



## inside

- cca kid jillian shepard . . . 2
- cca adult donna gossett. 3
- cleidocranial dysplasia . . . 4
- artwork needed . . . . . 5
- cher convention. . . . . 6
- pete's scramble . . . . . 7
- FUNraising . . . . . 7
- carrying the torch . . . . . 8
- she *did* have a point . . . 9
- 3 cheers . . . . . 12



## 2004 cher's family retreat

In the words of cowboy-hat-clad Jeremy Dale "Yeeee Hawwwww!" That best describes the feeling about the 14th Annual Cher's Family Retreat held in Tempe, AZ. Families from 24 states, with members having 24 different syndromes, gathered for a weekend of fun while making new friends, renewing old friendships and sharing resources, experiences and support.

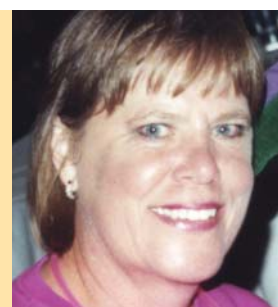
A wide age-range attended the 2004 Cher's Family Retreat, from several one-year-olds to 88-year-old Elizabeth Moulton, who traveled all the way from Maine with her adult son John, who has Apert Syndrome.

The Thursday night ice cream party brought a special treat when **Arizona Cardinals** football players, **Renaldo Hill** and **Damien Anderson**, signed autographs and posed for pictures with the families. They were great with the kids, and we enjoyed their company.



On Friday, the families enjoyed a full day of swimming. The 109-degree heat seemed tolerable in the

see **retreat**, page 10



## from the executive director

Another Cher's Family Retreat is in the record books. From a staff perspective, I believe it was one of the best. This is partially because of the wonderful mix of families and the gorgeous setting, and partially because of many friends from all over the country who gave of their time and/or talents to make it special. We'd like to take this space to acknowledge and thank each of them.

**Don, Diana** and **Amanda Critchlaw, Sharon Dick** and **Diana Sweeney** (all of whom have attended every or nearly every retreat) pitched in right off the bat and helped stuff the goody bags after CCA staff

see **exec dir**, 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 Jana Butera at 800-535-3643 or [JButera@ccakids.com](mailto:JButera@ccakids.com).

# meet jillian shepard

**S**even-year-old **Jillian Shepard** is one sunny girl on the go. The folks at CCA caught up with her while she was on a shoe-shopping expedition and were able to talk to her on her family's cell phone between stops.

Jillian has been enjoying her summer break, but second grade is just around the corner. She's looking

forward to going back to school, where math and religion classes are the subjects she likes best. She also loves her art classes. "Pink, red, purple and blue are my favorite colors," she said.

She rounds out her busy schedule with ballet, tap and cheerleading classes. And one of her hobbies is collecting Barbie dolls. It's been said she's got a pretty impressive collection.

She has three brothers, Danny, Matthew and Paul, and two pet birds, one of whom she calls Sponge Bob.

Jillian and her family went to this summer's Cher Family Retreat in Phoenix. She said she had a great time, enjoyed spending lots of time at the pool and had fun at the dinner. And she had the opportunity to meet some good friends.

She also had the chance to see Cher at one of her concerts. "I got to meet her [backstage] and talk to her," she said. She thinks Cher is very nice and likes her music a lot.

When Jillian grows up, she wants to be a doctor and a teacher. She's got everything going for her. It looks like she's well on her way to achieving those goals.

## cca kid



Jillian and her dad

### take charge for CCA

**n**ow's a great time to get a VISA credit card from Schoolpop. For every purchase you make — whether or not it's a participating Schoolpop merchant — Schoolpop will make a 1% donation to CCA!

Four people have already racked up more than \$200 for CCA — and that's just since January! Think of what can be done if families and friends used the Schoolpop VISA card for groceries and gas as well as for shopping at participating merchants. Visit [www.schoolpop.com](http://www.schoolpop.com) to sign up for your Schoolpop VISA credit card now!

