

ccanetwork



newsletter of the children's craniofacial association

Cher — honorary chairperson

spring 2005

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Andrew and Karin Perry having fun at a retreat.

andrew's story

by Karin Perry

becoming a mom is a hard job. No one prepares you for what will be the most difficult (and rewarding) job of your lifetime. When you become a mom of a child with special needs, it is even more difficult. When I had my son, Andrew, I was a first-time mom — and I was single.

My pregnancy was complicated throughout, and I had many ultrasounds. Despite all the prenatal testing, no one was prepared for the complications at Andrew's birth. I remember that things went terribly wrong. Andrew was rushed away from me, and then doctors told me that he would be taken to Children's Hospital in Boston. I was told that he had a multitude of problems, including a severe facial deformation. No one could tell me exactly what was wrong with him, but they did not feel confident that he would make it through the night.

Suddenly I was making medical decisions for a baby I had seen only for a moment. I was alone in a hospital, recovering from a c-section, giving permission by phone for doctors to do surgeries on my tiny premature baby who I had not even touched or held.

see **andrew**, page 4



message from the chairman

We are a very special community. We share things that many others — sometimes not even close friends or relatives — understand. Patients, parents and siblings, and the staff, volunteers and supporters of CCA look a little deeper, understand a little fuller what it means to love a person for who they are — not how they look.

It's really a wonderful benefit of being involved in CCA. We become more sensitive to the feelings of those around us because our horizons have been broadened. Yes, we see cruelties, but we also see wonderful examples of kindness and bravery.

see **chair**, page 11

2005 Retreat Info

The 15th Annual Cher's Family Retreat will be at the Gaylord Opryland Hotel in Nashville, TN, on June 23-26. For more information, contact Annie Reeves at 800-535-3643 or AReves@ccakids.com.

If you make your own reservations, please let them know that you are with Children's Craniofacial Association or use Group Code X-CCA05.

cca kid

meet andrew perry

andrew Perry is fearless. The 11-year-old from Hopkinton, MA, has perfected his snowboarding technique so much he now boards down the most difficult trails possible — double-diamond!

He is also very brave. He's had 20 operations so

far with a few more to go. Luckily, he celebrated his first full year without any operations. Congratulations, Andrew!

Right now, he has just about finished the fifth grade. He enjoys Math and Science the most. This summer he'll have more time to



Andrew Perry

play video games and collect Pokémon and Yu-gi-oh cards. He'll also pursue his other outdoor hobbies: swimming, camping and fishing.

He's also going to the upcoming retreat in Nashville, his third retreat so far. If you haven't heard his rendition of Cher's song, "Believe," you're missing out! He stole the show, and the mike from the DJ, last year. Hopefully he'll sing for us again.

As for **Cher**, she and Andrew are good friends. In fact, he saw Cher in concert on Tuesday, April 12. This is his second time to see her

show and visit her backstage. Last time he sat on the front row. This time he was further back, and Cher wouldn't have any of it. She had Andrew move seats so that she could see him during the show. How cool is that?

Andrew has gone through much in his young life. Twenty operations is a lot to endure. But his family and good friends, Cameron and Nathan, have stuck with him through the rough times. His advice to other CCA kids is to **be brave**. And on the practical side, he offers this advice: "Don't eat too soon after surgery."

meet robbie gorecki

my name is **Robert Gorecki**. My family and friends call me Robbie or Rob. I'm 18 years old and have lived in Brookfield, WI, all my life. I was born with a craniofacial anomaly called Goldenhar syndrome, which caused a facial cleft.

I was missing an eye and an ear and the roof of my mouth (palate). My mom tells me I had my first reconstructive surgery when I was three and half months old. Somewhere after two dozen or so operations she lost count.

My syndrome doesn't affect my mind's ability, but having a lot of operations when I was little set me back a bit. I didn't walk until I was two years old and I didn't know my alphabet until second grade. I never liked being in the "special" classes but it helped, and I've caught up. I will be graduating from high school this June.

People are pretty nice for the most part, but kids can be mean. I have an older brother, Erick, and when we were younger, he protected me a lot when people would stare. But we each went to different grade schools and jr. highs, and by the time I got to high school, he had already graduated. I had to learn

how to deal with the mean kids and fend for myself. Sometimes I'd just stare back. Sometimes they tried to get physical and pick a fight. I didn't back down and they usually left me alone. People seem to fear things they don't understand.

