.

be remembered… bequest!

As you consider your year-end giving and a 2005 income tax savings, this is also a good time to consider long-term tax savings. About 50 percent of what you leave behind at the time of death goes for estate tax. That's higher than income tax!

It pays to do some advance planning. When you consult an attorney or investment professional regarding your will and assets, we hope you'll consider a charitable bequest in your will to CCA. Such a bequest not only benefits CCA, but it also saves you tax dollars.

cca annual giving campaign

When you receive our annual funds appeal letter, you'll 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, CCA 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 do not receive our letter, you can access it at CCAKids.com, where you can also hear John play the piano.

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 AReeves@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

crawford's walk for cca

Special thanks to **Mary** and **Parker Crawford, their mom Lisa** and everyone involved in their Crawford's Walk for CCA. Even with a small turnout, their efforts raised over **$300** for Children's Craniofacial Association! Thanks!

If you are registered with Schoolpop to benefit CCA, please notify us at the CCA office: 800-535-3643.

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!

2005-2006 calendar of events

date	event	contact
December 10	**CCA Midwest Holiday Party** Noon to 2:00 p.m. (light refreshments served)	JGorecki@CCAkids.com 262.781.0056 800.535.3643
December 10	**CCA Dallas Holiday Party**	AReeves@CCAkids.com 214.570.9099 800.535.3643
June 22–25	**16th Annual Cher's Family Retreat** Hershey, PA	AReeves@CCAkids.com 214.570.9099 800.535.3643

year-end contributions

Cash donations to CCA can be made by credit card anytime through December 31st. The IRS considers the date the donation was charged to your card as the contribution date even though the bill won't come due until January.

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.com

family and friends raising funds

thank you, **Century Lodge #492 Independent Order of Odd Fellows.** Once again, they've stepped up and raised $1,000 for Children's Craniofacial Association. The Odd Fellows is an international, fraternal benevolent society, and the award-winning Century Lodge #492 in Carpenterville, IL, boasts many "biker" brothers. They became supporters of CCA after being introduced to **Rob Gorecki** during our annual motorcycle raffle at the Black Hills Rally in Sturgis, SD. Thank you Odd Fellows for making a difference for CCA kids!

And a thank you goes to CCA Mom, **Jennifer Guerra** and **Katz's Deli and Bar** of Houston, TX. They managed to raise $500 against incredible adversity during the past two months of weather and refugee/evacuee chaos!

Jennifer has twin daughters, **Natalie and Olivia.** Natalie was born with Pfeiffer syndrome. Jennifer submitted CCA as a recipient of Katz's "Benefit Table" funds. The restaurant gives 10% of the meals served at this special table for a month and they were kind enough to post CCA as beneficiary for two consecutive months.

Thanks again, Jennifer, for thinking to help others when you already have so much on your plate! And thank you, Katz's, and all who ate there!

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.

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!

If you have not yet submitted your recipes for our CCACookbook, please get them to us by mail or email asap!

teach your children well — give a meaningful gift this holiday season

Can't decide what to give those special people on your list who have everything? Consider a gift of $25 or more to CCA in honor of a relative, friend or business associate. We'll then send them a card that will acknowledge your generous gift on their behalf. What a wonderful way to honor someone, help your charity and teach your children the true meaning of the season.

regional volunteers

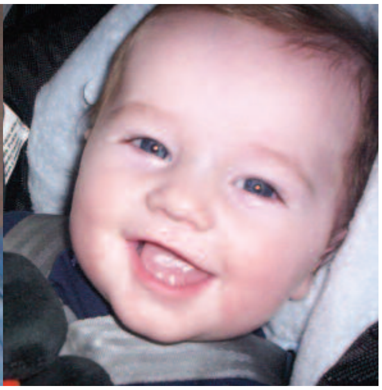
Public awareness about craniofacial conditions is important on several levels. It's important that families find quality medical care, that healthcare professionals are aware of the special medical and emotional needs of children and adults with facial differences, that the public understands and accepts 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 AReeves@CCAKids.com.

