ccanetwork



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

winter 2008

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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



miranda's story By Denise Larkin

y husband and I thought we couldn't get pregnant, so we reconciled ourselves to a life without children. Then we were blessed with our wonderful daughter, Miranda Peyton Larkin.

Miranda was born by emergency C-section. She had aspirated meconium, and her system had shut down. Her

> pediatrician saved her life by suctioning out the poison.

Three hours later, she died again. They resuscitated again, diagnosed her as terminal and sent her to Shands Teaching Hospital in Gainesville, FL., an hour away, while I stayed in Ocala.

see **miranda**, page 10



message from the chairman

C ixteen years ago, my husband and I were anxiously awaiting the birth of our firstborn child. If someone would have told me that 16 years later I would be writing this as a parent of a craniofacial child and chairman of CCA, I think my response would have been, "facialcranio what?" Or if they would have told me that I would become an honorary nurse and learn all sorts of medical jargon, I would have said, "No way, I can't handle going to the dentist without heart palpitations!"

see **chairman**, page 9

ccaadult

Andi Bartkowski, left, with CCA volunteer, Greg Patterson

meet andy bartkowski

y name is **Andy Bartkowski**. I'm 49
years old and have bi-lateral
facial paralysis as well as
mucormycosis, a rare but
often fatal disease caused
by fungi. It is sometimes
called zygomycosis or
phycomycosis.

This definition of mucormycosis describes it best:

Rhinocerebral mucormycosis is an infection of the nose, eyes, and brain. The fungus destroys the tissue of the nasal passages, sinuses or hard palate, producing a black discharge and visible patches of dying tissue. The fungus then invades the tissues around the eye socket and eventually the brain.

In 1978, because I had diabetes, worked two jobs, partied and didn't watch my blood sugars, my immunity system began to decline. One day, I felt excruciating pain in every nerve within every tooth. My head became so swollen that I felt ashamed

about how I looked. When any of my friends would visit me, I wore a towel over my head to cover the deformity. I didn't know I was actually dying.

I recovered but not without Amphotericyn B, nicknamed "Ampho the Terrible" because it gives you malaria-like symptoms, cold sweats and fevers of 105. A single dose could give you phlebitis.

But the hardest words I ever heard a doctor say was I would never smile for the rest of my life. What affected me more was the paralysis, which was predominantly on the one side of my face. When my friends kissed me, I could not feel a thing. I was severely depressed for a long time.

In 1981, I underwent a muscle transfer. It was not successful; the damage left by the infection, the arteries and veins was extremely brittle and blood supply wasn't good enough. Even though it did not work, it made my face tighter,



which gave it a better appearance, which in turn gave me confidence.

My plastic surgeon now is Dr. Scott Bartlett, who has performed several facia lata slings on me. I attended his lecture at Children's Hospital of Philadelphia, where I heard him speak about procedures that could rebuild a child's face. I asked if I could help any kids. He introduced me to CCA.

I went to my first CCA retreat in Denver. What blew me away is how much fun the children and their families had. There were plenty of great activities planned such as going to zoos, parks, ice cream parties and the ever-popular dinner dance. Oh yes, and many new friendships.

What is amazing, 10 years later, is that the kids I met have now graduated high school and moved on to college! Do you know how hard it is to undergo 30 or more surgeries and graduate on time?! They succeeded because of the

unconditional love within each of these families.

Every year, going to the retreat is like getting refueled for another round. Each time I met a new family with a child who has a different syndrome, they would tell me, "We thought we were the only ones!" It wasn't until I contacted CCA that I met other parents and children who were going through the same thing I did.

We aren't the only ones. Like Char Smith says, the doctors take care of the surgery, and the kids of CCA encourage and support each other pre and post surgery.

I've had more than 25 surgeries, and these kids may have had 10 to 100 by the time they were 16. Yet they are all happy at the retreat. Most of all, they have dignity.

You may notice that I don't smile for the camera. I felt embarrassed about that until I became a part of CCA. Now I smile through hundreds of happy faces!

meet alex matson

lex Matson is a fourth grader from Columbus, Nebraska. He has an older brother **Drew**, who is 23, and a younger brother **Erik**, who is five and a half. Alex will turn 10 on March 16.