I have a reconstructed ear and a fake eye. Other than looking different, my main challenge is my speech, particularly speaking clearly enough for people to understand.

Even with one eye and one working ear, I can do everything anyone else my age does. I drive a car (truck). I also own and ride a motorcycle.

I've liked motorcycles for as long as I can remember – maybe because we live in the Milwaukee area, home of the Harley. Bikers are nice to children, and while growing up I made a lot of friends in the motorcycle industry.

I think having CCA's support while I was growing up made a big difference in my life. I've been involved since the start, and I've only missed one family retreat. I met other kids like me, and my whole family found out that we aren't the only ones dealing with craniofacial problems.



Robbie Gorecki

Every year the retreat was our family vacation. I'd also get to visit the Harley-Davidson dealership in whichever city it was held to add to my pin collection for my biker vest.

My parents put up with my interests, but are not looking forward to my desire to get tattoos. I have scars on my arms and chest from surgery, and I figure a tattoo is no worse! I tell my mom, "God put me on this earth looking different; I might as well run with it."

When CCA started their summer fundraiser in 2001 raffling off a motorcycle, I became the charity representative/ poster boy. Each year we travel to Sturgis, SD, and I'm in my element with all my biker buddies. After graduation, I will attend MMI (Motorcycle Mechanics Institute) in Phoenix, AZ, in the fall.

I am not afraid to go out into the world and live my life, and I hope I inspire any younger kids with craniofacial difficulties to do the same.

cca grad

**"God put me on this earth looking different;
I might as well run with it."**

andrew, from page 1



BEFORE: Andrew at 3 months



AFTER: Andrew now at 11 years

I felt as if I might drown in my own tears. I felt as if the weight of the world was resting on my shoulders. My family tried to be helpful, but ultimately, I felt solely responsible for life and death decisions for my son.

When my parents took me to see Andrew in Boston, I was introduced to the overwhelming world of medicine and the NICU. Andrew had been diagnosed with micrognathia (a tiny, underdeveloped jaw), microglossia (essentially no tongue), seventh nerve facial palsy, optic nerve hypoplasia, a heart defect, and irregular brain activity, which the doctors thought might be seizure activity.

The doctors struggled to find a “syndrome” that fit Andrew. (They never did. He is totally unique.) Andrew remained on a respirator for eight days and was unable to eat by mouth. Eventually, Andrew began breathing on his own, and a g-tube was placed to feed him.

When I look back on the first year of Andrew’s life, I wonder how I survived. He was hospitalized until he was five weeks old, and then I brought him home. The bedroom we shared looked like a hospital room. I was totally unprepared for taking care of a newborn, never mind a newborn with all these extra attachments and parts!

I remember counting the number of appointments we had during his first year — 57 scheduled clinic appointments, not counting the trips to the pediatrician for weekly weight checks, colds, ear infections and bouts with pneumonia.

When Andrew was four months old, I returned to work to keep my medical insurance, and was struggling to stay awake at my job as a special-needs teacher. I paid a nurse who was home on maternity leave to care for him during the day, as I could not find a daycare center that would take him. I rushed home each day after school to take Andrew to Early Intervention and keep

appointments with speech therapists and occupational therapists that came to my home four times a week. I got up all night long to feed him by g-tube and felt lucky to have three or four hours of sleep a night.

During the next few years, things became easier. Andrew got healthier as he got older, and he had fewer appointments. The machines and equipment became part of my life and no longer seemed so overwhelming. I took many precautions to make sure my family knew how to operate his feeding pump and suction machine and knew his medication schedule. I had laminated index cards in his diaper bag with details about his care in the event I was unable to be there.

Andrew did not have another surgery until he was five years old, when they took a nerve from his leg and transplanted it into his face. When he turned eight, Andrew went through the most radical surgeries of his life. He had a multi-step jaw distraction that involved more than 11 trips to the operating room in 10 months. In total, we spent nearly 30 nights in the hospital. Together, Andrew and I have gone through 20 surgeries.


It is hard to be the sole caretaker during these stressful times. I have had to realize that I am only

human and that I do have limits. I allow myself to feel sorry for a while, cry, and let it all out. It is hard to be the one making all the decisions. It is hard to find time to get sick. It is hard to remain upbeat and positive when you see your child in pain. It is hard to ask for help.