### save those cells!

**p**lease save your old cell phones for CCA as well as empty laser disk and ink cartridges from your computer printers. CCA can turn them in for rebates! Send them to us or bring them along if you're coming to the family retreat. All families turning in rebate items will get extra door prize tickets for each item they turn in!

If you think you can fill a whole box, call us and we'll send you a collection box, ready to go with the UPS shipping charge already covered. Thanks for participating!

# ccaadult

## donna gossett

**m**y name is **Donna Gossett**, and I'm from a small town called Cullman, which is in the middle of Alabama. I'll be 36 in August.

I have Fibrous Dysplasia, a bone disease that affects my left cheekbone, causing a growth on my cheek that looks like a tumor. I was given this diagnosis when I was nine years old, after a lot of research by a team of doctors. When it came time to operate, I was told that the insurance company would not pay for the surgery because it would be considered cosmetic. To this day I've never had any operations.

I was told at the time that I was the only one in the state of Alabama with anything like this, so I felt very alone and isolated. In my senior year of high school I saw the movie, *Mask*. Then I knew there were other people like me.

I've been a fan of Cher for a long time. I watched "The Sonny and Cher Show"; I never missed an episode. Listening to her music helped me out when I was feeling down or made me feel even better when I was having a good day.

**Cher** is the reason I found CCA. When I got my computer in 2000, I found CCA through her Web site. How wonderful, I felt, that there was such an organization.

I've been teased and called names a lot while growing up, and as an adult, I still have to deal with stares and rude remarks. For example, an older lady asked me in front of my kids, "What is wrong with your face?" I just looked at her and smiled. Then, very matter-of-factly, I went into full detail of my disease. I hope she thinks next time before she asks someone a question like that again.



I've said many times that I'm having a T-shirt made with "Ask me." on the front and "I have a disease called Fibrous Dysplasia!" on the back.

I've had somewhat of a normal life. I met my wonderful husband who loves me for me; we'll be celebrating our 20th wedding anniversary next year. We have two kids: Kyle, 10, and Kayla, eight.

I learned how to deal with my situation, but it took a long time. I feel like a butterfly now. I owe CCA a lot of credit for that because I use to hide in my little cocoon until I had a reason to really come out. When the newsletter came out about the "Reconstructive

Surgery Act" HR 1499, I knew that I could do something to help.

I don't want another child to have to go through what I went through, so I went into full action. I called **Tim Ayers** at CCA. Then I contacted my representative and senators and started talking to them about the bill. Of course, they were unaware.

To get even more attention to the bill, I contacted my local newspaper, and they printed a feature article with a full picture of me. Then I contacted a local news station and had an interview with them. Because of what I

see **gossett**, page 8

# cleidocranial dysplasia

by Tamison Jewett, MD

## What is cleidocranial dysplasia?

Cleidocranial dysplasia, also known as cleidocranial dysostosis or CCD, is a genetic condition affecting bone growth. CCD is characterized by a larger-than-expected head with delayed closure of the soft spots (fontanels), underdevelopment or absence of one or both collar bones (clavicles) and short stature. This condition was first reported in 1760 and was later reported 1765. There is also evidence that it existed in prehistoric man. Greater than 1,000 cases of CCD have been reported in medical literature.

People with CCD have a characteristic facial appearance. They tend to have a short head from front to back (brachycephaly) and a prominent forehead ("frontal bossing"). There is typically delayed closure of the fontanels, and some adults with CCD have open fontanels. The eyes are widely spaced, and the nasal bridge is often flat. The neck appears long, and the shoulders are narrow and down-sloping.

Individuals with CCD often have abnormalities of the teeth, and many have extra teeth. The teeth may be unusually formed and positioned. Delayed erup-

tion of the teeth, especially the permanent teeth, is common.

The clavicles may be completely absent on one or both sides, but more commonly, they are underdeveloped, usually deficient at the end closest to the shoulder. Occasionally, the clavicle is normally formed on each end with a gap in the middle. Because of these differences in the clavicle, individuals with CCD may have the ability to bring their shoulders together in front of their bodies. Additionally, the muscles attached to the clavicles may be unusually formed and placed.

