

# ccanetwork



newsletter of the children's craniofacial association

Cher — honorary chairperson

winter 2007

## inside

cca teen  
nick lincavage . . . . . 2

cca teen  
elizabeth erickson . . . . . 3

cca supersib  
nathan lincavage . . . . . 4

new board member . . . . . 5

good news . . . . . 5

holiday parties . . . . . 6-7

calendar of events . . . . . 7

revamping the dream . 8-9

fundraising . . . . . 11

golf tournament . . . . . 13

fundraising  
news . . . . . 14-15

cca programs . . . . . 15

donors . . . . . 16-19

3 cheers . . . . . 20



Burzio family: (back row) Ashton, Bret, Catherine; (front row) Pauline, J.B., August

## life with pauline

By Catherine Burzio

Everyone has momentous days. Important days that etch into your memory. Marriage. The birth of a child. The first full night of sleep after the child's birth.

There is one unsung day that holds great significance to me each year—January 19. This was the day, after two months of “being watched” that solidified our journey on the road less traveled with our only daughter, Pauline. That day brought the confirmation of significant heart anomalies and a cleft lip in our unborn child.

Two days later, the first of four amniocenteses confirmed we were having a girl! And two weeks later, further confirmation showed our daughter had a genetic condition, Monosomy 18p. Right before she was born, we were prepped with the understanding that she would be three or four pounds and more than likely a “blue baby” because of her heart issues.

see **pauline**, page 10



## message from the chairman

As we start a new year, we always look back to see what we did right—and what we can improve upon. Our CCA families did a lot of things right in 2006, and we want to dedicate this article to them.

Family & Friends Fundraising events have grown beyond all our expectations, and we are amazed at how talented and resourceful you all are. There were numerous family fundraisers held in 2006, allowing CCA to support the programs and services that are so important to our families.

see **chairman**, page 9



We wish to thank Bally's, a corporate sponsor, for helping to fund the CCANetwork.

Please consider a corporate sponsorship. Contact Jill Gorecki, JGorecki@CCAKids.com

empowering and giving hope to facially disfigured individuals and their families



At left: Friend, Andrew Perry (left) with Nick Lincavage.

Below left: Nick at birth.

Below right: Nick with Bianca Moon.



## meet nick lincavage

**N**ick Lincavage is 14 years old and lives in Lutz, a town in central Florida. He's in eighth grade, and his favorite school subjects are math and gym.

He has plenty of after-school activities, too. Nick enjoys playing ice hockey and soccer. In fact, he has tryouts this month for his school's soccer team. And he is a first-degree black belt in karate. He also helps his younger brother **Nathan** play sled hockey.

Nick enjoys swimming, and since he lives in Florida, he's able to swim in the ocean often. One time last summer, when he went crabbing, a school of huge fish came nearby. He said it was so cool to be so close to them—there were about 40 fish total.

Nick also has a lot of hobbies. He likes to listen to 1990s metal rock bands like Slipknot and Godsmack, and he's into computer games. He likes action games, like Mortal Combat, and strategy games, such as Legacy of Kain. He's also plays Grand Theft Auto, which he considers a big stress reliever.

Nick likes a good scary movie, such as "Puppet Master" and "Child's Play" and any type of zombie movie. And likes funny movies, especially anything with Adam Sandler. Nick is also a great cook. He grills a good steak, and he's been known to make some delicious brownies and cookies. His pets include: Sophie, his eight-year-old dog, and a few greensingers, a type of finch.

Nick and his family have been involved with CCA for the past three years. He even went to a **Cher** concert, where he sat on the front row. He and his brother, Nathan, got to visit with Cher backstage afterward for about half an hour. Nick can't wait to go to his third retreat this summer in Salt Lake City, where he's looking forward to meeting up with friends, especially his good friend Andrew.

Nick was born with a cleft lip and palate. He has had 12 surgeries so far, with the first one when he was 10 weeks old. When asked to give advice for other kids going through similar circumstances, he said, "Just be yourself. Don't try to act cool." He added, **"Be happy with who you are and enjoy life."**

# ccateen



# ccateen

## meet elizabeth erickson



Elizabeth with her dog, Leo.

**m**y name is **Elizabeth Erickson**, I was born with Schimmelpenning syndrome. I enjoy reading, quilting, and watching TV. My family and I go on several vacations every year to places all over America including the annual CCA retreats. I love going to Camp Sunrise every year and hanging out with all of the other teens. I am going through leadership training right now and want to become a camp counselor. I love horses and going camping, and I spent a summer on my aunt's ranch in Colorado taking care of her horses. I'm really looking forward to

this year's retreat in Salt Lake City because I love traveling out west, and I can't wait to see everybody again.



John Beargrease Sled Dog Marathon in Duluth, Minnesota



Elizabeth backstage with Cher at a 2004 concert.



Elizabeth and her brothers: Brent, James and Mike, holding their poodle, Nikki.



# meet nathan lincavage



## ccasupersib

hello, my name is **Nathan Lincavage**. I am nine years old and the little brother to **Nicholas Lincavage**, who has a unilateral cleft lip and palate. I have Cerebral Palsy and am so lucky to have Nick as my big brother.

Because of my CP, I walk using a walker or forearm crutches. I often watch my brother play ice hockey and I wanted to play, too. My mom found out about the **Tampa Bay Lightning Sled Hockey Clinic** for people who have disabilities

Twice a month I go to the **St. Pete Forum**, which is sponsored by the **Lightning Rays**, and practice on my sled. My brother comes and assists me and all the other sled team members as an able-bodied skater.