Finding CCA three years ago was a gift. CCA has been the most valuable resource I have had in Andrew’s lifetime. I finally have people who I can talk to, and who understand what it is like to have a child who looks different. **Going to retreat was the best thing I have ever done.** Not only did Andrew meet other children who were different, but I also met some amazing families. I have become friends with other moms, and shared my story. I have found that there are a lot of single moms like me. Meeting them has been inspirational to me.

I am lucky. I have a child I adore, and now I have a wonderful man in my life who is supportive of both of us. When people ask me how I did it for all those years, I smile. My life was insane, overwhelming, tiring and crazy. But, I have this terrific kid, and when I see him smile his own special smile, I know he was worth it all — every minute!

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

did you receive "a special message from cher"?

by now, everyone on our mailing list should have received the CD message from Cher appealing for donations to CCA.

Please consider helping with an amount of \$25, \$50, \$100 or more so we may continue to fund our programs and services which are a vital part of the physical and emotional health of so many kids.

Your assistance furthers our mission to empower and give hope to facially disfigured individuals and their families.

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!



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
- Doctor referral
- Information and support
- Educational booklets
- Financial assistance
- CCA newsletter, *CCA Network*
- www.ccakids.com Web site
- Annual Cher's Family Retreats
- Public awareness
- Family networking
- Advocacy

2005 calendar of events

date	event	contact
June 11	Cleft Lip/Palate Care Birth through Maturity Conference on cleft lip and palate St. John's Mercy Medical Center St. Louis, MO	www.stjohnsmercy.org/professionals/cleftpalate.pdf
June 12-17	Camp About Face Bradford Woods Outdoor Education Recreation and Camping Center Indianapolis, IN	317.274.2489
June 23-26	Children's Craniofacial Association 15th Annual Cher's Family Retreat Nashville, TN	800.535.3643 www.CCAkids.com
June 24-26	NOVA Family Conference Conference concerning hemangioma and vascular malformations Triangle Park, NC	www.novanews.org
July 17-19	North American Craniofacial Family Conference Las Vegas, NV	www.cleftadvocate.org
August 12	CCA Win-a-Bike 2005 Raffle drawing in Sturgis, SD	www.CCAkids.com 800.535.3643
September	Craniofacial Acceptance Month	www.CCAkids.com 800.535.3643

facial palsy

by Christopher JM Brooks, MD

Think about the last face-to-face conversation you had. Consider how much your communication and understanding was derived from facial expression. Remember the feelings expressed, the subtleties conveyed, the joy or anguish instantly revealed. Now imagine the frustration and isolation felt by someone whose face does not speak — no smile, no blink, no pucker for a kiss. Facial paralysis can affect only a small part, or sometimes half, of the face. Occasionally, the entire face is enveloped in a mask-like silence. But whether it is a small area affected or the entire face, facial palsy is a devastating problem. Fortunately, there are some answers.

Nearly 40 muscles control our facial expressions. Used in various combinations, these muscles are capable of creating more than 5,000 different expressions. Almost all of these muscles are controlled by a nerve appropriately called the facial nerve. The facial nerve exits the skull behind the opening of the ear, then travels through the parotid gland in front of the ear, branching extensively to reach all of the muscles used for facial

expression. In people with facial paralysis the nerve can be absent at birth, rendered non-functional by virus or inflammation, or injured by trauma or surgery. Injury to this nerve can occur inside the skull, outside the skull before the nerve branches or to any of the individual branches. The exact location of the injury will determine the resulting deficit and ultimately direct the treatment.

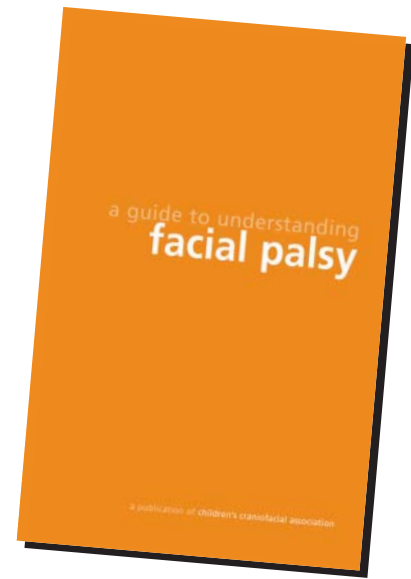
Static reconstructions, some of the earlier methods of reconstruction, still have a few limited applications. As implied by the name, static reconstructions do not move the face. They involve the suspension of facial tissues in a more normal (less drooping) resting position. These techniques can significantly improve resting appearance and oral competence (drooling) but do nothing to provide animation to the face. Animation requires nerve input and muscle response.

