ccanetwork

newsletter of the children's craniofacial association
Cher — honorary chairperson
winter 2006

inside

Helena Moriarty

helena's story

by Carol Moriarty

Helena Gabrielle Moriarty was born nearly nine years ago and has been a blessing and joy to me since her birth. Helena has been through three surgeries, two in her first year of life and one when she was five. The first two surgeries were to correct her skull shape and size, and the third was to create a vault and move her eyes closer together. I'm a veteran parent of cranial surgery, and I am extremely anxious every time a surgery is scheduled.

Helena's third surgery turned out to be the most difficult for her. The challenges started when her dura was ruptured during the removal of the bones of her skull. The rupture of the dura caused the surgery to continue for nearly six hours because the neurosurgeon tried to repair the damage.

see **helena,** page 10

welcome to 2006!

As the new Chairman for CCA, I look forward with enthusiasm to what we can accomplish during the coming year. I have been a board member with CCA since 1999 and have come to know many of our families and consider you to be part of my own extended family. I have watched some of our little ones grow to be taller than I am (That's you, Zachary!), and I feel very fortunate that our lives have crossed. You have made me a better person, and I am grateful for your dedication to your own families — and to CCA.

see **chair,** page 15

empowering and giving hope to facially disfigured individuals and their families

Ryan MacLennan

meet ryan maclennan

Ryan MacLennan is three years old and is from Farmington, NM. He lives with his mom, dad, seven-year-old sister, Taryn, and Louie, his big fat, solid-black cat.

Ryan attends the Farmington Special Preschool, where he draws, reads books, solves puzzles and rides his tricycle.

When he's at home, he likes to play with his cars and trains and play hide and go seek with his sister. He likes the TV show, *The Wiggles,* and his favorite movie, by far, is *Herbie: Fully Loaded.* He's also a huge Denver Bronco's fan, just like his dad. In fact his second word was "Bronco."

Ryan loves to play outside and especially loves to ride horses, and he participates in a local program called Reindance. Last year, he was part of the Special Needs Rodeo at the county fair, and he practiced two times a week for three months to prepare for the event. At the rodeo, he rode his horse through an obstacle course and won a trophy and a ribbon! Later this spring he'll get ready to win more awards in this year's rodeo. Good luck, Ryan!

Ryan has Goldenhar syndrome; he can't eat yet, and speaking is very difficult. Some sounds are possible, and he can communicate some words (like "Bronco!"). For now, he uses sign language.

He has gone through 13 surgical procedures and seven surgeries so far. Last year, he had a distraction device implanted, which will prepare his jaw for reconstruction by way of a rib graft. Luckily, he didn't have any surgeries or major recoveries late last year, so this past Christmas was the first one he was able to fully enjoy.

Ryan's family found out about CCA on the Internet and have met a lot of wonderful families at the Nashville and Tempe retreats. He and his family have met seven other children with Goldenhar and their families, which helps them to know that there are others out there with similar circumstances. They look forward to meeting everyone again at this year's retreat in Hershey, PA.

cca kid

ccateen

meet sabrina robineau

Sabrina Robineau

hi, my name is **Sabrina Robineau** and I live in Gatineau, Quebec Canada. I am 16 years old and was born with Pfeiffer syndrome. This is my last year of high school.

It's amazing how fast time flew by. I couldn't have gotten through it without the support of my mother. She has been there for me since day one. I'm also very lucky to have had an older brother who was always there for me. Despite my syndrome, I still have a normal life. I am able to do everything that teenagers typically do. I enjoy hanging out with my friends, reading, playing basketball and dancing. I love going to school, because it really makes me feel like I belong. Some of my friends don't even know I have a syndrome!

I remember once when I was in a store with a friend of mine and there were these girls that kept staring at me. It upset me very much and my friend noticed. When I told him about the staring, he said, "Forget about them. You don't look any different to me, I'm proud to be your friend and I'm proud to go places with you." This showed me that there are people in this world that will accept you for who you are no matter what. My friends have definitely given me more confidence, and they have helped me out a lot through my toughest times.