Nick and I also enjoy playing video games, fishing and cuddling up and watching a good spooky movie. I love going to the yearly CCA retreats, where I have met a lot of good friends. We have made the last two retreats: Nashville and Hershey. I can't wait to see everyone this year in Salt Lake City!

Older brother, Nick, pushing Nathan in a game of sled hockey.





## cca welcomes new board member

CCA is privileged to have talented individuals on the board of directors who are willing to offer their particular expertise to further our mission. Recently, **Kurt Allen** was elected to the board.

Kurt brings several much-needed talents with him. He is a CPA and attorney and has worked in financial consulting and as a financial advisor. Currently, Kurt is a financial advisor and partner with the Jones Group at Merrill Lynch.

Kurt lives with his wife and four daughters in Youngstown, Ohio. Join us in welcoming Kurt Allen to the CCA family!

## donors in the spotlight



Each issue this year we'd like to highlight special donors who've made a difference for CCA with their generous contributions and kind hearts.

This issue we want to express special thanks to all of our "Anonymous" donors.

You know who you are! Thank you!



## good news

**Adam Anderson**, son of **Terry** and dedicated CCA volunteer **Lou Anderson**, of New London,

Wisconsin, recently received the NCO sword. This sword is given to a Marine who has shown the ability to be the best in the Company. After having served three tours of duty in Iraq, Adam's superiors selected him for this distinguished honor. Congratulations Adam!





# holiday party DALLAS, TEXAS

**CCA**, together with **Dr. Jeffrey Fearon**, hosted its 17th annual holiday party in Dallas, TX, on Saturday, December 9, 2006. Around 500 kids, parents, doctors and staff gathered for a morning full of fun activities!



**Radio Disney** entertained everyone while they munched on cake, drank punch, decorated cookies and made holiday crafts. **The Dallas Cowboys Cheerleaders** as well as the **Dallas Desperado Dancers** were there, giving autographs. The children had the opportunity to go and see a real fire truck provided by the **firefighters of Plano, Texas**. Each kid who visited the fire truck



was given a goodie bag by the firefighters!

Families went home with numerous door prizes supplied by many Dallas and surrounding businesses. Prizes included passes to **Six Flags**; team poster, stickers, limited edition collector's ticket, hat, T-shirt, magnets and baseball cards from the **Frisco Roughriders**; grandstand seats to the **Mesquite Rodeo**; a gift certificate from the **Magic Time Machine**; passes to the **Fort Worth Zoo** and the **Dallas Zoo**; autographed items from the **Texas Rangers** and the **Dallas Mavericks**; and a gift card from **Pizza Hut**.

As expected, the highlight of the party was **Santa Claus**. Children had their pictures taken with Santa and went home with a toy and a keepsake photo.

CCA would like to thank our volunteers **Jana Peace, Beverly Butera,**

**JoAnn Turano** and **Rae Jene Mungioli**, as well as all of the wonderful companies that donated the prizes.





# holiday party MIDWEST



Once again in 2006, a group of CCA families from the Midwest (East North Central Region) gathered in Kenosha, Wisconsin at the **Parkway Chateau/Brat Stop** to celebrate the holidays.

They were visited by **Santa and his elf**, who passed out little Christmas trees for everyone to decorate. The kids posed with Santa for photos.

This year the noontime party served up a pizza lunch and yummy desserts. Families introduced themselves to one another and tickets were drawn for door prizes. Mom, **Marla Verdone** of Janesville has graciously accepted the task of planning next year's festivities. See you there!



## planning a vacation?

There's a new way to support your charity! Book all of your travel needs at [www.ytbtravel.com/ccakids](http://www.ytbtravel.com/ccakids) including flights, cruises, hotels, rental cars, even your passport. A percentage comes back in funds for CCA. And, you may rest easily, knowing the site is powered by reliable Travelocity.

## calendar of events

date	event	contact
May 19	<b>Fifth Annual Pete's Scramble for CCA</b> Beacon Hill Golf Club Commerce Twp., MI	Dede@perceptiondesigns.com
June 28-July 1	<b>17th Annual Cher's Family Retreat</b> Salt Lake City, UT	ARees@CCAkids.com 214.570.9099 800.535.3643
July 22-24	<b>2007 North American Craniofacial Family Conference</b> Alexis Park Resort Las Vegas, NV	debbie@aboutfaceusa.org 888.486.1209
August 25	<b>Second Annual Wendelyn's "Course of Dreams" Golf Challenge</b> Country Club of Arkansas Mauumelle, AR	wendelynyvonne@hotmail.com
October 13	<b>Third Annual Friends of Jeremy Golf Event</b> Willowcreek Golf Club Big Flats, NY	gdale@stny.rr.com www.friendsofjeremy.com

# revamping the dream

By Aretha M. Miller, M.S.W., M.B.A./HCM

## A Parent's Journey to Acceptance

An article in the American Association of Plastic Surgeons newsletter stated that in the United States a child is born with a cleft lip or palate every 75 minutes. The article also stated that nearly two out of every 1,000 infants born will have some type of craniofacial birth defect. Every day, new parents are introduced to the reality that their child may not just look different but may have physical, emotional and intellectual developmental delays.

### The Dream vs. the Reality

As the social worker for the Miami Children's Hospital Craniofacial Team, as well as the Dan Marino Center for children with autism, I am referred to parents whose children have been newly diagnosed with a craniofacial anomaly. Often at the initial meeting with parents, I can sense uncertainty and despair.

I look into eyes that ask "How did this happen?"

What in the world do we do now?" The visions of their children did not include receiving the news that their child has a cleft lip and/or palate or craniosynotosis.