When a nerve is injured, the nerve fibers between the injury and the target muscle die. These fibers then regenerate at a rate of about one millimeter per day. If an injury to the facial nerve or branch does not involve a loss of length,

then the injured nerve can be re-approximated directly. It will still take several months for activity to return to the muscle, as the nerve regenerates towards the target muscle.

If there is a loss of length of the nerve, as when a segment is removed with a tumor, then a nerve graft can be harvested from another part of the body, usually the leg, and attached between the two cut ends of the facial nerve. The facial nerve fibers then grow through this nerve graft to the target muscle. Alternatively, if the facial nerve is resected all the way back to where it exits the skull, a nerve graft can be placed from the facial nerve on the unaffected side of the face to the remaining nerve on the affected side of the face. This is called a cross-face nerve graft.

In cases of congenital or any long-standing facial paralysis lasting more than one to two years, the target muscle atrophies can no longer be stimulated by a nerve. Reanimation of a longstanding facial paralysis, therefore, requires new muscle, which can be stimulated to be placed in the face.



For more information about Facial Palsy, download this booklet from our Web site, www.ccakids.com

Local muscle transfer involves the use of other nearby facial muscles, primarily those used for chewing, to provide movement for the face. These muscles are controlled by a different nerve, which is usually not affected by the paralyzing process. Some of the more common techniques involve the use of the temporalis muscle or the masseter, two muscles used in chewing, or a combination of the two. While some facial motion can be gained with this type of reconstruction, the movements are often unnatural and never spontaneous, as the person needs to learn to "bite-down" to create a smile.

The most complex but also the most promising technique for facial reanimation is a combination of

continued next page ⇨

cross-face nerve graft and functional free muscle transfer. Transfer of a muscle to the face requires microsurgical reconnection of the blood vessels of the muscle to blood vessels in the face. In addition, there must be a microsurgical connection of the nerve of the muscle to a nerve in the face. There are several muscles that are frequently used, including the gracilis from the inner thigh, the pectoralis minor from the chest, and the serratus from the trunk. Each has its benefits and drawbacks, its proponents and critics.

Free muscle transfer for facial palsy requires at least two procedures. First, a cross-face nerve graft is connected to segments of the facial nerve on the unaffected side. The nerve graft is then tunneled to the paralyzed side and left under the skin in front of the ear, or in the upper lip. Nine to 12 months later, after the facial nerve fibers from the unaffected side have grown through the graft to the paralyzed side, the free muscle is transferred to the paralyzed side of the face. Its blood vessels are connected to blood vessels in the area, its muscle fibers meticulously oriented to produce the appropriate smile angle, and the nerve to the muscle connected to the cross-face nerve graft. After a couple of months to allow the facial nerve

fibers to grow into the muscle, function slowly returns.

In people with bilateral facial palsy, such as in Moebius syndrome, a cross-face nerve graft is not possible since neither side of the face has a normally functioning facial nerve. Here there is no choice but to use different nerves, such as the nerve to the masseter (chewing) or to the hypoglossal (tongue movement) to control facial movement. In separate procedures muscle is transferred to each side and one of these nerves connected to the muscle. While spontaneity remains a challenge, symmetry can be quite good.

Regardless of the cause, facial palsy can be quite devastating. While reanimation of the face remains a significant challenge, there are reconstructive options available to restore facial movement and thereby significantly improve socialization and self-esteem. Today the face that does not speak need not remain silent.

you talked. we listened.

Have you checked out the CCA Web site lately? We have made lots of changes to the site as a direct result of the survey we sent out in 2003. Check it out!

ccakids.com

new booklets

CCA is proud to announce the addition of three syndrome booklets to our series of booklets intended for new parents. *A Guide to Understanding Crouzon Syndrome*, *A Guide to Understanding Facial Palsy* and *A Guide to Understanding Fibrous Dysplasia* are currently available for downloading on CCAKids.com.

In addition, we updated four of our existing booklets: *A Guide to Understanding Craniosynostosis*, *A Guide to Understanding Apert Syndrome*, *A Guide to Understanding Treacher Collins Syndrome* and *A Guide to Understanding Hemifacial Microsomia*. You will find them at CCAKids.com, too.