People with CCD may have abnormalities in bones other than the skull and the clavicle. They may have unusual positioning of the hip joints, abnormalities of the bones of the spine, and unusual formation of the bones of the fingers and hands. The average height for an adult man with CCD is 156.6 (about 5'2") to 168.8 cm (about 5'6") and for a woman is 144.6 (about 4'9") to 148.5 cm (about 4'10"). Orthopedic care may be warranted if there are concerns regarding the bones or joints.

Occasional abnormalities that are associated with

CCD include scoliosis (curvature of the spine), extra ribs, a tendency to have bone fractures, cleft palate, small pelvis, hearing loss and respiratory problems (such as recurrent sinus infections or pneumonia). It is important that all women with CCD have adequate evaluation of their pelvic diameter prior to giving birth, as a cesarean section may be the preferred method of delivery. It is also important that individuals with CCD be monitored regularly for evidence of hearing loss. Hearing loss may be due to the structural and functional changes of the bones of the ear together with unusual formation of the palate, but it can also be due to abnormal function of the nerves of hearing.

Individuals with CCD typically have normal ability to learn. Affected, infants and children usually reach their developmental milestones as expected. Children may benefit from speech therapy, especially while undergoing treatment for dental problems.

CCD is usually inherited in an autosomal dominant fashion. Approximately 30 percent of cases are caused by a gene change occurring for the first time in the affected individual

(spontaneous gene mutation), and 70 percent of people with CCD have an affected parent. The condition is highly variable from one affected person to another.

A brief review of chromosomes and genes may be helpful at this point. Genes are the basic units of heredity, and they are present in almost every cell of the body. Genes are located on larger structures called chromosomes. There are typically 46 chromosomes in almost every cell of the body. These chromosomes are arranged in 23 pairs. Twenty-two of the pairs are numbered from largest (#1) to smallest (#22) and are the same in males and females. The twenty-third pair is called the sex chromosomes because it determines if a person develops as a male or female. Females typically have two X chromosomes, while males typically have one X chromosome and one Y chromosome. Because our chromosomes come in pairs and the genes are located on the chromosomes, genes also occur in pairs. One gene of each pair comes from our mother and the other from our father. Likewise, we only contribute one gene from each pair to a child.

## dysplasia, from page 4

CCD follows an autosomal dominant pattern of inheritance. "Autosomal" means that the gene responsible for the condition is located on one of the numbered chromosomes, not the sex chromosomes. "Dominant" means that only a single gene change is necessary for an individual to show features of the condition. Therefore, people who have CCD have one gene of a pair that is unchanged and working properly and one gene that is changed and is not working properly. The gene that is altered "dominates" over the unchanged gene, causing the features of CCD.

The gene that causes CCD is denoted by the symbol RUNX2, and it directs the body to make a protein that helps to control the development of osteoblasts, which are cells that are important in the formation of bone. Gene testing is available on both a research and a clinical basis. While most individuals with CCD either inherited their "CCD gene" from an affected parent or are the first in their families to have a gene change, there are several reports of families in which two siblings with CCD were born to unaffected parents, sug-

gesting that some parents may have a percentage of egg or sperm cells that carry the gene change. This phenomenon is referred to as "gonadal mosaicism."

Individuals with CCD should be followed by either a team of specialists or by individual specialists familiar with the problems that can be associated with this condition. In young children with CCD, the fontanelles may be so large as to warrant the wearing of a helmet to protect the brain. Hearing tests should be performed at birth and regularly (at least yearly) thereafter. Affected infants should receive their first dental evaluation by one year of age, preferably by a dentist who treats children with complex dental problems. Of note, it has been shown that extraction of primary teeth does not hasten the eruption of permanent teeth in this condition. Children with CCD may have recurrent otitis media (middle ear infection) related to abnormal formation of the palate and/or eustachian tube dysfunction; this may necessitate the placement of tympanostomy tubes. Individuals with CCD are more likely to have upper airway obstruction, and sleep habits must be carefully monitored. Regular snoring and/or restless sleep may warrant a sleep study. Occasionally, an

affected individual may have a very narrow chest that causes respiratory distress. Finally, it is important to note that people with CCD are expected to be shorter than their typical peers and family members. Nevertheless, with the proper anticipatory guidance, people with CCD usually lead healthy and productive lives.