While at school, he enjoys math, PE, music class and, what's probably the important time of the day, recess.

Outside of his studies, he's involved in sports. Alex plays quarterback for a local flag football team, and during the summers he plays right field and second base for the Angels. He also loves watching football and baseball games on TV. When he's not participating in or watching sports, he likes to play football and racing games on his PlayStation and Xbox.

As for TV, Alex's favorite show is anything with Tom and Jerry. And as for movies, his favorite is *Garfield*. This is fitting



because he has two cats, Butterscotch and Caramel. Caramel actually won Grand Reserve Champion in the pet show at his local fair.

He also plans to show his rabbits—he has 19—in an upcoming fair. And then there's Baxter, his two-year-old dog, who is a Boxer-Terrier mix.

Alex is also a bit of a motorcycle rider. He takes part in the Christian Motorcyclists Association Poker Run, participating in the event itself as well as riding in a convertible during the kick-off parade.

Alex has Crouzon syndrome and has had 10 surgeries so far with more planned in the future. Through CCA, he's been able to meet other kids going through similar situations. He and his family attended their first retreat in Salt Lake City, where they all had a great time.

ccakid

donor In the spotlight

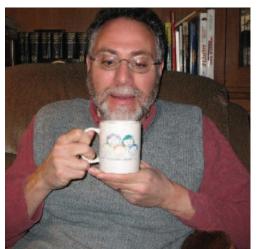


his issue we feature Benefactor-level donor, **Margaret Patterson** of Kilgore, Texas.

Margaret took advantage of the special IRS tax-free provision, for distribution of her IRA funds as contributions to charitable organizations, which was set to expire at the end of 2007. Children's Craniofacial Association is extremely grateful to be included as

one of the causes she supports. CCA received a generous year-end donation. Thank you Margaret, our first "Donor in the Spotlight" of 2008!





Ann and Howard Langner enjoy cocoa in the CCA mugs they received as holiday gifts.



meet drew and erik matson

rew is 23 years old and has been on his own the last three years. He lives close by and babysits his brothers about once a month.

He was 13 when Alex was born and I don't think there has ever been a brother so proud. Whenever we went to any of his high school activities, he would take Alex and show him off. In Biology class, he had to do a report and use visuals. He did his report on Crouzons syndrome and had me bring Alex in for one of his visual aids. This really impressed the kids. For years they would always ask about Alex whenever we ran into them in public.

Drew spent several summers working at a summer camp. When Alex was old enough to go, he stayed close by to be sure Drew didn't get homesick. (It was a two-night/three-day camp.)

Drew is working two jobs right now, full time at Torin (a manufacturing plant) and our local airport, where he refuels and cleans planes. He likes paintball, playing softball, watching his brothers play baseball, camping and riding horses.

rik...well Erik is as outgoing as his brother Alex is shy. He will talk to anyone and everyone.

He tells almost every doctor he sees all about Alex. He will answer their questions before Alex even gets a chance to. He also needs to know what they are doing and why at all times.

Everyone is his friend, and he goes nonstop, not needing nearly as much sleep as I, his mother, thinks he should. His favorite saying is "the sun is up, you can't sleep when the sun is up." Erik loves his big brother, Alex, and most times acts like they are the same age, wanting to do anything and everything Alex does. This includes riding his bike to school, playing sports, doing homework, etc.

Erik was so happy this past summer when he was finally old enough to play baseball (t-ball). Alex uses Erik as his shield, and Erik takes the role very seriously keeping up with all Alex does and helping (without knowing it) to push Alex along a little. Alex may not be too sure about doing something, but if Erik is going to do it or be there with him, then it's a pretty sure bet they will get it done together.

Erik likes baseball, animals, camping, riding motorcycles, riding his bike and playing with Alex.

good news



e're proud of CCA teen. Suzanne Ronczka of Voorhees, NJ. who was named Science Student of the Month in October for her hard work and exceptional performance in her Earth Science class. That snowballed into her November win for Guidance Student of the Month, which meant she excelled in all of her class subjects for the month. We think it's safe to say she's a great student throughout all the other months of school as well! Congrats

Suzanne!

ccasupersibs

holiday parties

Dallas, TX

CA, together with Dr. Jeffrey Fearon, hosted its 18th annual holiday party in Dallas, TX, on Saturday, December 8. About 500 attendees joined us for a morning full of fun!

