ccanetwork

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

fall 2003

inside

The 2004 Annual Cher's Family Retreat will be held in Tempe, AZ on June 24-27. For more information contact Jana Butera at 800-535-3643 or JButera @ccakids.com.

a mother's story

I was 29 years old when I became pregnant with my first child. My doctor estimated my due date to be October 3, 2002, my deceased mother's birthday, but I was actually induced October 4, my stepdaughter's birthday. Everyone had told me that I was sure to have a healthy baby. My family and I were very excited.

My daughter, Macey Gaitlyn, was born on October 5 at 8:10 am, weighing 6 lbs, 7.4 oz. The doctors seemed to think she was a healthy baby, saying that her head was swollen because of the journey through the birth canal. I wasn't so sure. Not being familiar with any other "syndromes," I immediately thought she had Down's Syndrome.

My obstetrician called a neonatal specialist to observe the shape of her head. He said that it was normal and the swelling would go down in a few days. Later a nurse

see **macey,** page 13

making a difference

The United States Army currently has a recruiting campaign based on the slogan, "An Army of One." Within CCA, we certainly have many examples of how one person can make a difference. I think we all know of individual patients, family members, doctors, nurses or other caregivers who have changed lives for the better.

One such person is **Donna Gossett** of Cullman, Alabama. When she was nine years old, Donna was diagnosed with fibrous dysplasia, a chronic skeletal disorder. In her case, the condition led to abnormal growth of her left cheek.

Donna grew up with the condition although the stares and comments of both children and adults on the street were often

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empowering and giving hope to facially disfigured individuals and their families

Freddie (right) and his brother, Jonathan (left) with their dirt bikes.

ccakid

meet freddie seitz

My name is **Freddie Seitz.** I am eleven years old. I was born in Youngstown, OH, on Monday, July 20, 1992. I have two brothers, **Jonathan** and **Robbie**. Robbie is two years old and Jonathan is eight. I live in Poland, Ohio with my parents, and my brothers.

I have a Honda XR70 dirt bike and so does my brother. We like to ride when we come home from school. I like to ride my stunt bike too with my brother and go off of jumps. I also race in the All American Soapbox Derby. It's a lot of fun — the best part is going fast. I'm a Cub Scout and a second year Webelo with Pack 44. We do a lot of fun things at Scouts. I also like to play Flag Football. My team's name is Funny Farm, which is the name of a comedy club in Youngstown.

I started a new school this year, where I'm a fifth grader. It was a little scary at first, but I like it, and all of the kids are really nice. I made a lot of new friends — many of them are in the sixth grade. They're learning sign language so we can communicate easier. I am deaf and I am trying to teach the kids some signs. My friends also talk to me by writing on a note pad that I carry with me.

I was born with Goldenhar syndrome and have had a lot of surgeries. We go to **Dr. Kawamoto** in Los Angeles for my surgeries in the summer. It's not fun having the surgeries, but when we go to L.A. we get to visit a lot of cool places. We've been to Disneyland and Legoland, where there are a lot of cool buildings made out of Legos.

I also belong to CCA. We go to parties with the group and have a lot of fun. Sometimes **Cher** comes too and brings a lot of cool things. I have a really good time seeing her at her concerts. She's very nice to us, and if she reads this I want to tell her, "Thanks!"

meet scott guzzo

I'm **Scott Guzzo.** I'm 20 years old and a senior at Central High School in Evansville, IN. My school aide, Mrs. Maxey, has been with me since third grade.

I've been singing in the school choir since seventh grade. Last year, I was in my school's production of Godspell. We had an all-guys, all-night cast party. That was so much fun, especially hanging out with the other kids.

My brother, **Aaron,** is 15, and he is my best friend. He sings and acts in school plays.

As for my hobbies, I love to watch NASCAR races, and Jeff Gordon is my favorite driver. I also listen to music in my basement, which is decorated with lots of disco lights. I play songs on the stereo while I run the lights. Golden oldies are my favorite songs and, of course, **Cher** is my favorite singer and actress. I like to travel and stay in hotels. Sometimes I book my hotel stays through the Internet, to make sure they're accessible for my wheelchair.

Hospitals have always been a part of my life, and I consider the doctors and nurses my friends. When I go to Riley Children's Hospital for my annual visits, we all have a good time together.

I've always gone to church and love God. And my parents have taught me that one person can make a difference in things. I think that I do make a difference.

I wish people would understand that I'm okay, just like I am. I know that I'm different, but that's okay. Every person is different. Sometimes I think about what it would be like to walk, to eat food through my mouth and to talk so everyone could understand me — but that doesn't necessarily mean I want to change those things. We all are supposed to do the best we can with who we are. **I love being me.**

Left: Scott Guzzo in his senior picture.

Below: Scott and his mom conference together at the Congressional Forum on the Reconstructive Surgery Act in Washington DC.

At bottom of page: The Guzzo Family poses with Cher during her World Tour.

mr. guzzo goes to washington

On June 25, 2003, I went to Washington, DC, to the United States Capitol with several other people from CCA to testify in a Congressional Forum on the Reconstructive Surgery Act. That was an awesome experience.