*Tamison Jewett, MD, is an associate professor in the Department of Pediatrics, Section of Medical Genetics, at Wake Forest University School of Medicine in Winston-Salem, NC. She is the director of Clinical Genetics Services.*

### References:

*Cooper, Sara C., et al, A natural history of cleidocranial dysplasia, American Journal of Medical Genetics 104:1-6(2001).*

*Mundlos, Stefan, Cleidocranial dysplasia; clinical and molecular genetics, Journal of Medical Genetics 1999; 36:177-182.*

*Visosky, Ann Marie B. et al, Otolaryngological manifestations of cleidocranial dysplasia, concentrating on audiological findings, Laryngoscope 113:1508-1514: September 2003.*

## 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.

## cca kids, grads, adults: artwork needed

We still need all artists out there to send in original artwork for use in holiday items for sale on our Web site next winter.

You can use pencil, crayon, paint or any flat-piece media to create your own art. (No photos or copies, please.) Then, send your art soon, to Jana Butera at CCA headquarters in Dallas! Have fun!

# third bi-ennial cher convention

On July 16 and 17, avid Cher fans converged at **Las Vegas' Riviera Hotel** to celebrate CCA's National Spokesperson, **Cher**, and her incredible career.

In 1999, convention originators **Judy Didelot, Jody Cantwell** and **Kim Werdman** had the idea of bringing Cher fans from around the world together to raise money for Cher's favorite charity, CCA.

The first convention was held in 2000 in Chicago, IL. Since then, **Linda Alamprese, Brad Wright, Robin, Fred, Edna**, and **Marina Fisher**, and **Mary**

**Ladd** were brought on board to help, and **Mike Werdman** joined the team to coordinate the audio and video. The staff, who are not compensated for their efforts, dedicate endless hours organizing this festive event.

On Friday, Cher fans from all over registered for the weekend events. That evening the convention kicked off with a dinner show that included Cher impersonators, who dazzled conventioners with their renditions of Sonny and Cher songs from the '60s and '70s; the "Heart of Stone Tour" from the '80s and the "Love Hurts" and "Believe" tours from the '90s. **Wayne Smith, Chad Michaels, Steven Wayne** and **Amy Hoheimer** starred in the shows, along with Sonny and Cher impersonators **Catherine Marie Carter** and **Mark Parry**, who came all the way from England.

On Saturday, Cher-related events and entertainment kept everyone busy all day, and Cher items and Cher Convention souvenirs were sold to eager fans. Cher impersonator **Amy Hohimer** kicked off the events by singing the National Anthem. **Mary Ladd** hosted the "20,000



Check donated by Wal-Mart of Las Vegas' Good Works.

Pyramid Game" and talk show host **Wayne Smith** interviewed Cher. Scrapbook author **Mary Anne Cassata**. Then the crowd enjoyed a Cher Impersonator Show with **Amy Hohimer, Heidi Thompson, Chad Michaels, Steven Wayne** and **Kenneth Blake**. A silent auction and two live auctions then took place.

The second of the live auctions was held after a delicious dinner on the penthouse floor of the Riviera, which displayed a spectacular view of the city. Auction items included six

autographed original Bob Mackie sketches (two of which were autographed by Cher), which sold for a total of \$15,000.

That day, representatives of the **Las Vegas Wal-Mart** were on hand to present CCA with a check for \$10,500.

Also, raffle winner **Kimberly Gelly** won a **Pagsta Mini Choppa**. Autographed by Cher, this one-of-a-kind bike was donated by **Johnny** and **Lynette Pagnini**.

On Saturday night, impersonator **Wayne**

see **cher conv**, page 9



Cher impersonator, Wayne Smith.



Johnny Pagnini and Robbie Gorecki pose next Kimberly Gelly, winner of the Pagsta Mini Choppa donated by the Pagninis.