My first operation was at 6 months old (heart surgery), and since then I've had 18 operations. The most difficult challenge I'm facing right now is my hearing. I have many ear infections, and it makes it very hard to hear well. Even though it gets tough sometimes, I have learned to just take it one day at a time, and I'll get through it.

Growing up, life wasn't always easy. I had to deal with a lot of people staring at me. It was then I started to question why I looked different and went to my mother for answers. When I learned about Pfeiffer syndrome, I wanted to teach other people about it. In fourth grade, there was a public speaking contest, and I wrote a speech about my syndrome. I said that even though I may look different, I was still the same as everyone else. My teacher was so impressed with my speech, that she chose me to represent my class in the contest that would take place in front of the whole school! I was very nervous, but I did it and everyone loved it!

I was very lucky during elementary school because I had many friends that knew me since kindergarten, so I fit right in. However, it was when I would go to public places such as restaurants or the shopping mall, I felt really different. There were many situations where kids and even adults would stare at me non-stop. I tried not to let it bother me, but it was hard. My advice to children that have to deal with staring is to try to ignore them or just smile at them.

see **sabrina,** page 5

meet jessica prince

Jessica Prince

My name is **Jessica Prince,** and I'm a 22-year-old student at the University of Connecticut, living with two roommates in Manchester. I plan on graduating with my degrees in photography and psychology this fall. I love photography, even outside from school projects, and I occasionally have photo shows where I can sell my work.

Although I'm very busy with school and working two jobs, I always find time to go to my mom's house and have a family dinner once a week. I love hanging out with my **mom** and brothers **Justin, Daniel,** and **Jason,** my sister-in-law, **Nancie,** and my nephew, **Kole.**

I have gone to CCA retreats with Justin for about the last nine years. We really look forward to going on vacation every June, and we usually extend the four-day trip to do some sightseeing. Justin's favorite was Disney a few years back. I'd have to say my favorite trip so far was Arizona. It was amazing — and great to photograph!

Even though I have moved out of my mom's house, I try to see Justin as much as I can, and sometimes he comes to my apartment for a sleepover. We love renting funny movies and having popcorn with way too much salt! Our favorite recent movie we saw in the theater was *The Hitchhikers Guide to the Galaxy.*

I don't know if I will be able to make it to the upcoming retreat at Hershey Park because I have to take summer classes, but I know Justin can't wait! And I definitely will see you in Utah next year!

ccasupersib

sabrina, from page 3

When I was 11 years old, I had my mid-face advancement operation. That was back in November 2000. It not only changed the way I looked but it changed my life for the better. Although the healing process was very long and frustrating, it was worth it. I'm really glad I went through with it.

Pfeiffer syndrome is so rare that my mother and I were never able to meet anyone else like me. It felt like I was the only one and was often upset.

In 2002, my mom found the Web site, Apert.org (Teeter's Page), and discovered that there were many kids all over the world that looked similar to me. She told me that they have Apert syndrome, which is similar to Pfeiffer, only those with Apert syndrome also have webbed fingers and toes.

That summer, my mom and I went to a get-together in Myrtle Beach and met many people who not only looked like me but were also going through the same things I went through. It was great and I made a lot of friends. I realized that I was not alone!

April 9, 2005, was my sixteenth birthday, and my mom surprised me by bringing me to Cher's concert. She had contacted **Diana Sweeney,** who arranged for us to have front-row tickets and also meet **Cher** backstage! I enjoyed meeting her; she was so nice to me. I found her to be very down-to-earth. It was definitely a birthday that I will never forget.

In June, with the help of CCA, we got to go to the family retreat in Nashville. It was amazing. For the first time, I met three girls with Pfeiffer syndrome: Olivia, Macey and Natalie. They are all so cute and brought back memories of what I was like at that age. It was great to meet the parents and other kids who were going through the same things I've been through.

Unfortunately, I will not be able to attend the family retreat in Hershey, PA, next June because it is at the same time as my high school graduation and my prom.