annie's bundle of joy

CCA welcomes Program Director, **Annie Reeves** back from maternity leave for the birth of her son, **Connor Glen**. Annie was disappointed to miss our Annual Family Retreat at the end of June, but Connor was almost due at the time. He was born just a week or so later on July 7, 2005, weighing in at 8lbs, 8oz and 21 inches.



chair, from page 1

Families deal with a gamut of feelings and emotions, and they also seek answers to their questions. They turn to family, friends and medical professionals for understanding and support. They also turn to CCA. Some CCA programs and services are designed to provide parents, regardless of income level, with immediate support and valuable information in the early stages. Those services include:

- Toll-free physician referral
- Toll-free support line
- Craniofacial Syndrome booklets
- Advocacy to ensure quality care
- Annual family retreat

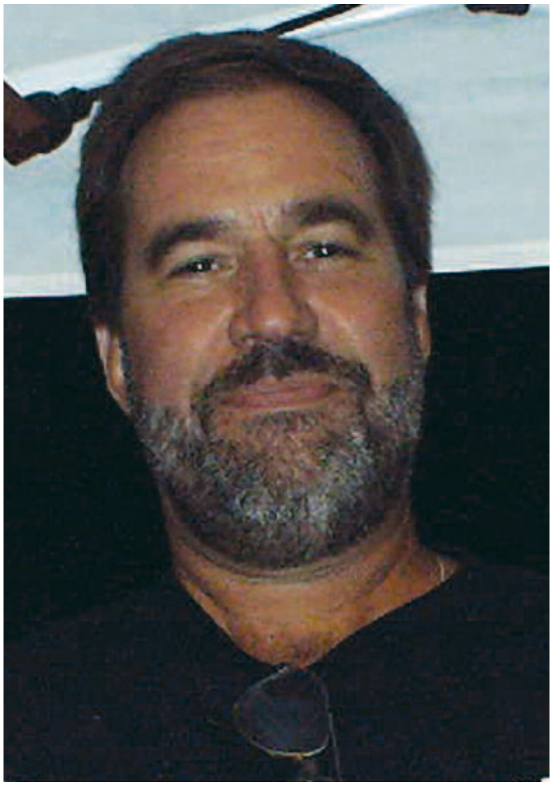
Katrina and Rita captured the entire media's attention. Most Americans now have vivid images of the destruction and many have responded with kindness and financial support. For CCA, each September has been designated craniofacial awareness month, and our goal is to capture greater media attention in the ensuing years. We need people's financial support to continue providing the level of services that are necessary. We need to educate the general public of our vision, "…a world where all people are accepted for who they are, not how they look."

In early October, U.S. Representative Mike Ross of Arkansas introduced legislation to guarantee insurance coverage for craniofacial patients. This proposed legislation was introduced because insurance companies will sometimes label needed reconstructive care as "cosmetic" and deny coverage for this or other reasons. The Reconstructive Surgery Act of 2005 or HR 4022 seeks to guarantee that insurance companies cover medically necessary care.

Approximately 100,000 children are born each year with some degree of craniofacial disfigurement. In addition, both children and adults can develop such conditions through trauma and disease. This legislation will help these children and adults. Families and friends, it's time to mobilize. Go to the following Web site for more information on this very important piece of legislation and to find out what you can do: www.aica-advocates.blogspot.com.

Robert Vargas, *Chairman*
Board of Directors

3cheers for volunteers!



Greg Patterson

You've seen his name mentioned often in our newsletter for a number of events. **Greg Patterson** has been a dedicated volunteer for CCA for more than three years.

Although Greg volunteers in many capacities, he's best known for his contribution to the annual Sturgis motorcycle raffle. In addition to selling tickets, he has spent numerous hours on the road transporting the raffle motorcycle and CCA equipment each year. Greg has generously donated all fuel and travel expenses, not to mention his personal time.

Greg also helps in the office with the quarterly newsletter and lends his photographic skills at various CCA events.

Greg is truly a special guy who always helps out when we ask. Three Cheers for Greg!

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