All parents hope for a non-complicated pregnancy and a healthy birth. Even when genetic testing and ultrasounds indicate with enormous certainty that a child will be born with some deformities, many parents still hold fast to a little seed of hope for the possibility that the medical team was incorrect in their diagnosis.

### Stages of Grief

For many parents, learning that their child has a "syndrome or disorder or craniofacial anomaly" is as traumatic as being told that their child is terminally ill. They often grieve for the child they thought they were going to have.

### Five Significant Stages of Grief

1. Shock
2. Denial/Anger
3. Guilt/Bargaining
4. Sadness/Depression
5. Acceptance

Just as if there was an actual death, parents experience the five stages of grief. This process is not experienced in a specific stage order. From my experience as a social worker, I have observed that the stages of shock and denial often go hand in hand. Also, some may re-experience some of these stages. For example, even when acceptance occurs, the feelings of guilt and grief may reoccur.

### It's Okay to Cry

Crying is truly a healing and cleansing reaction. When given traumatic or un-expected news, crying is one of the most natural reactions. It does not matter if it is good news or bad.

As a pediatric social worker in a hospital setting, I cannot count the number of times I am frantically paged in the hospital because a parent is crying. Whether the parent cries soft, silent tears or wails aloud, it is an emotionally healthy reaction.

At this time, the most I can do for them is provide emotional support and comfort by acknowledging their pain and heartache, assisting them with clarity of the physician's disclosure and begin providing resources that will assist them as they move forward.

What concerns me most is the parent who receives the unexpected physician's report and skips from the shock stage directly to the acceptance stage. These parents are in the social worker's office the next morning, taking notes and making detailed lists. They start calling at once for appointments and information. When it becomes difficult to speak to someone immediately, they become intensely frustrated and emotionally distressed. I have seen this happen often.

These are usually the people who need the most emotional/clinical support. They are still in shock, denial or any combination of the grief emotions. Often, it is not until they have this breakdown or

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breakthrough that they are able to truly grieve.

### Coming to Terms with the Reality

Parents who are able to accept, experience, adjust and reinvest, are ready to deal with what God or life has dealt them. The initial grief will be losing their “dream child,” but they reinvest in the child they have. For some parents, the grieving process may start again when they find that their child’s outlook is poor, if not terminal.

This is why psychological intervention is important for families who have an “atypical” family member. Support groups, as well as family and individual counseling provide an outlet and comfort which lets them know they are not alone. As a helping professional, there must be value placed in religious/spiritual types of support. Spiritual counseling is often sought as an alternative or in conjunction with clinical therapy.

As parents move forward in the acceptance stage, they are able to reconstruct their expectations for their child. With guidance, parents learn how to set

achievable goals for their children. Sometimes this process begins simply by encouraging the parents to get to know their children. Often parents get so caught up in the child’s diagnosis, treatments and therapies that they forget about the child as an individual. Parents have to learn their child’s strengths and areas of concern. This will assist with finding and building the appropriate medical and educational teams needed.

As a social worker, my responsibility in the acceptance process is to educate parents and arm them with resources that empower. With the right information and/or psychological help, parents can move through the acceptance stage and, ultimately, be the child’s greatest source of support.

**Arletha M. Miller, M.S.W., M.B.A./HCM** is a clinical social worker currently working in both pediatric and adult medicine.

### chairman, from page 1

This is a wonderful achievement, and you are to be applauded.

You held golf tournaments, bingo, yoga sessions, denim days, raffles, shopping and dining incentives, email campaigns and gift-wrapping—all for CCA’s benefit. These are just a few of the many events held around the country, and all were great successes.

As important as money is to operating an organization like CCA, belief in you is what makes us worthy. And without the dedication of our families, staff, regional coordinators and volunteering friends we would never be able to reach our goals.

This is YOUR charity, and I am thrilled to see how you have taken ownership of CCA. It brings a new dimension and clarity to our mission: *to empower and give hope to individuals with craniofacial conditions and their families*. It inspires us all to be more, be better, and think bigger. And, it gives strength and hope to those who need it most.

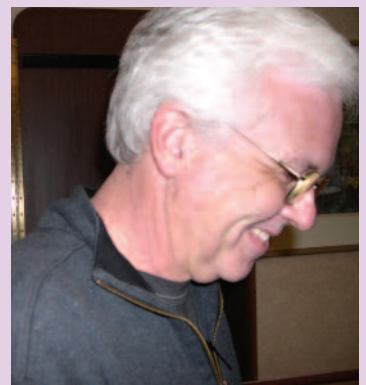
CCA is reaching a new level, which brings with it new responsibilities. In 2007, our goal is to enhance our website and make it more interactive to adults, teens and our younger children. We want to add to our list of syndrome booklets in order

to educate and comfort many more new parents.

With the help of our regional coordinators and local volunteers, we want to reach out to help thousands of families who are unaware CCA exists for them. You are our biggest and most important resource for both spreading the word and raising funds. With families and friends all across the country pitching in, we can reach our goals.

So, if you think you can get out in your community and spread the word, or if you think you can help by holding a fundraiser (big or small), just let us know. We will give you the tools to accomplish the job.

We thank you for your dedication and determination to see that those with craniofacial differences are seen just as everyone else—capable, talented, smart and beautiful.



Tony Davis, DMD  
Chairman of the Board



After weeks of prayer, preparation and grieving, our nine-pound, screaming—and pink—baby girl made a grand entrance into this world. Yes, they were wrong. The first of many times Pauline would prove the doctors wrong.