# second annual pete's scramble



**T**he **Second Annual Pete's Scramble for CCA** was a smashing success! Held again at **Beacon Hill Golf & Country Club** on May 22, the event hosted by **Dede, Darin** and **Peter Dankelson** of Commerce Township, MI, brought together 56 golfers and many other generous individuals and business folks to foster awareness and social acceptance of craniofacial conditions.

Festivities included a golf outing (no duffers in sight) as well as a silent auction.

The contribution to CCA — with a check for **\$5,400**

— more than triple last year's effort. Wow!

This is just another family fundraising success story that anyone can duplicate in their own town. Call CCA if you'd like information on how the Dankelsons did it. Congratulations, Dede and family. Thank you!



# FUNraising



The Atkins Family: Steve, Macey, Stacey and Raven

**S**tacey Atkins of Baton Rouge, LA, has been busy raising money for CCA.

First, she got approval from her manager, **Anthony Huysmans**, and then enlisted the help of her co-workers at **Hibernia National Bank** to hold a **\$5 Denim Days** fundraiser throughout June.

And she didn't stop there. On June 18, she rounded up family and friends and held a **Jambalaya Dinner** feast at \$6 a plate. Stacey, her mother-in-law, **Joyce Atkins**, and best friend, **Hope Taylor**, cooked green beans, green salad, bread and dessert to go with her cousin **Alton Fisher Sr.'s** catering specialty, chicken and

sausage jambalaya. They served 172 dinners!

Not to be outdone, Stacey's husband's cousin, **Frederick Williams**, and his wife, **Jolander**, helped Stacey deliver the meals to 13 area businesses.

Along the way, others added to the funds, with **Rebecca Jackson, Charles Spears Sr., Carla Woods, John Fisher Sr.** and **Dawn Batiste** helping Stacey collect donations as well as meal orders. Look for a list of donors in the next newsletter.

The Atkins family came to our Family Retreat with a check to present to CCA for **\$1,438** — just another wonderful example of how much a creative family can do!

gossett, from page 3



did, I got a lot of attention brought to this bill in the state of Alabama.

Then I had some kids writing letters to congressmen on my behalf. I'm a substitute teacher, and of course the kids are curious as to why I look so different. I explain to them that I was born this way and the fact that someone may look different doesn't make them a bad person. I try to teach them not to treat others differently because of their looks. I explain to them how bad someone could feel and how I have felt when others were mean like that to me.

Through selling raffle tickets I've spread the word about CCA in my community. I've become friends with the staff of CCA, and they are just the most wonderful people.

It's so great to know that there are such understanding people out there.

When CCA invited me to come to the Cher Family Retreat, I was just so excited to get a chance to finally meet others like me. I've met the most beautiful children, parents and adults. I never felt like I was being stared at or being judged for the way I look. Everyone treated me like part of a big family. I had a FABULOUS time. Thanks, everyone!

I would also like to give a big thanks to **Karin Perry** for giving me a scrapbook page, so I could write to Cher and thank her for all she has done. Maybe one day I'll be able to meet her.

We had such a great time at the retreat, and I cried when it was over. I can't wait until I can see everyone again. I hope to come back next year.

I plan to continue using my story to help and teach others. In fact, this fall I'll speak with kids and share photos at a fund-raiser my school is having for CCA. Maybe one day I can make an even bigger difference in this world.

# 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 Jana Butera at 800-535-3643 or email [jbutera@ccakids.com](mailto:jbutera@ccakids.com)

## Programs we offer

- Toll-free hotline
- Doctor referral
- Information and support
- Educational booklets
- Financial assistance
- CCA newsletter, *CCA Network*
- [www.ccakids.com](http://www.ccakids.com) Web site
- Annual Cher's Family Retreats
- Public awareness



## carrying the torch

**p**lease join us in congratulating recent high school graduate **Scott**

**Guzzo** who carried the Olympic Torch, about 400 meters in his wheelchair, through St. Louis, Missouri this summer.

Scott and his family have been involved with CCA for many years and are regular attendees of the Annual Cher's Family Retreat and the bi-ennial Cher Convention. In June 2003, along with his parents, Scott spoke at a legislative forum in Washington, DC about the lack of insurance coverage for craniofacial treatment.