Radio Disney was once again the entertainment, and everyone really participated in the fun, music and games. We enjoyed cake and punch as well as arts and crafts. The kiddos decorated their own cookies, and made picture frames and reindeer.

The **firefighters** of nearby **Plano** joined us, bringing a real fire truck for the children to see. And the **Dallas Cowboys Cheerleaders**, as well as the **Dallas Desperado Dancers**, were there and gave autographs.

Families went home with lots of door prizes, which were donated by several local businesses. Prizes included passes to **Six Flags**, grandstand seats to



Guerin Bell with a couple of the Dallas Cowboys Cheerleaders

the Mesquite Rodeo, a gift certificate to the Magic Time Machine, passes to the Fort Worth Zoo and the Dallas Zoo, autographed items from the Dallas Mavericks, Texas Rangers, Dallas Stars and Dallas Cowboys, and numerous items from the Frisco Roughriders.

As always, the highlight of the party was **Santa Claus**. Children took their picture with Santa, and everyone went home with a keepsake photo and toy.

CCA would like to thank the **Wyndham Garden Hotel** for donating the space and all of the wonderful volunteers from the **Italian Club of Dallas!**



Midwest

Santa joins Jill from CCA, Kim & Kate to thank holiday sponsors for contributions.

CA held another holiday party in the Midwest at the Parkway Chateau/Brat Stop in Kenosha, Wisconsin.
Although heavy snowfall hampered attendance, there was a respectable turnout for the event, which was organized by Marla Verdone of Janesville, WI, with the help of Kim Rogers in Bradley, IL.

Funding for the special day was generously provided through contributions, including checks from the FOP (Fraternal Order of Police) and the LEO (Law Enforcement Organization), both of

Orland Park, IL. The money was given in honor of Kim's daughter, **Katherine**.

Door prize donors included Troy Trepanier of Rad Rides by Troy (www.radrides.com), Nicole Guzack, Kim and Don Rogers, the Verdones, George and Denise Weiland, Tom and Diane Dietz, Pat and Joe Gwozdz, O'Conner Hyundai and Michelle Weiland.

Everyone enjoyed lunch, a visit and photos with **Santa**, craft activities, chatting with one another and door-prize bingo. Thanks to all who made this a wonderful time!



The Italian Club of Dallas



Annie Reeves, Char Smith, Dr. Jeffrey Fearon, Cindy Podner and Dr. Ahmed Nawres

parents: you are the official care manager!

By Karen Melnick RN, BSN

earning to actively manage your child's health and wellness is a topic most parents would prefer not to think about. Yet parents whose children have health or developmental issues have been thrust into the role of being advocate, researcher, observer, educator, coordinator and all-round mountain mover.

As an RN, BSN and parent of three children who have all had various health issues, I can tell you that you can influence your child in achieving his or her potential. Trust your instincts. Learn how to talk so health professionals clearly understand your concerns. And embrace your new role as your child's care manager.

Keep accurate records.

Maintaining complete and accurate records has far-ranging implications for you and your child.

- Decisions can be made quickly and accurately in an emergency.
- Patterns of illnesses and developmental delays can be quickly identified and acted upon
- Parents are less likely to be told to "wait and see"

- Concerns tend to be taken more seriously
- Parents can have knowledgeable discussions with practitioners
- Parents and practitioners are more likely to set and follow up on goals
- There is less chance for potentially disastrous errors
- Your child will receive better care Important information includes:
- Contact information and emergency information
- Pregnancy and prenatal health
- Family history
- Newborn health
- Growth and development
- Illnesses and conditions
- Medications
- Operations
- Primary physician visits
- Medical specialist visits
- Other health and wellness professionals (ex. occupational therapist, chiropractor, naturopath, speech therapist)
- Professional's contact information

Having accurate records will make your life much easier. You will be asked for details over and over again, so having a single record will be very helpful.

If your child is older, go through all records that you do have and summarize them. Ask your team of practitioners for copies of their records. From here on, make brief notes whenever a health or wellness event occurs.

Make the most of appointments.

Here are suggestions that will help you to get the most out of your appointments and to develop mutually respectful relationships with your child's health and wellness team.