A brief kiss of her cheek showed us there was more in store. Her sweet face was misshapen, low set ear nub on the left, smaller/closed left eye, and a cleft lip and palate. It was a startling addition to the long list of life-threatening issues that began our unknown journey.

All of this was new. My husband and I come from an arts background. Neither of us could

describe, even in the simplest of terms, what a genetic condition was or how it would potentially affect the bearer.

After a few days in the NICU, it was confirmed, Pauline not only had 18p, she also had Hemi-facial Microsomia, or HFM. After two life-altering surgeries and two months in the NICU, Pauline was allowed to come home and begin her “normal” life. Normal for Pauline included alarms, feeding tubes, oxygen and ‘round-the-clock care—more than a typical infant.

With the love and support of family and friends, we slowly moved into a routine that included time with our then four-year-old son, Ashton. We

spent countless hours on the road seeing specialists and surgeons those first few years. I wish I had a penny for every mile we have logged on the road to and from doctor and hospital visits over the past 12-plus years. It might just get us out of medical debt!

This life is a perpetual learning curve. Once I think I have a grasp on where we are, the rules change. This was the case November 8, 2005.

A loud “tink” and the cries of a man on our street prompted us to run out of our home to see our beautiful girl who had beaten so many odds and defied so many doctors, lying in the middle of the road, unconscious and bleeding. Pauline was hit by an SUV as she rode her bike, a blindsiding event that left us all hurdling through a maze of emotions—again.

There was a time when I thought I could handle whatever came next. But, “whatever” came and I was not so ready. After our first medivac helicopter ride, we landed in the beginning of a yearlong road to recovery and restoration.

Pauline did an amazing job of healing and astounded everyone around her. With multiple injuries, we thought she

would be out of commission for many months. She was back to school in roughly four weeks and riding a bike again in just under one year.

I am learning there are many waves in this life, but one thing remains constant: our faith. It is a choice of faith to find joy in each day.

Pauline’s name means “short in stature, but great in heart”—a perfect name! Her brothers prefer to call her “Miss Sassy Pants” or “Pest.” I guess some things ARE normal.

Ashton is 17 now and an amazing big brother to Pauline. There are times when she asks for him after surgeries and not us!



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J.B. is almost 11 and is a great helper, someone who readily jumps in to pick up the slack. August is 8 and a smiley boy, who promised me that he will always give me hugs and kisses—no matter how old he gets.

When I look at my kids, I know God doesn't make mistakes. He has a great sense of humor, but He doesn't make mistakes.

After the news was given of our baby girl's impending medical issues, our OB/GYN pulled Bret and I aside and said firmly, "Today you have two things to do. First, go downstairs and make sure your insurance is in order. This is your 'million dollar baby.' And second, decide today whether or not you will stay married."

That day, we confirmed our insurance and drove home in silence. We made a silent vow to each other and our growing family. With the divorce rate at roughly 50 percent nationwide and upwards of 80 percent when there is a child with special needs included, we chose the road less traveled, and that has made all the difference.

# how to raise funds for cca

**C**CCA depends on funds donated by individuals, proceeds from family and friends' fundraising efforts, corporate giving and foundation grants. The need is great as we grow to provide programs and services to many more affected individuals and their families. Any help our readers contribute is most appreciated. Here are some ways to help.

- **www.goodsearch.com**

Enter Children's Craniofacial Association as your beneficiary charity. (You only have to do this the first time. You may add others if you wish.) CCA will receive up to a penny each time someone uses the GoodSearch search engine.

- **Cash for Trash!**

Save your discarded cell phones and empty laser / ink cartridges and CCA can turn them in for rebate funds. Call us at 214-570-9099 or 800-535-3643 for more information.

- **Matching Gifts**

Many companies offer a matching gift program that could double or even triple your gift to CCA! Contact your human resources office to find out if your company has such a program.

- **Planned Giving**

Tax preparation time is also a good time to consider long-term tax savings. When you consult an attorney or investment professional

regarding your wishes for distribution of your assets in your will, consider a provision for CCA. Your planned gift in the form of an endowment will live on after you.

- **CCA Web Store**

You can now shop at CCAKids.org for your T-shirts, mugs, caps and more. So shop now and shop often!

- **Clubs / Hobbies**

Have your club organize a benefit for CCA. Use your hobby or something you love to do to raise funds.

- **Denim Days**

Raise funds at work for CCA. Establish a special day or days for employees to make a designated donation (cash or check) to CCA in return for wearing blue jeans. The donation is usually \$1 to \$5, depending on how often the event takes place (for example \$1 for a weekly donation, \$5 for a monthly donation). Any higher amount would be at the discretion of the donor.

- **Civic Organizations**

Public awareness leads to contributions. Contact and solicit opportunities to speak to your local civic organizations such as Rotary Clubs, Kiwanis Clubs, even HOG organizations (CCA has many 'biker' supporters). Distribute brochures and/or newsletters or other CCA-sanctioned materials for awareness and information. Ask for contributions.

- **Friends / Family**

**Letter Appeal** Draft letter to family, friends and acquaintances—anyone who has met or encountered your child. Contact CCA for a sample letter.

- **Kitchen Shut Down**

Raise funds by raffling off chances to win meals for every day of the week, so the winner can "shut down" their kitchen. Local restaurants can donate meals or coupons. This idea could be used for a week of entertainment, such as movie rentals or theater tickets. Call CCA for more information.

- **Collection Cans**

Ask local businesses to place a can or box (provided by CCA) to collect donations or take a can around to collect donations.