We thank **Dr. Scott Bartlett**, **Dr. Ian Jackson**, **Dr. Hrayr Shahinian** and **Dr. Linton Whitaker** for their contributions toward these publications. And a special thanks to **Diana Sweeney** for her help with coordinating them. Printing of four of the booklets was generously donated by **CRW Graphics** located in Pennsauken, NJ. Layout was donated by **Robin Williamson** of **Williamson Creative Services, Inc.** located in Carrollton, TX.

More booklets will be available soon.



new program director

We are sad to announce the departure of Program Director **Jana Butera**. Although Jana is not in the office anymore, she will continue to serve on the Program Committee and remain very involved with the organization.

At the same time, we're happy to announce that our former office manager, **Annie Reeves**, with whom many of you have spoken or met at the Tempe retreat, has accepted the Program Director position. Annie has already jumped right in, with this edition of *CCA Network* being her first project.

Congratulations Annie!

If you have any program needs please email Annie at AReeses@CCAKids.com or call her at 1-800-535-3643.



Rob Gorecki hangs with a few of the capable cooking/cleanup crew of Century Lodge #492 Odd Fellows after the St. Patrick's Day fundraising dinner.



Noble Grand of the Century Lodge, Ken Loos and lodge brother/fundraiser organizer, Doc Remer accept Thank You certificates from Jill Gorecki on behalf of CCA.

good odds

a big Thank You to "**Doc**" Remer, his wife, **Maggie** and all the lodge brothers of **Century Lodge #492 Independent Order of Odd Fellows**. The group held a fundraising dinner for CCA on St. Patrick's Day and raised \$470 in a few hours.

Jill Gorecki traveled with her son Robbie to Carpentersville, IL for the evening event which was held at the lodge headquarters. They presented framed certificates of thanks to Doc and the group. Rob, who was befriended and introduced to the Odd Fellows in 2001 during CCA's motorcycle raffle fundraiser in Sturgis, SD and joined them for a CCA fundraiser with Robbie Knievel in 2002, enjoyed hearing how much he'd grown since they saw him last!



cut-a-thon raises \$1,682

dallas-based **Salon D** (www.salond.com) and CCA teamed up for a Cut-A-Thon fundraiser on April 3. Salon D's top stylists gave their time, and their amazing expertise, to create trendy new hairstyles for a minimum \$25 donation.



CCA Kid, Torey Harrah and her friend are all smiles after getting their new dos.

From 11 that morning until 5 in the evening, the salon was abuzz with laughter, smiles and amazing new dos. **Jason's Deli, Chili's and Celebrity Bakery** donated a yummy selection of sandwiches, appetizers and sweet treats, and **Southwest Airlines, Black-Eyed Pea, Pappas Brothers, Del**

Frisco's and Starbucks donated door prizes. **Salon D** gave away a massage, **Beverly Butera** donated a tennis racket and **Annie Reeves**, CCA's new program director, gave a Mary Kay gift basket. A representative from **Jingles** gave away gift bags filled with fabulous hair care products. **April Johnson** donated a doggie treat basket and a gift certificate for **April Showers** (her invitation/card company).

Everyone had great time. CCA kid **Torey Harrah** and her friend got haircuts. **Jylian Bilbow** and **Preston Johnson** were also on hand to join in the festivities.

Many thanks to **Ardem**, owner of Salon D, for working closely with CCA to coordinate this event.

"The Cut-A-Thon was a success," said Annie Reeves.

"We had a great opportunity to help the kids and their families as well as walk away with a new look," she said. Annie plans to coordinate the next Cut-A-Thon later this year with another salon.

If anyone wants to host a similar event in their town, call Annie at 214-570-9099 or toll free at 800-535-3643.