Our family and **Wendelyn Osborne** drove from our hotel to the guard gate beside the Capitol building, looking for a parking place that was wheelchair-accessible. The guards first did a security check on our van. They

see 2003 **washington dc,** page 14

empowering children to cope with teasing

by Amy Dodge, Child Life Specialist, North Texas Hospital for Children at Medical City of Dallas

teasing can happen to anyone, but some research indicates that children with disabilities are at a greater risk because teasing is usually about a visible difference. According to Ms. Joseph, social worker at Bloorview's neurodevelopmental program, "It's human nature to be curious, so from an early age children with disabilities need to be armed with the information to respond to questions, stares, and unkind comments." Parents and professionals play a critical role in preparing and empowering children with disabilities to cope with challenges of their chronic condition.

Talking with children about their facial difference can be a powerful beginning for more discussions regarding feelings and expectations for the future. It's important to use developmentally appropriate language and concepts children can understand. For example, preschool age children may learn about differences best by understanding differences around them. For example, parents can point out differences such as: some dogs have short legs and some have long legs. Whereas school age children may understand simple explanations, but have questions about the causes. Such as, "Do other children have these differences?" Is the condition permanent?" In order to come to terms with the condition, children need the opportunity to ask questions, take an active role in self-care, and learn how other children cope with their feelings and condition.

Adolescents need to make the decision about how much or little information they want to disclose to different people. Being involved in decisions regarding possible options is also essential for this age group because this control will foster relationships, increase compliance, and improve self-esteem. Children who learn, practice, and utilize strategies in teasing situations will cope more easily, and have less feelings of helplessness. Ms. Freedman, author of *Easing the Teasing: How Parents Can Help Their Children* says, "Teasing cannot be prevented, and children cannot control what others say; however, they can learn to control their own reactions."

The following are effective strategies developed by Ms. Freedman to be utilized in teasing situations, which can strengthen coping skills. The self-talk strategy encourages the child being teased to think of positive attributes about themselves. For example the child could say, "Whose opinion is more important, the teaser's or mine?" A teaser is seeking a reaction, so ignoring the teaser can also be very effective. Children should be encouraged to role-play walking away or pretending like they are invisible to show they are ignoring the teaser. Reframing is another way to cope with teasing. For example, if a teaser is calling a child "four eyes" that child can respond back with "thanks for noticing my glasses." Yet another coping strategy is using the "I" message in which children express how they feel and what they want changed. For example, "I feel upset when you call me brace face and I would like you to stop." Other strategies include visualization in which the child pretends to have a protective shield that makes the teasing comments bounce off. Sometimes adult intervention is necessary so children need to know it is okay to ask for help. Strategies that are effective in one teasing situation may not be in all situations. It is important for children to practice possible responses to teasing that they plan to utilize in teasing situations.

Tips for parents to help children cope with differences

- Show your love and acceptance of your child's facial difference by smiling, being physically close, touching your child, especially his or her face and by making eye contact.
- Tell your child about their facial difference in simple, honest words they can understand, emphasizing it's nobody's fault and at the same time pointing out strengths.
- Support your child's efforts in developing friendships by encouraging sharing, giving, fairness, kindness and consideration.
- Help your child make a simple plan to respond to questions or comments. A simple, matter of fact explanation such as "I was born this way" or "This is just the way I am" is sufficient for most children.
- Brainstorm together a list of possible questions to anticipate from children:

see **teasing**, page 5

teasing, from page 4

"How did it happen?" "Can I catch it?" "What is it?" "Will it go away?"

- Help your child understand they are not alone by introducing him/her to other children who share similar experiences.
- Children need the control of how much or little they want to disclose to different people depending on how they feel at that time.
- Communicate with your child's teacher throughout the school year to explain any medical limitations and ways to enhance learning.
- Discuss with your child why some children ask questions or make comments about their differences. Help your child to understand for the most part other children are just curious and do not mean to be hurtful.
- If your child is teased, help him or her to problem solve how to handle the situation with a positive response.
- Practice and role-play with your child different strategies to use in teasing situations.
- Allow older children an active role in surgical decision-making to help your child feel he or she has a say and that their opinion is valued.
- Your young child may want to present information such as a show and tell session in their classroom about their facial difference.
- It is human nature to protect your child from stressful situations; however, when children try new things they gain confidence and obtain the skills necessary to be successful in life.
- Consult with a child psychologist or social worker for additional support and resources.