- When you make an appointment, be clear about what you concern is. If you have more than one issue that you would like addressed, specify this to ensure that the appropriate time is scheduled. If new concerns have arisen since you made the appointment, call ahead to see if the time can be adjusted. Similarly, call ahead or make a separate appointment if vou have another child who needs to be seen.
- Be prepared. Arrive at the appointment with all of the information you think will be required.

Bring a list of current medications that your child is taking, including vitamins and natural remedies. If you are seeing specialists, have all of the related details with you. Write information down if you think you may forget. If you have been using a health journal to record details, take it with you.

- Prioritize your concerns. Share your most important concerns at the beginning of your appointment, so that you and your health practitioner can organize your time. It is tempting to leave the concern that is hardest to talk about to the end. Don't. This is usually the most important one.
- Be brief, very specific and factual in your description of the problem. Busy health professionals must quickly arrive at conclusions, and you want these conclusions to be based on the facts that are most important. Come to the appointment with details, and offer them without being asked. Include:
 - When you first noticed this problem. Has it

- stayed the same, or changed?
- What made it better? Worse?
- Had this ever happened before? How was it treated in the past?
- Have your child's sleep/eating/behavior patterns been affected?
- How have you been treating it until now? Has that helped?
- What medications, vitamins and natural remedies is your child receiving?
- Is there anything else happening with your child?
- What do you think the problem is?

If you are concerned about your child's growth and development, review and complete the developmental milestone charts given to you by your health practitioner or found in your health journal. Educate yourself on typical development, so that you can be an educated observer of your child.

• Do your research. This will help you to ask relevant questions and to participate in the discussion. The Internet is a great source of information. The library and various health associations can also be very helpful. Just remember that not all information from the Internet, or other sources, is credible. Stick

- with the websites of the various children's hospitals and treatment centers, teaching hospitals, medical associations, pediatric associations and various health associations. Discuss your findings with your team of health professionals.
- Ask questions during appointments. If you are not sure you will remember questions when you get there, write them down. Some questions include:
 - What is the diagnosis?Why do you think that?
 - What are the treatment options?
 - What would you do if this was your child?
 - Is there anything we should know about this treatment?
 - When would you expect to see improvement?
 - What should we do if we don't see improvement?
 - Where can we get reliable information about this illness/condition?
 - Is there an expert in this condition that you can refer my child to?
 - What additional resources are available?

If you don't know how to spell something, ask for it to be written down. If you don't understand, then say so. Request a copy of any reports.

- Follow exactly the advice and instructions you are given. Take note of what makes the situation better, what makes it worse and what has no effect. If this situation does not improve in the way that you and your health practitioner expected, you should call or make another appointment to review this.
- If you feel that your concerns have not been adequately addressed, be sure to state this clearly. A review of details may be helpful in clarifying your concerns. If you disagree with your practitioner's choice of treatment. state this clearly. Then listen to the response. Should you continue to be dissatisfied, it is reasonable to seek another opinion. Most health professionals will welcome this and can be instrumental in facilitating a referral. Communicating with

health professionals is not difficult and becomes easier over time. This does not require you to be aggressive or confrontational. When you have your facts, offer clear details, participate in the treatment decisions and follow instructions, you are on the road to establishing a mutually respectful relationship with your

child's various health and wellness professionals.
The end result is definitely worth the effort and your child will reap the benefits of having the best care manager for the job — you!

Karen Melnick RN, BSN, is the author of Your Child's Health & Wellness Record. Order at www.healthandwellnessrec ord.com. (Use code Q101 for 15% discount.) Or contact her at karen@healthandwellnessre cord.com. Karen is also available for speaking at parenting and health-related events.

financial assistance

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.

third annual friends of jeremy golf tournament



hen it came to warm weather, luck was not on our side, but when it came to a generous community and dedicated golfers, luck was not needed! The Third Annual Friends of Jeremy Golf Tournament was held on Saturday, October 13, at Willow Creek Golf Club in Big Flats, NY.

We had an incredible turnout and overwhelming support from the community, our coworkers, and friends and family. A total of 105 golfers came out to have fun and show their support for the kids of CCA.