After I graduate, I plan to go to college to study law and psychology. I hope to become a criminologist or some other profession that has to do with criminal law. **I believe that we can achieve anything if we set our mind to it.**

And remember, don't ever give up!

in memorium

This issue of CCA Network is dedicated to the memory of **John Michael Chambers,** who passed away on December 9, 2005. He and his family attended the annual Cher's Family Retreats, and John Michael was loved by everyone. He lived in Joshua Tree, CA, and is survived by his mom, **Allie,** and his grandmother, **Bea.** He will be greatly missed by all of us.


John-Michael with his mom, Allie Chambers.


JM eating cake on his first birthday.


JM with his cat, Bill.


Here he is riding his pony, Scooter.


JM in the arms of Donna Gossett, CCA board member.

2005 holiday parties

Dallas, TX

CCA, together with the **Craniofacial Center at North Texas Hospital for Children, Dr. Jeffrey Fearon, Dr. Kenneth Salyer,** and **Dr. David Genecov,** hosted its 16th annual holiday party in Dallas, TX, on Saturday, December 10, 2005. Around 400 kids, parents, doctors and staff gathered for a morning full of fun and activities.

Radio Disney entertained our partygoers as they participated in activities, such as cookie decorating, holiday crafts and face painting. Partygoers met and received autographed pictures from the **Dallas Cowboys Cheerleaders** and the **Fort Worth Cats'** mascot and they got the chance to go and see a real fire truck provided by the **firefighters of Plano, Texas.** Families went home with numerous door prizes supplied by many Dallas and surrounding area businesses. Prizes included an autographed Game Day Program from the **Dallas Cowboys;** movie passes from **Cinemark** and **IMAX;** passes to the **Fort Worth Zoo;** a gift certificate to the **Magic Time Machine;** family fun packs to **Celebration Station;** a baseball T-shirt, cap, novelty ball and baseball from the **Frisco RoughRiders;** an autographed hockey puck from the **Dallas Stars;** passes to **Six Flags Over Texas** and seats to the **Mesquite Rodeo.**

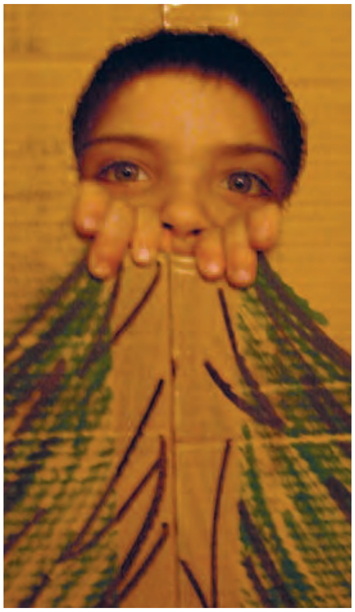
As always, the highlight of the party was **Santa Claus,** who arrived shortly after the party started. Children had their pictures taken with Santa and went home with gifts out of his goodie bag, along with keepsake pictures. CCA would like to thank our volunteers **Beverly Butera, JoAnn Turano, Ginger Morrone,** and **Natalie Mulvey** as well as all of the wonderful companies that donated the prizes.

Kenosha, WI

a group of CCA families from the Midwest gathered in Kenosha, WI, at the **Parkway Chateau/Brat Stop** to celebrate the holidays.

Santa (Ron Luke) visited once again, and passed out teddy bears and listened to gift wishes as the kids posed on his knee for photos taken by **Mrs. Santa (Pat Mehigan).** Also joining the group were friends from **AboutFace** in Chicago, **Rickie Gill, Dr. David Reisberg** and CCA Volunteer extraordinaire, **Lou Anderson**, and her husband, **Terry.** Crafts, carols, cookies and a competition for door prizes rounded out the afternoon.

Thanks to all involved. See you next Christmas!



2005 holiday parties, continued

Dallas, TX, continued

Kenosha, WI, continued

first annual friends of jeremy golf tournament

October 15, 2005

For the past couple of years we've been talking about organizing a golf tournament to raise money for CCA. But it wasn't until we met the **Dankelsons** at the 2005 family retreat in Nashville that we finally decided to do it. They have been very successful with Pete's Scramble the past few years, and we were extremely motivated by their success.