Books for children and parents

- *The Berenstain Bears and Too Much Teasing* by Stan & Jan Berenstain
- *Chrysanthemum* by Kevin Henken
- *Anansi and the Talkling Melon* by Eric A. Kimmel
- *Princess Penelope's Parrot* by Helen Lester
- *Snail Started It* by Katja Reider & Angela von Roehl
- *Easing the Teasing: Helping your child cope with name-calling, ridicule, and verbal bullying* by Judy S. Freedman
- *Bullies are a Pain in the Brain* by Trevor Romain
- *What to do...when kids are mean to your child, Parenting Guides,* vol. 1 by Erin McCoy
- *How to Handle Bullies, Teasers and other Meanies: A book that takes the nuisance out of name calling & other nonsense* by Kate Cohen-Posey, & Betsy A. Lampe
- *Stick up for yourself. Every Kid's Guide to Personal Power and Positive Self-Esteem* by Gershen Kaufman, & Leu Raphael

References

Bloorview MacMillan Centre, 2001. *Preparing Kids for Teasing.*

Freedman, J.S. 1999. *Easing the Teasing: How Parents Can Help their Children.*

Pope, A., 2003. *Advice for Parents: Helping Children to Tell Peers.*

Snyder, H., 2003. *What Parents Should Know about Self-Esteem.*

kidshealth.org.

give a gift…

in honor of a loved one this holiday season

You can give a gift to CCA in honor of a loved one. What a great way to make a person feel good, and make a difference, this holiday season. Maybe have the kids give up one gift for themselves and donate in honor of someone else — get creative! We will acknowledge your donation and note "in memory of" or "in honor of" on a card to the gift "recipient."

year-end contributions

did you know…

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.

Source: Financial Literacy Center

We apologize to those of you who didn't receive your newsletter in August. We are working on the problem. Remember you can always go to CCA's Web site **www.CCAKids.com** and download the latest issue.

more corporate opportunities for 2004

The date's set. The bike's been ordered. The schedule's coming together. Now we need your help! We need sponsors/underwriters for our yearly summer fundraiser, our Cher-autographed Harley raffle and motorcycle rides.

Several opportunities to get your corporation's name in front of thousands of bikers and the community at large are described below. We're looking for corporations that want to be involved with making a difference in thousands of kids' lives, while getting extensive exposure and PR for your company. **The Black Hills Motorcycle Rally averages more than half a million people in attendance daily.** And you know bikers could be anyone — your neighbor, doctor, CPA etc.

Your corporate sponsorship helps underwrite the Harley Raffle, as well as the two rides we will be conducting in 2004: Buffalo Chip Campground owner Rod Woodruff's Rod's Ride for Cher's Kids, and CCA's Inaugural Women's Ride.

Title sponsor
$50,000

- One $50,000 sponsor for complete title rights or two $25,000 sponsors to share spotlight
- Event named for Title Sponsor: "(Your name) Raffle/Rides for Children's Craniofacial Association."
- Name in all press releases
- Name prominently placed on printed materials
- Name prominently placed on CCA web site
- Five "Rod's Ride for Cher's Kids" registrations and five Women's Ride registrations, if appropriate (includes ride, dinner and gift bags)
- Your promotional materials at point-of-sales displays
- Ten event T-shirts

Gold Mine sponsors
$20,000

- Name placed on printed materials
- Name placed on CCA web site
- Three "Rod's Ride for Cher's Kids" and Three Women's Ride registrations, if appropriate (includes ride, dinner and gift bags)
- Your promotional materials at point-of-sales displays
- Six event T-shirts

Silver Mine sponsors
$10,000

- Name placed on CCA web site
- Two "Rod's Ride for Cher's Kids" and Two Women's Ride registrations, if appropriate (includes ride, dinner and gift bags)
- Your promotional materials at point-of-sales displays
- Four event T-shirts

Prospector Sponsors
$5,000

- Name on point-of-sales displays
- Two "Rod's Ride for Cher's Kids" and Two Women's Ride registrations, if appropriate (includes ride, dinner and gift bags)
- Two event T-shirts

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 **1-800-535-3643**. All we ask is that you apply at least four to six weeks prior to your next trip.

KlubHouseKids

tThe KlubHouseKids are concerned about and want to make a difference in their community.

This group is dedicated to holding an annual fundraiser to raise awareness of kids with craniofacial conditions and raise funds to support CCA programs and services.

Does this sound like something you'd like to do? Well, in April 2004 you will have a chance. The charter chapter of KlubHouseKids invites you to try out being a KlubHouseKid for the month of April. The KlubHouseKids will spread awareness and sell raffle tickets for a trip for four to Disney World! The grand prize will include airfare, hotel and Disney World tickets.

Sound like fun? Want to help or know some kids who'd want to help? Get a few of your friends together and be a KlubHouseKid. If you have fun helping others and want to start a KHK club, we'll help you get started. If you just want to help CCA during the annual event you can do that too.

For more information about the raffle, email Jana at JButera@ccakids.com

For more information about the KlubHouseKids, see page four of the Spring 2003 *CCAnetwork* newsletter on ccakids.com.

ccabikernews

special insert to the newsletter of the children's craniofacial association
Fall 2003
Cher—Honorary Chairperson

more extended family…

CCA values its volunteers who generously give their time and talents to create awareness and raise much needed funds for programs and services. We worked throughout the year on our Harley Raffle (**Cher** signed the gas tank of a 100th anniversary Heritage Softail), and along the way we encountered many selfless, helpful folks:

The **Eagle Rider** people, especially **Darius "Snowman" Blake,** got us passes and let us set up next to their booth to sell raffle tickets at the Austin **ROT** (Republic of Texas) **Motorcycle Rally.**

We were invited to the **Lonestar Corvette Club** festivities at the **Texas Motor Speedway** outside Dallas in Justin, TX, to sell tickets at their annual gathering.