Along with many celebrities, Scott was among chosen few to carry the Olympic torch through the Gateway Arch, various neighborhoods and on to Francis Field on the campus of Washington University. Congratulations, Scott! We're proud of you!



**cher conv**, from page 6

Smith's "Cher" was surprised by special diva guests, "Diana Ross" and "Bette Milder" (**Brent Allen**). The trio sang "You Gotta Have Friends." Then Wayne performed his version of Cher's current "Farewell Living Proof Tour." Produced by Wayne's brother, **Sonny**, and accompanied by dancers from Dallas, TX, Wayne's elaborate show included an entrance on an elephant for his rendition of "All or Nothing," just as Cher does in her concert.



Sonny and Cher impersonators, Mark Parry and Catherine Marie Carter pose with Mike Werdman.

This year's convention raised around \$42,000, bringing a grand total of \$100,000 in donations to support the programs and services of CCA.

All of us at CCA are so glad these generous people came into our lives. Not only are they really good at what they do, but working with them is such fun! We make a great team!



Jill Gorecki, CCA's Development Director, poses with convention organizer, Kim Werdman and Gorecki's son, Robbie.



\$42,000 check presented to Charlene Smith of CCA by Cher Convention coordinators.

# jill gorecki *did* have a point.

When I was at the **Cher Convention**, I had the chance to talk about how my family came to know CCA and Cher. I gave everyone background information to better explain why the Cher's Family Retreat is such an important program for our family.

Then, like I tend to do when I speak in front of people, I went down a different path, and I didn't get my original point across.

Here's what I wanted to say: **CCA was there for our family when Rob was little, and they helped each of us — Rob, Mom, Dad and brother — get through the years of Robbie's challenges.** I credit CCA, the retreat (our family vacation each year) and the overall therapeutic value of being able to talk to other families as the core of our family's well being, Rob's great self image and confidence, and my sanity.

**Rob** and **Scott Guzzo**, having both grown up with the charity, represented the thousands of CCA kids and their families at the Cher Convention. They wanted to "give back" and make sure these important programs and services continue.

Fortunately, most of our kids are not facing death like Rocky Dennis in Cher's movie, *Mask*, but with disfigurements and unfair disadvantages, they all must face life.

The efforts of the Cher Convention Foundation are vitally important to so many. What a huge impact their generous participation as Cher fans is to all our kids!

Thanks for letting me (finally) get to the point.

— Jill Gorecki, CCA Development Director

**retreat**, from page 1

beautiful football field-sized pool carved into the side of the Butte. After a pizza lunch, an extremely talented magician/juggler amazed young and old alike with a remarkable show.

Friday evening the crowd visited Rawhide Western Town and took a mule-pulled hay wagon ride into the Arizona desert for a sundown cookout. Back in town, the group saw a wild west shootout, gun-fights, stunt shows and stagecoach rides; took part in desert train rides, bull riding, gold panning, camel rides, games and horse-back riding; and visited a petting zoo, a working blacksmith, western shops, and much more. Whew! Needless to say, we didn't lack for entertainment!

A fun-filled Saturday started with breakfast in the Top of the Rock Restaurant complete with a breathtaking, panoramic view of the city of Tempe. Later that morning we boarded buses for The Science Center of Arizona, where interactive exhibits provided hours of fun. The state-of-the-art planetarium shows, tailored to each age group, were fun and educational. One of CCA's staff discovered an interesting object in the gift shop that most everyone found quite amusing. It was a "Wind Breaker." (Use



your imagination.) Young **Paul Shephard** adeptly described what followed. "The adults are acting like the kids, and the kids are acting like the adults," he exclaimed!



As usual, the highlight of the retreat was the Saturday evening dinner/dance. After a Mexican food buffet everyone donned their dancing shoes, lighted necklaces, stick-on hearts and stars, bracelets, and lighted jester and princess hats and danced the night away. And, as usual, **Scott Guzzo** led the group during the song, "Locomotion." The kids competed for prizes and door prizes were given away.