Jylian Bilbow and her mom share in the fun.

donors, october 1, 2004 – march 31, 2005*

Gifts from Individuals

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CCA Sponsor (\$1,000 +)

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Megan Marie Brassler
Jana Butera
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SBC Employee Giving
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The Frugal Flower, Inc. (Purchases Percentage Incentives)
The Mortgage Center
The Prudential Foundation Matching Gifts
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United Way of Fresno County (Directed Donations)
United Way of Metropolitan Tarrant County Humanity Fund (Directed Donations)
United Way of Long Island (Directed Donations)
United Ways of New England (Directed Donations)
Van Andel Arena
Richard S. Ward Lumber Company
Wellpoint Foundation (Employee Giving/Matching Funds Management)
World Craniofacial Foundation
World Reach, Inc. (Employee Giving Funds Management)

Corporate / Foundation Gifts

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

AT&T Employee Matching Albertsons (Purchases Percentage Incentives)
America's Charities (Employee Giving Funds Management)
American Express Employee Giving
Bank of America Employee Matching
Bonzai, LLC
Cars Helping Charities, Inc.
Castle Custom Cabinets, LLC
Dell Employee Giving
Doug Doggett Jewelers
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HP Employee Giving
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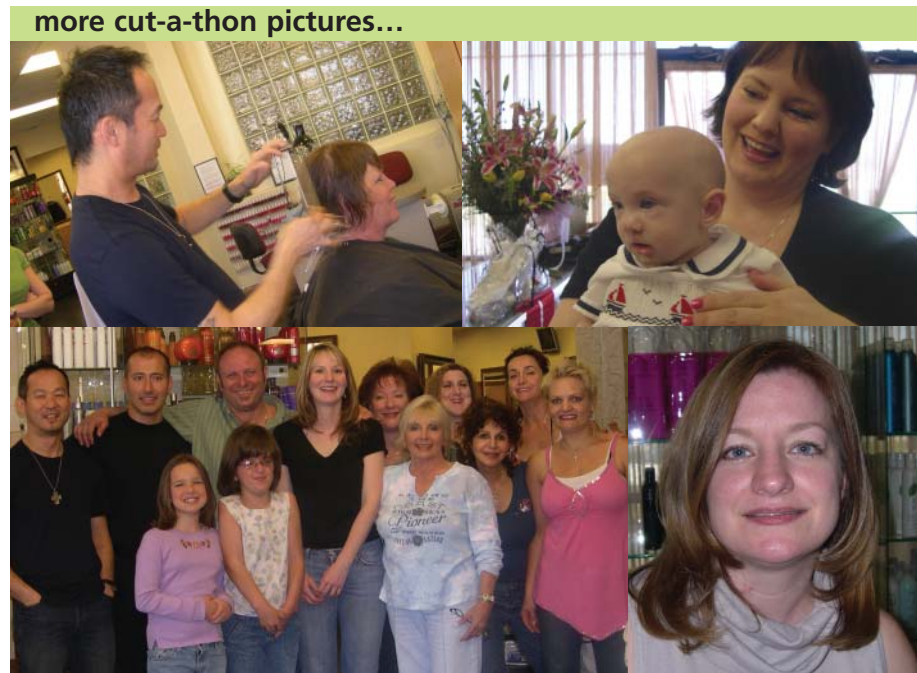
CCA Corporate / Foundation Partners (\$5,000 or more)

Biedenbarn Foundation
The Chatlos Foundation, Inc.
Edmund & Alice Opler Foundation
Wal-Mart Foundation

* 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.

CLOCKWISE from top left: Char Smith, CCA executive director, gets her hair cut by one of Salon D's best stylists. Preston Johnson and his mom have a good time in Salon D's lobby. Kelly Liszt, CCA's newsletter editor, gets a new look. Meet the Cut-A-Thon gang.



3 cheers for volunteers!

East Elementary School wanted to do something different this year for their PE fundraiser. For many years the school participated in the "Jump Rope for Heart," a wonderful fundraiser, but they wanted to do something for another charity. **Coach Chuck Bowling** and **Ms. Parker** asked me if CCA had a similar type of fundraiser. I told him I did not know of anything, but I was sure we could come up with something.

After some thought, I had the idea of having the

kids walk instead of jump. The kids could get people to sponsor them, for any amount, to walk in a walk-a-thon, which would take place during each grade's PE time. The kids would walk for at least 30 minutes on the playgrounds of the school. Prizes would be awarded for different money levels raised. Coach Bowling thought it was a great idea.

I wanted the kids to know who they were raising the money for, so I did a presentation featuring pictures of CCA kids I met



Donna Gosset shares how she organized a Walk-a-thon for CCA



last summer at the retreat. They all know that I have a craniofacial condition, but I wanted them to understand what some of these kids have to go through. They are kids just like they are — they just look different.