The **Buteras** and their friend, **Nancy** at **Pier 121** at Lake Lewisville, TX, let us sell tickets to folks on the dock.

We also held our annual ride for Cher's kids while out in the Sturgis area for the Black Hills Rally. Help with items for our **goodie bags** for **"Rod's Ride"** included in-kind donations from **Hal's Harley-Davidson** in New Berlin, WI, **Karim Merali** at the **Radisson Hotel** in Rapid City, SD, **John "Bud" Curtis** of **CSC Distribution, LLC,** in Waukesha, WI, **First Gold Casino,** Deadwood, SD, **Virchow Krause, LLP,** Milwaukee, WI, **Patrick Jackson** of **Premier Cigars,** in Brookfield, WI, **Rod Woodruff** and **Buffalo Chip Campground.**

Daredevil, **Kaptain Robbie Knievel** jumped 100 Harleys in honor of the 100th anniversary year

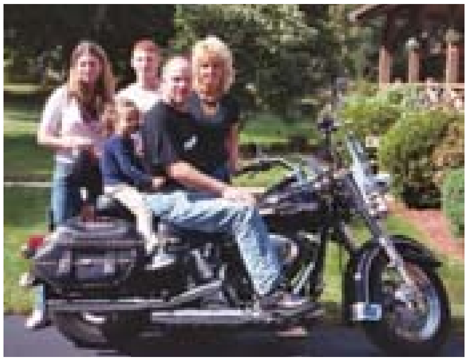
Robbie Goreckie with Kaptain Robbie Knievel.

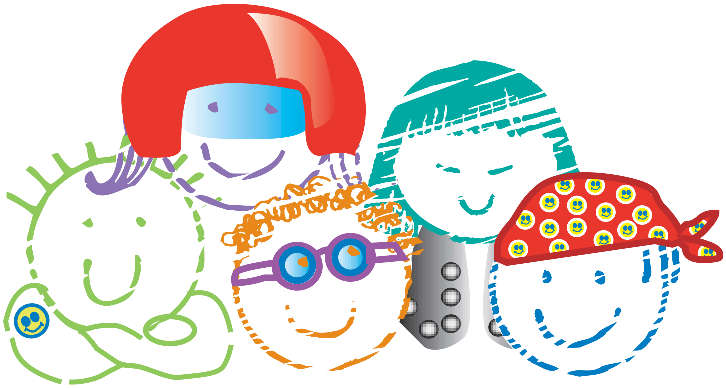
see **friends,** page 9

2003 harley winner

Our 2003 Raffle is over. **Steven Lopriore** of Oxford, MA is the lucky winner of a Black, 100th Anniversary edition Heritage Softail® Classic autographed by Cher! Another on-line ticket buyer (5 for $20) Steve didn't remember entering at first. It didn't take long for the fun of winning to take hold of Steven, his wife Darlene, and their kids. Steve's own words about winning: "It's beautiful. It's a real dream come true for me. When family and friends see it they can't get over the fact that I won it. I'll always remember the reason for the raffle."

Congratulations Steve!





ambassador's report

hello again! **Robbie Gorecki** here, with your report on all the CCA happenings in Sturgis, SD. Since this is the 100th anniversary of Harley-Davidson, we raffled off a special 100th-anniversary edition Heritage Softail Classic. **Cher** signed the gas tank, which made it even more special.

We arrived at the **Buffalo Chip Campground,** our "home" for the week, where **Rod "Woody" Woodruff,** his wife **Carol,** daughter **Toni** and the entire staff treated us like family. Woody's right-hand man and grounds manager, **Dave Vice,** had a motorcycle waiting there for me to use. So, now I can say I learned to "ride" at the Chip. **De Arnold** made me a biker vest just like Dave's to wear, and I had a great time helping Dave and motoring around the campground, meeting new friends and getting them to come to our CCA booth and buy raffle tickets.

Shortly into the week, we made a video commercial, with the help of **Tom Kingsbury,** to run on the big screens between shows at the Chip. This year **Mike Sanborn** made sure we had the local radio stations behind us full force, along with **New York Myke,** talking up our raffle. And to benefit CCA, **Kaptain Robbie Knievel** celebrated the 100th anniversary with a world record jump over 100 Harleys! Thank goodness for **Steve's crew** who helped us set up for Kapt. Knievel's jump.

Friday before the jump we had **Rod's Ride for Cher's Kids.** This year our grand marshal was **Lt. Shane Osborn,** a military hero, and he brought along his wife, **Teri.** The ride began at **Sheridan Lake Marina,** where our new friends **Karen Anderson** and **Mike Yore** helped us stage the ride, and ended with a buffalo pitchfork fondue dinner at the Chip.