We had a record number of tournament and hole sponsors and tremendous support from local businesses and national organizations, who donated prizes and silent auction items. The tournament included a raffle, silent auction, closest to the pin 50/50, closest to the line prize and a skins game. The event was a huge success, raising \$22,200 for CCA!

In addition to continued support from local newspapers, we were extremely fortunate to have had the support of our local TV stations this year to help advertise the tournament and spread the word about CCA.

The added exposure helped us come in contact with two local families who have children with craniofacial conditions.
Sophia Lorenz and Ryan Gulich joined Jeremy at the tournament to welcome

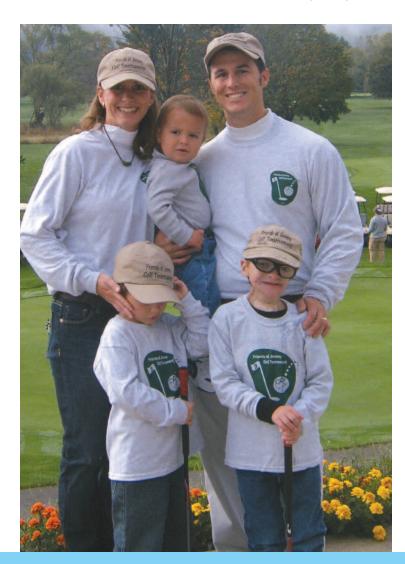
the golfers and help kick off the tournament. Sophia is 12 months old and was born with Stickler Syndrome. Ryan is 6 years old and has Aperts.

In addition to Sophia and Ryan, Angela Mitchell from Corning, NY, (20 years old with Craniosynostosis) and Andrew Perry from Boston, MA, (known for his multiple performances of "Believe" at CCA retreats) attended the event and participated as golfers in the tournament.

We are so grateful to everyone who supported this event and the kids



from CCA. The Fourth Annual Friends of Jeremy Golf Tournament will be held at the Corning Country Club on October 4, 2008. For more information and to see photos from the tournament, visit www.friendsofjeremy.com.



2008 heroes of hope gala

hildren's Craniofacial Association is proud to announce they will join the Beneficiaries Circle of the Jorge Posada Foundation's 2008 Heroes for Hope Gala. The Gala will take place on Monday, June 16, at 583 Park Avenue in New York City. The event will begin with a cocktail reception at 6:30 p.m., followed by dinner at 7:30.

Joining other organizations such as **Montefiore Medical Center** and the **National Foundation for Facial Reconstruction**, CCA will raise funds and awareness for programs and services. The Jorge Posada Foundation covers all expenses allowing 100% of the ticket price to go directly to support CCA's mission.

The Jorge Posada Foundation is a nonprofit organization founded by the New York Yankees' All Star Catcher, Jorge Posada and his wife Laura. Their son, Jorge, Jr. was

diagnosed with Craniosynostosis when he was just 10 days old and had to undergo seven major surgeries to correct the condition.

Heroes of Hope Gala is attended by many of Jorge's friends from the New York Yankees team, both past and present, including **Derek Jeter**, **Bernie Williams**, **Jason Giambi**, **Alex Rodriguez**, **Tino Martinez**, **Mariano Rivera**, **Robinson Cano**, **Bobby Abreu**, **Willie Randolf** and **Joe Torre** as well as many other celebrities and close friends.

Tickets are on sale at \$750 per ticket or a table of 10 for \$7,500. For more information on tickets and corporate sponsorships, please call CCA Development Director, Jill Gorecki at 1.800.535.3643, or email her at jgorecki@ccakids.com.

chairman, from page 1

We were supposed to be the perfect parents with the perfect child. We had established our careers and had waited 12 years for a child. We were on our way to a life we had planned, but God had bigger plans for us. I know that many of the families reading this are nodding their heads because they "get it," and I think that is what bonds us as CCA families. We feel a bond when we meet someone who "gets it". CCA has afforded us that opportunity.

When my son was born there were no Internet resources. I spent many hours at the library researching, making phone calls, talking to doctors and then, by God's grace, my mother-in-law was watching Maurie Povich and saw our development director, Jill Gorecki, Cher and other craniofacial families. I made a call to CCA and the rest, as they say, is history.