As soon as we returned home from the retreat we got to work. **Dede** and **Darin Dankelson** really helped us in the beginning by showing us all of their work and talking to us about the details of their tournament. We couldn't have pulled it off without their help!

We spent the next three months advertising throughout the community, soliciting sponsors and prize donations and rounding up interested golfers. Both local newspapers, the *Corning Leader* and *Elmira Star Gazette,* did very nice articles about Jeremy and our involvement with CCA. It was great advertisement for the tournament, and it raised awareness about facial differences. Jeremy felt like a celebrity, especially when a group of kids came up to him on the playground one day and said "Hey, you're the kid we saw in the newspaper" and then started to play with him.

Jeremy practicing his putting skills!

Planning the tournament was a lot of work, but it was also a lot of fun and so rewarding. The tournament was held at **Willow Creek Golf Club** in Big Flats, NY. The weather was beautiful; it was the first sunny day after about seven days of continuous rain!

We had an incredible turnout and so much support from the community, our co-workers, friends and family. Our support came from **94 golfers, 34 hole sponsors, 21 local businesses** who donated prizes, **seven professional sports organizations** that donated items for the silent auction, and various **friends and family members** who volunteered their time to help with the tournament.

We kicked off the tournament by welcoming all of the golfers and giving them a little background about CCA and the purpose of the event. Jeremy officially started the tournament by yelling "Let's Play!" in the microphone and then sounding the horn for the first tee shot.

Each golfer received a goodie bag filled with information about CCA, snacks for the day, golf balls, Friends of Jeremy Golf Tournament golf tees and a CCA golf towel. The money raised came from sponsors, golf registrations, charitable donations and tournament activities such as a raffle, silent auction, closest to the pin 50/50 and closest to the line contest. **The tournament was a huge success raising $14,331 for CCA!**

We are so grateful to everyone who supported this event, and we are already planning the Second Annual Friends of Jeremy Golf Tournament, which will be held at Willow Creek Golf Club on October 14, 2006.

George, Kristine, Jeremy and Tommy Dale

helena, from page 1

The craniofacial surgeon was also not able to fully repair the bridge of her nose as planned. The surgeons wanted to do as much of the scheduled repair as possible, but they had to give up some of the desired repairs due to the time spent repairing the dura.

After an agonizing wait, Kevin and I were finally told why the surgery was taking so long and about the complication with the ruptured dura. We were also told about the potential dangers to her if the dura was not completely repaired. Helena had to remain intubated post-op and was leaking spinal fluid from her nose. The doctors were hopeful that the dura would seal, however we were told if the dura would not seal Helena would have to undergo another surgery to repair the dura or to potentially install a shunt.

For me, this was devastating news; I never let myself really think about the surgery not going as planned. I waited by Helena's bedside, and every time I wiped spinal fluid from her nose my heart would break.

The neurosurgeon decided to try a lumbar shunt to take the pressure off of the brain and to give Helena one more chance to heal herself. By this time our very large families had mobilized to support Helena, my husband and me.

After getting the lumbar shunt, we encountered further setbacks. Helena would not eat or drink, and the swelling in her face and head was getting worse. Finally, after much prodding from my husband, Helena was put on TPN (total parental nutrition). We finally saw some improvement in our sweet little girl. Slowly her swelling went down and she began to ask for ice.

After five days in the PICU, Helena was strong enough to have the lumbar shunt removed. We were told this was the last chance we had of avoiding another surgery. The shunt would be removed and she would be able to have her head elevated and if she leaked spinal fluid another surgery would be immediately required.

Shortly after the shunt was removed and her head was raised fluid started coming out of her nose. I was devastated; I really thought she would finally be better. Seeing my distress the nurse quickly went and got a ph strip to check the fluid. The fluid dripping from Helena's nose was not spinal fluid, and she would not require any further repair of her dura. Thankfully, we had this good news to get us through the rest of her hospital stay.

When we finally left the hospital, Helena was extremely weak and frail. Yet I was overjoyed I was bringing my little angel home. It took many months for Helena to regain her strength and stamina.