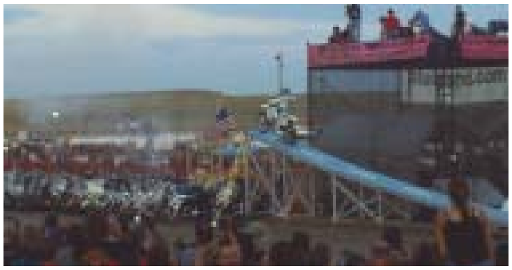
After the ride and jump, people got to meet Robbie Knievel. It was pretty cool. **Brad,** who was backstage, let me meet some of the performers like **Mark Slaughter** and **Alice Cooper.** Each night, our friend, **Bonnie** hauled our stuff out to our booth and back again on an ATV!

Our regular volunteers, **Greg Patterson, Mike** and **Mary Parsons, Lisa Sharp, Tammy Van Ness, Kevin Braden, Jody Klemann** (another CCA mom) and her whole family helped sell tickets and hand out free T-shirts. **Terry Schmidt** coordinated with **Dave Smith Motors,** a major sponsor with Woody, to provide the shirts to give away with ticket purchases. Of course, **Megan Bennett** our local volunteer had us out at Spearfish again to sell tickets at the **B&B/Back Porch Bar & Grill** with **Leland** and **Teri Ruzicka** and my good friend **Fred Sala** from the **Frisco Hells Angels. The Petersens** at the **Pierre Harley** dealership provided a replica bike for **First Gold Casino** in Deadwood, and all my friends there including **Marilyn, Brad, Kim, Derick, Ann, Shari** and the entire staff sold tickets for us during the week.

I met lots of great people, especially all of those helping us raise funds and all of you who bought a raffle ticket. We plan on another great fundraiser next summer, and I will be happy to tell you all about it then!

Robbie Gorecki, CCA
Ambassador to Sturgis

BUFFALO CHIP


Above: Kaptain Robbie Knievel prepares to make his world record jump over 100 Harleys.


Above: Some of the bikes all lined up for the jump.

Above left to right: Char Smith; New York Myke of San Diego Harley Davidson; Jill Gorecki.


Above: CCA's Team Sturgis. Left to right: Executive Director, Charlene Smith; CCA Ambassador, Robbie Gorecki; CCA Office Administrator, Annie Reeves; Volunteer, Greg Patterson; Development Director, Jill Gorecki.

Left: Char and Jill work late into the night selling raffle tickets.


Left: Jill snags a donation for the goodie bags handed out at Rod's Ride for Cher's Kids.

Above: We couldn't sell nearly as many tickets without our volunteers! Left to right: Kevin Braden, Tammy Van Ness, Mary and Mike Parsons

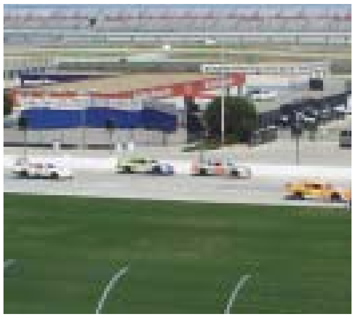
friends, from page 7

of the Harley-Davidson motorcycle. He asked for a $100 donation for CCA from the owner of each bike!

While we were out in Sturgis, **Josh Mueller**, who'd been on our ride the previous summer, and his friends at **Calhoun Station** in New Berlin, stayed back in the Milwaukee area and held a **Poker Run** for CCA.

Many families went above and beyond in a short time period to sell raffle tickets, especially **Donna Shea, Kristine Dale** and **Casey Deakins.**

Thanks to everyone here and all who participated. Welcome to the family!



sturgis 2004

While 2003 Black Hills Motorcycle attendees are still getting the dust off their chaps, CCA is full throttle planning for Sturgis 2004! Next year CCA will once again raffle a beautiful Harley-Davidson Heritage Softail®, and hold our annual **Rod's Ride for Cher's Kids,** hosted by the legendary **Buffalo Chip Campground owner Rod Woodruff.** The ride will tentatively take place on Wednesday, August 11, 2004. To insure you have the most satisfying experience and view the most beautiful scenery, we have assembled a committee of veteran riders to plan the ride, including Rod "Woody" Woodruff, **San Diego Harley Davidson** dealer and host of American Cycle Talk Internet radio show, **New York Myke, Kaptain Robbie Knievel** and CCA's own volunteers **Tammy Van Ness, Kevin Braden** and **Greg Patterson.**

And hold onto your helmets… On Tuesday, August 10 (tentative date), CCA will hold the inaugural **Women United on Harleys** (or any other bike) **Ride.** Yes you heard it — a ride for women in the driver's seat! CCA strives to teach children with facial differences to be confident and independent. Women who ride bikes demonstrate independence, so it's a perfect fit. We are assembling a committee of biker ladies who will put together a ride that will be lots of fun and help kids at the same time! We are also working on some surprises, so stay tuned for details!

You don't want to miss out, so mark your calendar now and plan to join us on one or both of the rides during rally week, August 7 to 14. It promises to be the highlight of your 2004 Sturgis experience!