- **Get On Board!**

Read our newsletter and learn about and participate in the events, raffles and funding efforts of CCA and our supporters. Pass the donor envelope to someone you know looking to support a charity. And when you are finished with your copy of our newsletter, spread the news! Pass it along or leave it in a waiting room. (Remember to remove your address label.)

## Looking for ideas?

Contact Jill Gorecki at J.Gorecki@ccakids.com



## attention cca friends and families:

**W**e'd like your "Mugshots"! When you purchase a CCA Logo Mug, send us a snapshot of you with your mug for a "Mugshots" section...each newsletter we'll post new mugshots!

## tie one on for cca

**V**ineyard Vines, well-known producer of 100% fine silk ties and other products sporting whimsical motifs, has created a tie especially for CCA donors and friends, using the happy faces on our charity logo.

These high-end quality ties come in a choice of two popular background colors, light blue or royal, and may be purchased for \$100 each, gift-boxed and delivered.

The first 100 CCA logo ties were produced to



observe the month of September, proclaimed by CCA as "National Craniofacial Acceptance Month" and

some are still available.

Please, wear one in support of your charity and to raise awareness that fosters acceptance of individuals with facial difference. Call our office or go online to order your ties!

## win a jamaican trip!

**O**n January 1st we kicked off the 2007 New Year with a raffle to win a trip for two to Jamaica!

Thanks to the legwork of CCA dad, **Paul Shepherd**, our friends at **Liberty Travel** and **Air Jamaica** have donated a trip for two to Jamaica and as a bonus, **Levinthal's** in Philadelphia donated His/Hers luggage!

Tickets sell for \$5 each or \$20 for 5 tickets (includes 1 free), or \$100 for 30 tickets (includes 10 free).

There is still time before the March 15th sale deadline to buy a chance to win. **THE DRAWING WILL BE HELD ON THE FIRST DAY OF SPRING, MARCH 21ST.**

Tickets may be purchased online at [www.ccakids.org](http://www.ccakids.org).

## regional volunteers

**p**ublic 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 [AReves@CCAKids.com](mailto:AReves@CCAKids.com).



# friends of jeremy golf tournament



**t**he second annual Friends of Jeremy Golf Tournament was held on October 14, 2006, at **Willow Creek Golf Club** in Big Flats, NY. It was a cold, windy and rainy day. There was even a short period of time when it actually started to sleet! But the weather did not stop our dedicated golfers and volunteers.

We are so grateful to everyone who supported this event. We had an incredible turnout and so much support from the community, our co-workers, friends and family. Eighty-nine golfers, six tournament sponsors and 28 hole sponsors participated. Fifty local businesses and national

organizations donated prizes and silent auction items, and various friends and family members volunteered their time to help with the tournament.

The tournament included a raffle, silent auction, closest to the pin 50/50, closest to the line prize and a skins game. The tournament was a huge success and **we raised \$16,100 for CCA!**

The Friends of Jeremy Golf tournament was extra special this year because we welcomed a couple of guests. CCA kids **Andrew Perry** and **Staci Kuppe** joined Jeremy at the tournament. Having Andrew and Staci there was very heartwarming to the golfers. It made

everyone realize that Jeremy is not alone and that CCA and the kids supported by the organization are extremely special.

In addition to the money raised directly from the tournament, two of the golfers shared information about CCA to family members. Those families chose to organize a charitable donation fund in lieu of Christmas gifts this holiday season. The total amount donated to CCA was **\$2,250!** Special thanks go out to **Beth** and **Sean O'Neil** and **Mike Bernd** for their support and generosity!

The third annual Friends of Jeremy Golf Tournament will be held again at

Willow Creek Golf Club on October 13, 2007. For more information and to see photos from the tournament, visit [www.friendsofjeremy.com](http://www.friendsofjeremy.com).



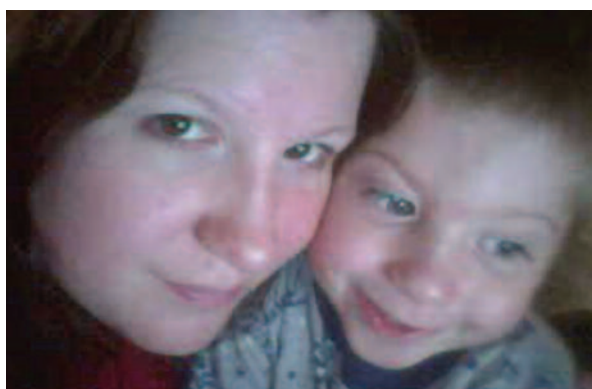


# fundraising news



Jennifer Guerra pictured here with daughters Olivia and Natalie Wardlaw.

**K**atz's Deli in Houston, Texas, posted CCA another two times as beneficiary of their fundraising table, giving 10% of the meals served at that special table and raising **\$400** for CCA kids, and then an additional **\$200!** Thank you!



Carrie Kinlen and son, Gryffin

**C**arrie Kinlen of Woodbury, New York, raised funds by garnering a percentage of meal sales through her workplace, **Applebees**. She raised **more than \$100** in one afternoon through the "Dining to Donate" program. She also held a 50/50 Raffle to raise additional funds for CCA. Her efforts are inspired by her son, **Gryffin**, who was born with craniosynostosis.