Thanks to the support of our family and friends I was able to make it though such a difficult time. Having seen Helena so vulnerable and sick makes some of the other challenges of having a child with a craniofacial anomaly seem small. I am grateful every day that she is mine and I am hers. I learned to focus on the small things, and I do not take her good health for granted.

Helena will turn 9 in a few weeks, and she knows exactly who she is and what she likes. She desires

continued next page ⇨

helena, from page 10

to be on stage, she loves going to plays and wants to perform for others. Helena also wants to own a business with her cousin when she is older. Helena is homeschooled and has just started to attend a local public school that has a program for homeschoolers once a week. She has a bubbly, happy personality and wants to be friends with everyone she meets.

I was first introduced to the annual Cher retreat through our surgeon's office a few years ago. Since it was held in our hometown of Phoenix, we decided to attend. What a boost this retreat was to our entire family. It was so good to get together with all of the families for fun and relaxation.

Our family attended our second retreat in Nashville. During the dinner dance, Helena came running up to me and said, "Guess what some girl said to me: 'Pleased to meet you.' And she wants to be my friend." Helena spent the rest of the evening dancing with **Grace** and another friend named **Brenna.** This was truly a great experience, and I look forward to going as often as we can.

2006 Retreat Biggest Ever!

Registration is open for the 2006 Cher's Annual Family Retreat to be held in **Hershey, Pennsylvania June 22–25th.** Contact **Annie Reeves** at 800-535-3643 or email her at AReeves@CCAKids.com for a registration form and reservation information. Our block of rooms at the Hershey Lodge has already sold out! We are placing families in a second, nearby hotel. Please call Annie for additional hotel information.

gifts to cca "in honor"/ "memorials"

When our donor list is published twice yearly, you may have noticed this section noted. Donations during the holiday season made in someone's name are acknowledged to the honoree through a card from CCA. Your gift at any time during the year may be made in honor or memory of a special person. Just let us know.

CORRECTION: We inadvertently reported the wrong totals from our high raffle ticket sellers, the Dale Family. The Dales sold 629 tickets for $2,575. Thanks again!

contributing non-cash assets to cca

Children's Craniofacial Association has teamed with the **MYCHARITIES™ Donor Advised Fund.** This association now allows us to work with donors who desire to give assets other than cash.

MYCHARITIES™ DAF is a Dallas, Texas-based 501(c)(3) public charity equipped to serve clients with trustee requirements and planned gifts. In addition, the professionals affiliated with the MYCHARITIES™ DAF specialize in the acceptance and management of alternative donations such as gifts of real estate and life insurance.

What is a DAF?

A DAF is a charitable organization that accepts and manages charitable donations that are subsequently distributed to other public charities. The assets contributed to a DAF are really charitable gifts over which the donor is given certain "advisory" rights on their management or later distribution. The benefit to the donor is the ability to enjoy an income tax deduction in the year the contribution was made, while still having many years to actually advise where those funds should ultimately go.

If you have a life insurance policy which you no longer need, please consider a gift of the policy to a charitable remainder trust or a DAF account for the benefit of CCA. The MYCHARITIES™ DAF professionals will show you how a life insurance policy can be converted to a cash amount much greater in value than the surrender value. Please call David Nelson with MYCHARITIES™ DAF at 214-871-3838 for more information about contributing non-cash assets.

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

congress considering insurance rights for craniofacial patients

Make Yourself Heard

representative Mike Ross of Arkansas recently introduced legislation in the US Congress to guarantee insurance coverage for craniofacial patients. This legislation (HR 4022) was proposed because insurance companies often label needed reconstructive care as "cosmetic" and deny coverage for this or other reasons. The Reconstructive Surgery Act of 2005 seeks to guarantee that insurance companies meet their obligations to cover medically necessary care.

The American Medical Association has developed clear and simple guidelines regarding the differences between cosmetic and reconstructive. The legislation proposed by Congressman Ross incorporates the AMA definitions. The legislation also is virtually identical to the language in federal law requiring coverage for reconstruction after mastectomies.