Check our Website to buy 2004 raffle tickets!

picking up the pace

Pace American, Inc., was again a sponsor for our Harley Raffle, loaning us the use of a new Legacy enclosed motorcycle trailer to haul our 100th anniversary edition Heritage Softail. We picked up the trailer in Utah, then the bike in San Diego, then went through Las Vegas, Denver, Dallas, Austin, Longview, Kilgore, Justin, Lewisville, Daytona Beach and, finally, to Sturgis. Having the bike on display while selling tickets at all the different venues really helped sales. Our volunteer driver hauling the bike even reported being stopped for raffle tickets on the way to Sturgis! Thanks again, Pace American!

ccaprograms

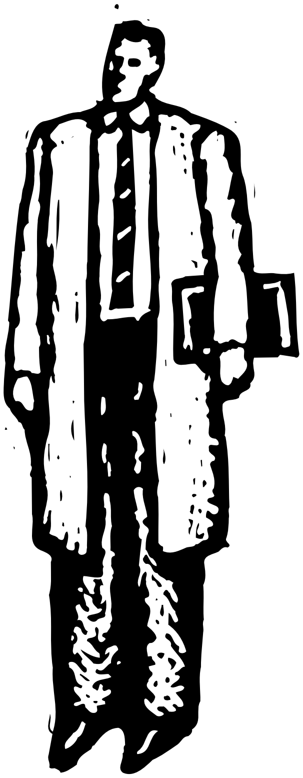
and services in the spotlight

toll-free hotline

CCA provides a toll-free 800 number so families don't have to pay for a long distance phone call. It is very possible that without referral to a craniofacial center, affected children would not receive the comprehensive, quality medical care imperative to optimum results. Via the toll-free hotline CCA also provides much needed educational materials and emotional support.

1-800-535-3643

doctor referral



Children's Craniofacial Association refers to the full members of the International Society of Craniomaxillofacial Surgeons. These surgeons head teams of specialists specifically trained in the surgical management of problems involving the face and head. Centers with craniofacial teams working together have the advantage of greater experience to provide comprehensive, quality care, which leads to better results and fewer complications. In addition, ongoing research at these centers offers patients the latest breakthroughs in treatment. As there are only a few experienced teams in the country, it is quite common for families to travel long distance to get the best care. **A list of these surgeons may be obtained by calling CCA's office, or from our Web site www.CCAKIDS.com.**

families raising funds

pete's scramble for cca

Darin and Dede Dankelson of Commerce Township, MI, are this issue's famed fundraising family! Their son, **Peter,** was born with Goldenhar Syndrome. In August they held the first annual "Pete's Scramble for CCA" at the Beacon Hill Golf Course in their town. This first effort was a "hole in one," netting more than $1,400 for our charity as well as a lot of fun and more awareness for their community. Hats off and many thanks to the Dankelsons for getting in the game and "scrambling" to help! If anyone is interested in learning how they went about planning the golf outing, please let us know.

the RED device

by Jeffrey Fearon, MD

What is the RED device? The RED device is not red; it is actually purple. It gets its name from: rigid external fixation device and is used to bring parts of the face forward.

What are some of the conditions that doctors use the RED device to treat? The RED device was first developed in Chicago by two doctors, Drs. Polley and Figueroa, who were looking for a better way to treat children with cleft lip and palates. Some children born with a cleft lip and palate require surgery in teenage years in order to bring the upper jaw forward. In these children, it can be very hard to get the jaw far enough forward, so, the RED was developed for this purpose.

In 1998, I made a few small changes to the device and started using it to treat a different, younger group of children who were born with craniofacial dysostosis (this is a general term that includes syndromes such as Apert, Carpenter, Crouzon, Pfeiffer, Saethre-Chotzen, etc.). In addition to the craniofacial dysostoses, I have also used the RED to treat bifacial microsomia, as well as a number of other conditions.

How does the RED device work? In addition to just bringing the upper teeth forward, which is sometimes necessary for teenagers born with a cleft lip and palate (this operation is called a LeFort I), the RED is now used to bring the entire midface forward in an operation called a LeFort III. This operation is just about always necessary for children with Apert, Crouzon, Pfeiffer, etc. The midface is area between the top of the nose, (or the bridge, where glasses sit), down to the upper teeth, including both cheekbones. For children born with one of the craniofacial dysostoses, the LeFort III is usually performed somewhere between ages 5 to 8, depending on a number of factors. I have found that the RED has greatly improved the results in these children and is much better than either doing a LeFort III without the RED, or using bilateral distraction devices that can be placed on either side of the cheekbones, under the skin.

The RED device looks like a horseshoe, which is attached to the head with pins that go through the skin into the skull. Once the device is on, most children do not feel any pain, unless it is necessary to tighten one of the screws going into the head. A bar hangs down vertically in front of the face. Attached to this bar, near the mouth, are two wires that attach to the upper teeth (either by braces or a dental splint).

The RED is put on in the operating room, after a surgeon has performed either a LeFort I or LeFort III. After the operation, the parents are taught how to turn two screws, twice a day. As these screws turn (children tell us that this does not hurt), the bones of the face are slowly moved forward. After the face has been brought forward the correct amount, the RED is left on (without turning any screws) for about a month to allow the bones to heal in this new location. The child is then usually brought back to the operating room for a short 15-minute procedure to take everything off.