The Dalton family: John, Elizabeth Ivy and Margaret

**f**or the second holiday in a row, **Margaret Jenna-Dalton** of Austin, TX, whose daughter, **Elizabeth Ivy** was born with Apert syndrome, stood for approximately 35 back-aching hours wrapping gifts at **Border's Books** in Austin to benefit CCA. Still, she reports it was an easy and fun way to raise funds for our cause and says anyone with a Border's nearby should try it. She'd like to thank her "posse" who helped and so would we. Many thanks to **Marie Bevins, Holly Hillis, Robin Perry and Meredith Perry!** Altogether they raised **more than \$750** from hundreds of customers donating for the gift-wrapping. And kudos to Border's for this wonderful way to help charities.

Brenna Johnston



**b**renna Johnston's mom, **Robyn**, of Eugene, OR, held a raffle fundraiser in her daughter's name. (Brenna was born with Crouzon's syndrome.) Robyn raised **more than \$500** for CCA! Additionally, Robyn has started a business with her jewelry-making hobby and will be passing along a percentage of her profits to benefit other CCA kids. Visit her website at **www.rrenee.com**. Thank you, Robyn!





**R**ose Seitz of Poland, Ohio, along with her family and friends, participated in the **Simon Properties' "Evening of Giving"** fundraising opportunity. Held the weekend before Thanksgiving throughout the country, charities are provided tickets they sell to

family and friends for a special night of holiday shopping and refreshments. Rose reported that **Tara Angelilli** sold the most tickets for CCA. Thanks, Tara!

Another friend of Rose's, **Michelle White**, is a **BeutiControl** director and suggested doing a "Spa Escape" as a fund raiser. About six girlfriends got together one night for margaritas and a relaxing evening of shopping for some great products they could use every day. Rose joined the BeutiControl team as a consultant in order to give her commission for that night, **\$200**, to CCA. Thanks, Rose!



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www.BeutiPage.com/ccafriends**

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**Questions? Email Rose Seitz at**

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# 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](mailto: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](http://www.ccakids.com) website
- Annual Cher's Family Retreats
- Public awareness
- Family networking
- Advocacy

## financial assistance

**d**o 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 appointment.

## download the newsletter

**i**f you are currently receiving the newsletter by mail, but would rather download it from CCAKids.org, let us know by sending your email to [AReeves@ccakids.com](mailto:AReeves@ccakids.com). As an added bonus, the online version is in full color!

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Samantha Wayne  
Leo Dalton, in memory of Kevin M.  
Dalton  
Roger Dalton, in memory of Kevin M.  
Dalton  
Sarah Delvento, in memory of Kevin  
Dalton  
Department of Social Services Social  
Club, in honor of Jacob Palmer

Conrad DePinto, in memory of Kevin  
Dalton  
Dodd Middle School, in honor of Justin  
Prince  
Lorraine Dolecki, in honor of  
Christopher Dolecki  
Nicole Dretar, in honor of Jeremy Dale  
Duncan Aviation, in memory of Kevin  
Dalton  
Amy Escher & Donna Poyner, in honor  
of Heather Lermont-Pape's birthday  
Hope & Antonio Estrada, in honor of  
Antonio Estrada  
Mary & Mike Estrada, in honor of  
Antonio Estrada  
Paul & Michelle Fahey, in honor of  
Jeremy Dale  
Mr. & Mrs. Robert Fallon, Jr., in honor  
of the marriage of Marybeth Ayres  
& Jim King  
Robin Farinholt, in honor of Parker  
Liles  
T.M. Farrell, in honor of the marriage  
of Marybeth Ayres & Jim King  
Niki & Matt Feret, in honor of Isobel  
Fine Design, LLC, in honor of Jonathan  
Siebert  
First Grade Team at Bebensee  
Elementary, Arlington, TX,  
in honor of music teachers, Ms Scott  
& Mrs. Atchley  
Toni E. Fitzwater, in honor of Natalie  
Wardlaw  
Cheryl Frederick, in honor of Mary &  
Parker Crawford  
Stephen & Marion Frost, in memory of  
Kevin Dalton  
Mr. & Mrs. Bert Fuller, in honor of  
Olivia Sanborn  
J. William Gadsby, in honor of  
Benjamin Kettelle  
Mark & Tammy Gipple, in honor of  
Dominic Rossi  
Ken & Susan Godwin, in honor of  
Natalie Wardlaw  
Arthur Goldberg, in honor of the mar-  
riage of Marybeth Ayres & Jim King  
Erma J. Gorecki, in honor of Robbie  
Gorecki  
Jill Gorecki, in honor of Robbie  
Gorecki  
Mr. & Mrs. Curtis Graf, in honor of Jake  
Wharton  
Linda Haines, in honor of Lindsey  
Baker  
Alfred Harf, in honor of Chase Ingram  
Amanda Hartman, in honor of Ryan  
Lambert  
Annabelle Hartmann, in honor of  
Brendan Walsh  
Jim & Arleen Heirly, in memory of  
Cornell Cotosman  
Jim & Arleen Heirly, in memory of Joe  
Creed  
Jim & Arleen Heirly, in memory of  
Hugh Farmer  
John J. & Arleen Heirly, in memory of  
Bill Genthner  
John J. & Arleen Heirly, in memory of  
Tammi Kleis from Jim & Arleen  
Jim & Arleen Heirly, in memory of  
Wanda Marosz  
Jim & Arleen Heirly, in memory Kathy  
Stoker's Dad, Fred  
Jim & Arleen Heirly, in memory of  
Warren Stoker  
John J. & Arleen Heirly, in memory of  
Gene Zuk from Jim & Arleen  
David & Ginger Henshall, in honor of  
Jeremy Dale  
Kelly Hernandez, in honor of Cher's  
birthday  
Highland Elementary School Staff, in  
honor of Justin Prince