The community really came together and donated prizes and money to

purchase T-Shirts for prizes. We had parents purchase some top prizes, like a bicycle, a Game Boy Advance and gift cards. The kids at East were touched by the presentation, and got really excited to raise some money for CCA.

We held the walk-a-thon on April 1, and the kids and I had a ball. I learned we have a lot of caring and wonderful kids and parents at our school. East Elementary raised more than \$7,000!

First place winner **Micha Waters**, a third grader, won the top fundraiser

continued next page ⇨



prize with \$367 raised. He won the bicycle. Second place winner, **Levi Hicks**, also a third grader, raised \$215 and won the Game Boy Advance. Third place winner, **Lauren Rasbury**, a fifth grader, raised \$186 and won a \$50 Wal-Mart gift card. Fourth place winner, **Stephanie Swindle**, a fourth grader, raised \$146 and won a \$10 gift card from Blockbuster.

I am proud of them all for doing such a wonderful job. We are planning on making this an annual fundraiser. Hopefully other schools will do the same.

With activities like this walk-a-thon, kids can learn the valuable life lesson of being kind and respectful to those who they perceive as different, no matter where they may go.

— Donna Gossett
CCA Board Member

chair, from page 1

I have often tried to explain to people not involved with CCA how great the annual retreats are. How comforting and fun they are. It's a time — sometimes the only time during the course of a year — when the CCA "Kids" (many well into adulthood now) can let down their hair and relax and do some giggling. They and their families don't have to explain anything to anybody.

My daughter, **Shannon**, introduced me more than a dozen years ago to CCA. The yearly retreats were always a high point for us. Always a special time to meet new people and have some kick-out-the-jams fun at The Party. I'll always be grateful to Shannon for getting me involved in CCA. It's been one of the best and most rewarding experiences in my life.

At the May board meeting, I am resigning as chair of the Board. We have a great Board of Directors, which now has a strong

committee structure that is accomplishing a tremendous amount of fabulous work. I'll continue to serve on the Board until the end of my term and after that I'll be a CCA volunteer. I can't ever imagine not being involved in the organization in some way.

It has been an honor to serve with the past and current board members. They bring a deep commitment and lots of time and energy to our organization. Thanks also to **Sheryl** and **John Paul of Association-Works**, our advisors who helped us chart a course for the future and continue to make sure we stay on that course. The amazing — and growing — body of volunteers that contribute so much to the Association deserve a huge "Thanks." Of course, one person deserving of tremendous appreciation is our Honorary Chairperson, **Cher** (and you, too, **Deb** and **Jennifer**), who kept this organization alive through some hard times.

Last and far, far, far, far from least is the staff. They

are there day in and day out working with families. **Jana Butera** did great work with our families, and we're sorry to see her leave the staff but happy to know that she will continue to be involved with our work. **Annie Reeves** is moving into Jana's position and brings the same level of care and commitment to our programs. **Jill Gorecki** has been toiling for several years to build a base of funding support for the Association, and I believe that work will pay off with interest in the near future.

And a very special thanks goes to the amazing **Charlene Smith**. Name a virtue and Char has it — compassion, good (and sometimes weird) humor, professionalism and, most of all, a dedication to the core value of CCA — the need to empower and give hope to facially disfigured individuals and their families.

Tim Ayers, *Board Chair*

If you feel you have skills that would benefit CCA, please call 800-535-3643 and ask for a volunteer application.

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!



Go to our Web site to buy tickets or for info on the CCA Motorcycle Raffle! IF YOU WOULD LIKE TO SELL RAFFLE TICKETS CALL KELLY at 800-535-3643.

craniofacial acceptance month

knowing the reason – accepting the difference

CCA has designated September as **Children's Craniofacial Acceptance Month** to support the association's vision of a world where all people are accepted for who they are, not how they look.

September will also mark the time when many children are returning to school. We encourage parents and our many volunteers to continue to help promote belonging, hope and friendship between our kids and their community.

As an effective way to get out the message and

help build awareness, we encourage you to visit **ccakids.com** and share your story and perspective of craniofacial conditions.

If your story is chosen, we will contact you for permission to use it in one of our media campaigns.

In addition to your story, please let us know of any groups that might like to be involved in our fund-raising.

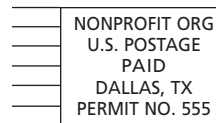
There will be many activities during the month of September, so watch our Web site for more information in the coming months.

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.

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!



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children's craniofacial association

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