What are some of the problems with using a RED? The RED device is still relatively new, and only a few doctors have had any significant experience using it. This means that for those doctors who have only used the RED on a few children, the complication rates may be higher. Some children find it hard to wear a device as big and bulky as a RED for the 8-week treatment period, others seem to do just fine. There are also some other, very rare, complications that may occur and these should be discussed with your doctor.

What are the advantages of using the RED? In the very first publication of this technique, back in 2001, I found that the RED was able to bring the midface much further forward than could be done using the standard LeFort III (without the RED). It was also found that using the RED did not raise the complication rate over that of the standard operation. Since that first report, I have found that by doing these operations using the RED, almost 2 hours are shaved off the operation. Moreover, the complication rate has fallen even lower, and children now only spend a total of 3 to 4 days total in the hospital.

Should my child have an operation with the RED? For children needing a LeFort III, I recommend using the RED only between the ages of 5 to12 (doing a midfacial

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advancement before 5 should be reserved for very unusual circumstances, and in very young children, the skull may not be strong enough to support the RED). After age 11 or 12, it almost always makes more sense to do a standard LeFort III.

Will using the RED save my child from needing the usual second LeFort III in teenage years? One of the main reasons that I developed the RED technique for children needing LeFort IIIs was to try to get the midface far enough forward with the first operation, that the traditional second operation in teenage years could be avoided. To my knowledge, I was the first surgeon to perform a LeFort III using a RED, and this was done in early 1998. This means that the longest follow up is not even six years. At this point in time, it seems that the older a child is when he or she gets the first LeFort III, the more likely it is that the second LeFort III can be eliminated. There are a number of complicating factors that affect this decision and these need to be discussed on a case by case basis with your own doctor.

macey, from page 1

observed Macey and said she'd have the doctor on call come and observe. The doctor noticed that Macey's ears were set low and did a test to make sure her liver was working properly. The test came back fine, so the doctor said we just have to see how she develops over the next year. The nurse thought that this doctor wasn't proactive enough and, since Macey had a low temperature, recommended we stay another day and see her pediatrician. Macey's pediatrician ran a chromosome test and a CT scan of her head.

We found out that Macey had Craniosynostosis. The next day she was taken to NICU for jaundice and feeding problems. We were devastated by everything, to say the least.

After three days in the hospital, Macey came home. After consulting with two craniofacial teams and doing lots of research on the Internet, we scheduled her first operation with Dr. Fearon, a plastic surgeon and Dr. Sacco, a neurosurgeon.

Macey's operation began on January 8, 2003 at 7:30 am. Shortly after the incision, the doctor stopped and came to talk to us. Her CO level was 140+ and could not be controlled. She was taken to PICU and put on a ventilator. On January 14, Macey received a tracheotomy. Her right lung collapsed during the operation, so she needed a chest tube. About five days later, her breathing failed again. An otolaryngologist said that her airway was barely open. The next day the doctor fit Macey with an adjustable tracheal tube. It seemed to work, so she spent the next two months in the hospital on a ventilator.

On February 24, around 4:00 am, Macey went into cardiac arrest, and they weren't able to get her to breathe. Her tracheal tube became stopped up. At this point the nurses and the social worker became very concerned about us — we had no place to stay while in town.

The social worker told us about CCA. Char Smith came over and assisted us with lodging and food. What a blessing! This took a burden off of us, and we were able to focus on Macey getting better.

On March 6, Macey was taken via CareFlite to Cincinnati Children's Hospital. She underwent trachea reconstruction surgery. With many prayers, Macey did exceptionally well and was able to get her tracheal tube taken out and also able to get off the ventilator. After five weeks we took Macey home. An insurance company will not pay for a plane ride home, so CCA helped us again.

Macey was home but in and out of the local hospital for three weeks. Then it was time to return to Dallas for her frontal orbit advancement craniofacial surgery. CCA helped once again with transportation and lodging. CCA also helped with traveling to her post-opt appointment and her posterior cranial vault surgery.

We are very grateful for the support that CCA has given to us. In addition to the financial assistance, CCA shared information, prayers and time. Jana Butera (CCA's program director) even waited with our family during Macey's craniofacial surgeries. Macey is now 11 months old and recovering from her second surgery. We pray that CCA will continue to receive support and donations to help other families like us.

Thanks,
The Atkins family

charge for cca!

holiday* news we can all use!

Now you can do some feel-good spending for the holidays! CCA is registered on Schoolpop. This means that at least 1% of everything you buy can go to the school or youth charity (CCA) of your choice—at no additional cost to you!

It's simple to sign up. Just visit **schoolpop.com** and enter **Children's Craniofacial Association, Dallas, TX 75240.**

(Remember to also download a "shopping buddy" that will ensure your purchase is credited at any participating merchants while shopping online.)

You'll be asked if you'd like CCA to know about your contribution. Please indicate, "Yes," so we can report back on how much you all charged for CCA!

You'll see that almost everyplace you shop for the holidays is a participating merchant. This includes in-store, online *and* catalog shopping. Some grocers and magazine subscriptions also qualify.