Mandie Hiznay, in honor of Freddie  
Seitz  
James & Carol Hopkins, in honor of  
Kathryn Hopkins  
Jeff Hopkins, in honor of Kathryn  
Hopkins  
Lori Hoppe, in honor of Guerin Bell  
Richard & Judy Horn, in honor of the  
marriage of Marybeth Ayres & Jim  
King  
Michael & Tiffani Howell, in honor of  
Ruby Howell  
Kathy Hubbard, in honor of Lizzy  
Hubbard  
Kathy & Steven Hubbard, in honor of  
Elizabeth Hubbard from Mom &  
Dad  
Dorothy & Matthew Hunyadi, in mem-  
ory of Kevin Dalton  
Barbara & Joe Iannaccone, in honor of  
Christopher Dolecki  
John & Margaret Ingram, in memory  
of Clarence Altis  
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Samantha Klinger  
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Lee & Jenny Knutson, in honor of  
daughter, Nalani from the Knutson  
Family  
Martin P. Koop, in honor of Brendan  
Walsh  
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of Robbie Gorecki  
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Katherine Leahy  
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Charlene Smith  
Karen & Charles Lee, in honor of the  
marriage of Marybeth Ayres & Jim  
King  
Lexie Lermont, in honor of Heather  
Lermont-Pape's birthday  
Elaine Liveoak, in honor of Mary &  
Parker Crawford  
Wayne Loeb sack, in honor of Jaci  
Samhammer  
Ronald & Rosemary Logue, in honor of  
Christopher Dolecki  
Robin Longoria, in honor of Matthew  
& Mitchell Herring

Javier & Lenia Lopez, in honor of  
Gabriela Lopez  
Mary Lovell, in honor of Peggy  
McDannel  
Paula Lowell, in honor of Robert  
Walston  
Don & Ann Lucas, in honor of Brody  
Lucas by Nana & Papa  
Greg Luetkemeyer, in honor of mother,  
Betty Luetkemeyer  
Doris & Norbert Lustine, in memory of  
Ruth Cohen  
Janis & Doug Macut, in honor of Dr.  
Savi  
Janis & Doug Macut, in honor of  
Dotti Macut  
Joan Maddock, in honor of Cindy  
DeLaRosa  
Marion Mahlmeister, in memory of  
Marie Ackerman  
Joseph Malangone, in memory of  
Kevin Dalton  
Diane Manning, in honor of Jonathan  
Siebert  
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Marie Ackerman  
Greg & Patti Mathers, in honor of  
Katelyn Mathers  
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Jaclynn Samhammer  
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of Elizabeth Hubbard  
Ellen McPadden, in honor of Jeremy  
Dale from Aunt Ellen  
Ellen McPadden, in the name of  
Jeremy Dale  
Bill & Christine Mecklenburg, in honor  
of Morgan Keahn Mecklenburg  
Ann E. Melendy, in honor of Dianna H.  
Allen  
Ann E. Melendy, in honor of Emily  
Mendez  
Susan & Chuck Michlik, in honor of  
Ashley Bock  
Midway Materials, Inc., in honor of  
Brittany Balentine  
Nellie R. Miller, in honor of Samantha  
Klinger  
Laurie Monnier, in honor of Jeremy  
Dale  
Jane Monell, in memory of Tom Law  
Juan R. Moran, in honor of Gabriela  
Lopez  
Kim Morris, in honor of Robbie  
Gorecki  
Alison & Joe Morrissey, in honor of  
Rachael Morrissey  
Patricia Lewis Murphy, in honor of  
Andrew Perry  
Pam Newcomb, in honor of Jeremy  
Dale  
Barbara & Bruce Newman, in honor of  
Nathaniel Newman  
Alland & Mary Karen Newstadt, in  
honor of the marriage of Jessica &  
Jeff  
Michael & Marti O'Brien, in honor of  
son, Brendon O'Brien  
Julie Oden, in honor of Kathryn  
Hopkins  
Rose Olson, in honor of Robbie  
Gorecki  
MaryAnn Pallante, in honor of Freddy  
Seitz  
Nancy Patterson, in honor of Jaci  
Samhammer  
Fred Paul, in memory of Kevin Dalton  
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Peter Dankelson  
Dennis & Carlotta Pawley, in honor of  
Peter Dankelson  
Jana Peace, in honor of Macey Atkins  
Joan Pedersen, in honor of Heather  
Lermont-Pape's birthday