Sunday morning brought the usual hugs, tears and promises of keeping in touch. We had a wonderful time. In the words of 11-year-old **Chris Frederick**, "This rocks!"





**exec dir**, from page 1

arrived late because of a flight delay. The bags, which doubled as beach bags for the pool, were donated by **Julee Rico** of Richardson, TX. In the bags were the CCA retreat shirt designed by **Bruce Williamson** and the program designed by **Robin Williamson**, both of Carrollton, TX; retreat name badges designed by **Lisa Evans**, of Dulles, VA, and constructed by her mom **Cathy Evans** of Royse City, TX; stickers from **Mrs. Grossman's Sticker Factory** in Petaluma, CA; Crayola demin bags with art supplies donated by **Lori Young** of Nazareth, PA; phone cards donated by **Claire Dittrich** of **Discover** in Chicago, IL; and note pads donated by **Julie Lyle** and **Jana Butera** of Denton and Plano, TX.

splash shopping for pool toys, and **Anita Burt** of Snyder, TX, donated Splash Balls for the pool party on Friday.



**The Craniofacial Foundation of Arizona** sponsored the trip to the Science Center of Arizona, and **Tamara Carter** of the **Buttes Resort** arranged for **Arizona Cardinals'** players **Damien Anderson** and **Renaldo Hill** to join our group for the ice cream party.

**Lou Anderson**, CCA's wonderful volunteer from New London, WI, made and donated blankets and treat bags for each family. And **Jessica Prince** of Cheshire, CT and **Greg Patterson** of Kilgore, TX served as volunteer photographers.

We are thankful for these wonderful folks who so generously helped make the retreat special.

And, now we anxiously await June 2005, when we will all be back together again in Nashville, TN.

*(Details for the 2005 retreat will be posted soon on [ccakids.com](http://ccakids.com).)*



**Cher** sponsored the Friday pool party. **Diana Sweeney** of Philadelphia, PA, and **Martha Brown** of Buffalo, NY, made a big



# 3 cheers for volunteers!

CCA would like to applaud **Karin Perry** for illuminating our hearts with her talent at this year's retreat. Karin is one among many of our parents who juggle the demands of a



hectic schedule yet still finds inspiration to embrace these children with gentleness.

She lit up the room this year with her quilt of a thousand smiles, which featured pictures of CCA kids and their families.

Karin also brought out the creative side of our families this year with her idea of a memory book as a gift to thank **Cher** for all



her support and generosity. Everyone joined in on the fun personalizing their pages with pictures in a unique style.

Three cheers for Karin Perry, who brought a warm touch to helping others express themselves!



Honorary Chairperson:  
Cher

**Board of Directors:**

Tim Ayers, CHAIR Washington, DC  
Tony Davis, Tuscaloosa, AL  
Bill Sims, CPA, Dallas, TX  
Robert Vargas, Dallas, TX  
Robin Williamson, Carrollton, TX

**Medical Advisory Board:**

Jeffrey Fearon, MD, CHIEF ADVISOR

**CCA Network Editor:**

Kelly Liszt

**CCA Network Design and**

**Production:**

Robin Williamson, Williamson  
Creative Services, Inc.

**Executive Director:**

Charlene Smith

**Program Director:**

Jana Butera

**Development Director:**

Jill Gorecki

**Office Administrator:**

Annie Reeves

**Business Manager:**

Cathy Evans

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

VOICE 214-570-9099

FAX 214-570-8811

TOLL-FREE 800-535-3643

URL CCAkids.com

children's craniofacial association

13140 Coit Road, Suite 307 • Dallas, TX 75240

NONPROFIT ORG  
U.S. POSTAGE  
PAID  
DALLAS, TX  
PERMIT NO. 555

If you no longer wish to receive this newsletter, please email your wishes to [JButera@CCAKids.com](mailto:JButera@CCAKids.com) or mail the label to the CCA office and ask that it be removed from the mailing list.

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