This is the easiest "giving" you will ever do! And the giving is not just for the holidays — you can charge for CCA all year 'round!

If we all do this, the money given to CCA will add up fast. So happy holidays — and happy shopping!

*AND ANYTIME, ALL YEAR 'ROUND!

donors, april through september 2003*

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washington dc,

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even used a little round mirror attached to a long stick to look under the van (for bombs, I guess). Finding none (thank goodness!), they allowed us to park on Capitol Hill really close to the building.

Then we hit a snag. Someone had thrown up in the guardhouse at the Capitol, and it was closed down for"hazardous waste decontamination." All of our security information was on the computer, which was in the locked guardhouse. Mr. Ayers had to get in touch with someone inside the Capitol to get us in.

Most everyone went up the big steps and in the building, but a few people and I had to go to the wheelchair entrance on the side of the building. We all registered and were given identification tags. Then we went up the elevator to meet everyone else for the forum.

Our meeting was held in the LBJ Room. It's called that because it was where Lyndon B. Johnson had his office. It's really unusual to get to use the LBJ room since it's only used for special occasions.

The hearing started with Mr. Ayers talking about why we were there. Some people talked about medical things relating to the

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from page 14

bill. Then the Congressman from Arkansas spoke. Next, CCA families told what it is like to have a craniofacial anomaly. That was really interesting because I knew some of them, but we had never really talked about things like that. When we're together at retreats, we just like to have fun.

Finally, my Dad, Mom and I told our story. I used my Pathfinder (augmentative communication device) for my part of the story. Since I don't speak clearly, the Pathfinder talks so others can understand what I want to say. I had fun telling my story. Everyone really laughed when I added monster sound effects when I spoke about some people thinking people with faces like mine look like monsters. Mostly, our family talked about how lucky we have been that insurance has paid for my 22 surgeries. We want people to know that some insurance companies do recognize that craniofacial surgeries are necessary.

I was a little disappointed because not very many senators or representatives were there.

After the hearing was over, we were in the hall and Sen. Arlen Specter from Pennsylvania came to talk with us. He asked what brought us to Washington.

We talked with him about the bill and gave him copies of the information.

Then, our family and the Seitz family ate in the Senate Dining Room. It was cool because I saw Senator Jeffords and his wife. I had met him in 1997 when I was at the White House with President Clinton for the signing of the Individuals with Disabilities Educational Act. Senator and Mrs. Jeffords came to our table and talked with us. So, we told them about the bill, too.

My family tried to see our Congressman, John Hostettler, from Indiana to talk about the bill. While we were there, the president of the company my Dad works for came in. We were surprised to see each other. Then one of Congressman Hostettler's aides escorted us back to the Capitol building. He took us through the tunnels underground, which I enjoyed a lot.

From there we went back to the hotel and began our fun 2003 CCA Retreat!

chair, from page 1

difficult to take. She wanted to have her condition corrected, but was told by surgeons that the necessary operations would not be covered by insurance. Donna accepted her condition, went on with her life, got married, had two wonderful children and now is a substitute teacher.

Not long ago, Donna read in this newsletter about CCA's efforts to win passage of the Reconstructive Surgery Act of 2003—a measure that will guarantee insurance coverage for craniofacial patients. She decided that this was a cause worth fighting for—and on a more personal level—going public about.

Donna contacted her local newspaper and television stations to tell them about the Act and how important it is. Her local newspaper did a major story about her accompanied by a three-column photo. The article even included the contact information about the U.S. Senators and Representatives from Alabama who should be called and written to urge passage of the Act. Likewise, her local television station did a very positive segment on her fight for fair treatment by insurance companies. Donna is also gathering signatures on a petition that will be presented to Congress about the legislation.

Donna Gossett is no longer interested in having operations to correct her condition. She is not on this crusade for herself, but rather for others who follow. She had been living a quiet family life and had accepted her facial disorder. It took a great deal of courage for her to go public, but she is happy she did. Now people stop her on the street to tell her how important her crusade is. Donna is making a difference.

Another person who has made a difference is **Sally Longroy.** Sally is an attorney who served on CCA's Board and was the source of much sage advice for our organization. Because of time commitments, Sally has resigned from the Board. We will miss her good counsel on the Board, but can happily report that she has agreed to continue to provide pro bono legal work for the Association. We greatly appreciate her generosity and ongoing commitment to CCA.

Another former Board member who continues to make a difference is **Diana Sweeney.** Many CCA families know Diana and have benefited from her dedication to the Association and her work at Children's Hospital in Philadelphia. Diana continues to serve as a volunteer with CCA and is deeply involved in keeping our network of families in touch with each other.

Tim Ayers
CCA Board Chair

3cheers for volunteers!

From left to right: Greg Patterson, Phil Patterson, Ginger Morrone, CCA Program Director–Jana Butera, Jim Butera, Tina Webb, Beverly Butera, JoAnn Turano, Lily Salvato. Not pictured: Rudy Salvato

CCA is fortunate to have a group of volunteers who prepare the Newsletter for mailing each quarter. We would like to recognize and sincerely thank them for their dedication and time.

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