To make this proposal the law of the land, however, depends on support from citizens—and that's easy to do. Just go to www.aica-advocates.blogspot.com/ scroll down the right side of the page, type in your zip code and you will have the information you need for contacting your senators and representative by email, by phone, or by postal mail. Your message to them should be simple and to the point: "Please support HR 4022, the Reconstructive Surgery Act of 2005. This legislation simply requires insurance companies to meet their obligations. It's a matter of fairness." That's all you have to say. If you want to include some details about your personal situation, that's even better—but keep it simple and to the point. Ask your friends, relatives, and neighbors, church groups, community organizations, school classes, bowling leagues, and anyone else you can think of to do the same.

ccaprograms

and services in the spotlight

Families of craniofacial patients often call CCA to seek emotional support, discuss problems and identify resources. Through our database, we are able to network families with support groups and/or others who have similar conditions and experiences. We also keep a list of helpful resources and are always willing to listen and offer emotional support to family members who need a shoulder upon which to lean. For further assistance or information call Annie Reeves at 800-535-3643 or email AReeves@ccakids.com

programs we offer

- Toll-free hotline
- List of qualified physicians
- Information and support
- Educational booklets
- Financial assistance
- *CCA Network,* a quarterly newsletter
- www.ccakids.com Web site
- Annual Cher's Family Retreats
- Public awareness
- Family networking
- Advocacy

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

be remembered, bequest!

as you gather your donor receipts to do your taxes for April, this is also a good time to consider long-term tax savings. About 50% of what you leave behind at the time of death goes for estate tax. That's higher than income tax! It pays to do some advance planning. When you consult an attorney or investment professional regarding your will and assets, we hope you'll consider a charitable bequest in your will – to benefit CCA while you save tax dollars.

cca annual giving campaign

by now you've received our annual funds appeal letter*, and have read the amazing story of **John Moulton** and the struggles his family dealt with as he grew up with Apert syndrome in a time when CCA was not around. Today, Children's Craniofacial Association is making a difference for many children and their families and through your donation, you can too. Please think about contributing to the best of your ability. Gifts of cash, stocks, real estate, trusts and annuities will allow CCA to continue to provide programs and services and will allow you a tax advantage.

*If you did not receive our letter, please see it on our Web site, www.CCAKids.org *and* hear John play the piano.

download the newsletter

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

regional volunteers

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

CCA has formed a network of regional volunteers across the country who have banded together in an effort to educate and inform the public. The regional volunteers and CCA will now turn to local areas to recruit volunteers who will distribute educational materials throughout their communities.

If you would like to help educate your community and take part in this national awareness effort, call or email CCA Program Director, Annie Reeves at 800-535-3643 or AReeves@CCAKids.com.

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.

new column!

We're always happy to hear about **good news** from our families and we believe the success of one CCA Kid or Grad will inspire them all. Please send us your good news blurbs, whether it's your child who's a patient or another "patient" child! We'll list the news bits in the *CCA Network!* We recently received the following note from one of our donors.

> **"My son, Tom , had 22 surgeries for a bilateral cleft lip and cleft palate. He is very successful with a BS in Electrical Engineering and an MBA from the University of Michigan. He is now 42 years old."**

coming soon

Our new online Web store will be available soon on our Web site. Watch for lots of great items featuring our logo which will also serve to spread awareness of CCA!

www.ccakids.org or www.ccakids.com

save those cells!

Please save your **old cell phones** for CCA as well as **empty laser disk** and **ink cartridges** from your computer printers. CCA can turn those in for rebates! Just send them to us. If you think you can fill a whole box, call us and we will send you a labeled, UPS pre-paid collection box. It's that easy.