Mary Perkins, acknowledged to Michael Perkins  
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 Liz Prince, in honor of Justin Prince  
 Suzanne Prince, in honor of Justin Prince  
 Karen & Mark Proctor, in honor of the marriage of Marybeth & Jim King  
 Joan Pupillo, in honor of Isobel Pupillo  
 Rebecca & John Pupillo, in honor of Isobel Pupillo  
 Tommy & Annie Reeves, in memory of Jerry Anderson  
 Angie Rhodes, in honor of Kathryn Hopkins  
 Tanya Rhodes, in honor of Max Abel  
 Rib-X Pharmaceuticals, Inc., in memory of Kevin Dalton  
 Alec & Kim Roark, in honor of Jylan Bilbow  
 Lynn Robinson, in honor of Jonathan Siebert  
 Mr. & Mrs. Andrew Rodriguez, in honor of Christopher Dolecki  
 Kim & Frederick Romeo, Jr., in honor of Freddie Seitz  
 Aya Romero, in honor of Eric James Romero  
 Joyce Ronczka & Family, in honor of Joseph P. Ronczka  
 Cynthia Rosario, in honor of Emily Mendez  
 Jim & Diane Rumbo, in honor of the marriage of Marybeth Ayres & Jim King  
 Fran & Gray Sanders, in honor of Wesley Sanders  
 Carol Schatt, in honor of the marriage of Marybeth Ayres & Jim King  
 Richard Schini, in honor of Samantha Wayne  
 Roberta & Robert Schini, in honor of Samantha Wayne  
 Steve & Brooke Schini, in honor of Samantha Wayne  
 Hildegard & Milton Schlesinger, in memory of Marie Ackerman  
 Paul Schmidt, in honor of Peter Dankelson  
 Eric & Susie Schneider, in honor of Jeremy Dale  
 Fred & Rose Seitz, in honor of Freddie Seitz  
 Brenda Siebert, in honor of Jonathan Siebert  
 Tom & Jean Silva, in memory of Kevin Dalton  
 Mary Ann Silvestro, in honor of Anthony Silvestro  
 Rand Sinanian, in memory of Kevin Dalton  
 Solange Skyer, in honor of Richard Skyer, Jr.  
 Mildred Slater, in memory of Marie Ackerman  
 Charlene Smith, in honor of Robbie Gorecki  
 Sue Stemen, in honor of Heather Lermont-Pape  
 Jane Stickney, in honor of Caroline Dale

Szaferman, Lakind, Blumstein, Blader & Lehmann, in honor of Avery Lytle  
 Tag Aviation (USA) Inc., in memory of Kevin Dalton  
 Mary Tauge, in memory of Marie Ackerman  
 Wayne & Patty Taylor, in honor of Jon Simmons  
 Truman & Mary Terrell, in honor of Justin Prince  
 James & Susan Thompson, in honor of Natalie Wardlaw  
 Harold & Pat Timmer, in honor of granddaughter, Kara Butterly  
 Tower Softball Team, Austin, TX, in memory of Kevin Dalton by John's Teammates  
 Mary Alice Tulimieri, in honor of Brianna Alfeiri  
 Turken Industrial Properties, in honor of Fabian Bustillos  
 Jean Vancore, in honor of Lidia DiFrancesco  
 Lucia & Scott Van Cleef, in honor of Avery Lytle from Emma Van Cleef  
 Dwight & Carrie Vaughn, in honor of Hannah Vaughn  
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 Ted Verdone, in honor of Lara Verdone  
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 Steve Vivo III, in honor of Sadie Vivo  
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 Pete & Jackie Zoellick, in honor of Robbie Gorecki

## Corporate / Foundation Gifts

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

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 America's Charities (Employee Giving Funds Management)  
 American Express (Employee Giving)  
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 The Biella Foundation by Mart Bert  
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 The Frugal Flower, Inc.(Purchases Percentage Incentives)  
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Safeway, Inc. (Purchases Percentage Incentives)  
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## Fundraising Events

### Up to \$1,000

Applebee's "Dining To Donate" / Carrie Kinlen, CCA Volunteer  
 Borders Books Fundraiser for CCA / Margaret Jenna-Dalton, Organizer, CCA Volunteer  
 "Cheers for Kids" Car Wash / Waukesha (WI) West High School Cheerleaders / JoAnn Kopshinsky, Organizer  
 Cher's Birthday / Cher.com Fans  
 Cronin Fund Appeal for CCA / Cronin Family  
 Evening of Giving, Rose Seitz, Organizer, CCA Volunteer  
 Fifty-Fifty Raffle / Carrie Kinlen, CCA Volunteer  
 Evan Goldman Honor Fundraiser / Aaron Goldman, Organizer/CCA Volunteer  
 Highland Elementary School Denim Days Fundraiser / in honor of Justin Prince  
 Home Interiors party for CCA / Darnell Menard, CCA Volunteer  
 FiServ Omaha Denim Days for CCA / Glen Peterson, Organizer/Trevino Family  
 Katz's Deli Fundraising Table / Jennifer Guerra, CCA Volunteer  
 Smiley Face email campaign / Peggy McDannel, CCA Volunteer  
 Spa Day / Michelle White, Organizer  
 Tamales Fundraiser in honor of Natalie Wardlaw  
 Yoga For Charity / Suzanne Chiasson, Organizer / CCA Volunteer

### \$1,000-\$5,000

American Medical Association Denim Days Fundraiser / Carolyn Hall, Organizer/CCA Volunteer  
 Dean Bingo Social Fundraiser / Karla & Olivia Dean, CCA Volunteers

### \$5,000 or more

Fourth Bi-Annual Cher Convention / Cher Convention CCA Volunteers  
 Eagleville Elementary Walk-A-Thon / Family of Andrew Hartley  
 Second Annual "Friend's of Jeremy" Golf Event / George & Kristine Dale, CCA Volunteers  
 Fourth Annual Pete's Scramble for CCA / Darin & Dede Dankelson, CCA Volunteers  
 Wendelyn's Course of Dreams Golf Challenge for CCA / Wendelyn Osborne, CCA Volunteer

# 3 cheers for volunteers!

Volunteers: (left to right) Kitty Kemp, David Noblet, Charles Lee, Lois Park, Ina Lee Chaffin and Judy McCallum



CCA would like to thank **Kitty Kemp**, the **AT&T Pioneers**, the **Richardson Senior Center** and all of the volunteers for their generous Hug-A-Bear donation. These bears are handmade by the members of the senior center and a group of volunteers. The Hug-A-Bear

program was established to give comfort to youngsters who are in traumatic or unfamiliar situations. These bears are a perfect fit for CCA, and we feel truly honored to be chosen as a recipient.

Thank you!

**children's craniofacial association**  
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