calendar of events

date	event	contact
March 10	**cleftAdvocate Getting to Know You Event** 3:00 to 5:00 p.m. Shriners Hospital Chicago, IL	Debbie@cleftadvocate.org 702.769.9264
May 20	**Fourth Annual Pete's Scramble for CCA** Beacon Hill Golf Club Commerce Twp., MI	Dede@perceptiondesigns.com
June 22–25	**16th Annual Cher's Family Retreat** Hershey, PA	AReeves@CCAkids.com 214.570.9099 800.535.3643
July 23–26	**2006 North American Craniofacial Family Conference** Alexis Park Resort Las Vegas, NV	rickie@aboutfaceusa.org 888.486.1209
July 28–30	**Genetic Alliance** Bethesda North Marriott Bethesda, MD	www.geneticalliance.org
September	**Craniofacial Acceptance Month**	AReeves@CCAkids.com 214.570.9099 800.535.3643
October 14	**Second Annual Friends of Jeremy Golf Event** Willowcreek Golf Club Big Flats, NY	DaleK@corning.com

cca welcomes new board members and says goodbye to an old friend

two talented individuals have recently joined the CCA Board of Directors.

Deborah DeLay is from Fort Collins, Colorado and is a Licensed Social Worker. Debbie's professional experience includes work in both the medical and nonprofit fields. She lives in Fort Collins where she enjoys hiking, backpacking and horseback riding. Debbie has two granddaughters and a grandson who is expected to be born in March.

George Dale comes to CCA as both the father of 6-year-old Jeremy who was born with Goldenhar syndrome and as an active fundraiser. George lives in Corning, NY with his wife Kristine, Jeremy and their younger son Tommy. George and Kris are expecting their third son in May. George and Kris are very active in CCA. Both serve on the fundraising committee and volunteer for several projects such as selling tickets for the motorcycle raffle and conducting their first golf tournament in September which raised more than $14,000.

Welcome to both Debbie and George!

After serving on the board of directors for seven years, CCA staff and volunteers bid farewell to **Bill Sims**. Bill has volunteered his expertise as a CPA to oversee CCA's financial responsibilities. Located in Dallas, Bill works across the freeway from the CCA office as a partner in the accounting firm of Salmon, Beach & Company. We want to thank Bill for his years of dedication to CCA and the families we serve and wish him all the best.

cca board of directors elects officers for 2006

at the December meeting of the CCA Board of Directors officers were elected for 2006 as follows:

Chairman, **Tony Davis, DMD**

Vice Chairman, **Rose Seitz**

Secretary, **Heather Lermont-Pape**

Treasurer, **Dan Paulson**

chair, from page 1

I am continually amazed and inspired by the spirit of the children I have met since joining CCA. You are the true heroes and the heart of this organization and it is for you that we all dedicate our efforts. You approach life with so much excitement and always have a smile.

I hope that 2006 will bring awareness of craniofacial conditions to the millions of people who do not understand what we are all about. Our children are the key; they are the real teachers and the ones who can bring our cause to the world's attention. And all they have to do is be themselves.

With so many natural disasters during 2005, it's easy to see how quickly our lives can change. There will be new challenges in 2006 but if we face these challenges together, there is nothing we cannot accomplish.

My best to each of you and I hope to see you in Hershey!

Tony Davis, DMD
Chairman
Board of Directors

3cheers for volunteers!

CCA provides an array of services – everything from helping families with financial assistance when they must travel for medical care and even helping plan the trip, to publishing booklets, keeping families connected to others, providing a comprehensive Web site filled with important information, conducting an annual family retreat, advocating for fair insurance benefits, launching a nation-wide public awareness effort and publishing this newsletter. Additionally, there are administrative responsibilities and of course to fund all of these services there are many fundraising efforts. Whew! Sound like a lot of work? Sound like more than a staff of 4 can accomplish? Well you're right.

The CCA staff relies on many volunteers to make all this happen. Besides the numerous family members and friends who take a very active role on committees and other volunteer commitments, CCA's board members dedicate numerous hours volunteering their time and expertise. For some charities their board of directors attend meetings and oversee the fiscal management of the charity. But, CCA's directors are dedicated to actively making a difference for children and adults with facial differences. You'll see their contribution on almost everything CCA accomplishes. The staff would like to start the year by recognizing the members of the CCA Board of Directors and thanking them for their dedication and commitment to the CCA families and to ensuring the delivery of our programs.

children's craniofacial association
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