CCA gave us hope that our son could live a "normal" (don't you just love that word) life. We talked to families who had been through what we were about to enter, and they were OK. Because we were able to meet others, share information, get access to qualified centers and call when we needed help, we are better than OK. We are empowered. Today, we have family all over this country because of CCA.

CCA has grown, too. Soon we will be celebrating our 20th anniversary. Services provided in the early years entailed some financial support and family networking. Today, as the premier craniofacial support organization, we offer many more services, including the ever-popular annual retreat, toll-free hotline, educational materials, physician listings, qualified center listings, newsletter, syndrome booklets, legislative advocacy, raising public awareness, and family networking, just to name a few.

We started with a couple hundred families. Today I am happy to report that we have empowered and given hope to more than 8,000 families! This sounds like a lot, but our work is not done.

We are continually evaluating and adding new services as our families' needs change. Early on, a large part of what we did was focused on the craniofacial child and while it still is, we realized that it affects all members of the family in different ways and at different stages of life. Over the years, we

have added programs and services to address those needs as well.

I am very excited about CCA's future and the future of our families. We will be expanding our website to include a Family Forum, a Teen Spot and will be offering more exciting programs.

I would like to thank our hardworking staff. We couldn't have gotten a better group! And a big thank you to our donors. We couldn't do this without you! You are giving hope to so many children with a facial difference.

Finally, I would like to thank our CCA kids. You have taught me MANY things. You are the TRUE definition of beautiful, and you define who a real HERO is. I love you all!

Rose Seitz CCA's Board Chairman

miranda, from page 1

The doctors described her as a floppy baby and unresponsive, and they could not tell us if she would live or not. She suffered brain damage from lack of oxygen, and her head was misshapen.

Finally, at three days old, I saw her for the first time and was able to hold her. When I said her name, she opened her beautiful blue eyes for the very first time. I continued to hold her, only putting her down for nurse changes and to go to sleep.

As I held her, I told her about her cousins, aunts and uncles. I also promised her that if she got well, I would give her the best life that I could.





They gave her a CAT scan and an MRI. These tests revealed that she had a condition called craniosynostosis and would need major skull surgery.

Finally, at eight days, they were able to remove the oxygen. At 13 days, she began to accept a bottle, and we were allowed to take her home.

I remember shuttling Miranda back and forth to mental clinic for her brain damage and a pediatric eyes were not parallel. She also had to wear a skullcap 18 hours a

At 10 months old, she underwent a cranio remodel. They cut her from ear to ear, pulled her scalp down, broke apart her skull and installed plates to hold it together. Four months later, they took the hardware out. Both times she was in intensive care.

At 18 months, she began physical therapy for torticolis. She could not hold her head up, and she could not turn her head to the right.



Miranda at 18 months old

The next three years were a flurry of doctor appointments, hospital stays and clinic visits. From age 4 to 6, she led a somewhat normal life clinic visits but no surgeries.

At age 6, Miranda went to Miami Children's

> Hospital for a major surgery. She had bone shaved from the back of her head, which

was used to raise her left eye. She also had her

forehead reshaped. A little later, she had eye muscle surgery. Unfortunately, it took three surgeries to get it riaht.

Though Miranda has overcome many issues, she still has some challenges. She has a recurring sickness where she gets dizzy, has a major headache and vomits constantly for about 12 hours. We have had MRIs and CAT scans to try to determine the cause, but there is no diagnosis yet.

The Shands Educational Clinic determined that she is very smart but severely impaired in brain processing and has no short-term memory. She is also severely impaired in motor and fine motor skills, and she has ADHD.

Well, now that you know what she has been through, let me tell you who she is. Miranda is a very sweet, loving, funny child who is a joy to everyone she meets.

She is an only child who loves animals and helps care for all of her pets: Jasmine, a Golden Retriever; Jamie, an Australian Shepard; cats Abigail, Bianca, Tiffany and Notail; a rabbit named Madison; Elvis the guinea pig and Angel, a beta fish.

Miranda loves singing and dancing and all kinds of music — from country to hip-hop. She loves to watch "American Idol," "Dancing with the Stars"





Miranda at 3 years old

and just about anything on the Disney Channel, especially "Hannah Montana."

On weekends. Miranda loves to play at home in her playground and swim in her pool — she swims like a fish. She also loves to play on her computer, especially with her virtual Webkinz pets. She loves to play her keyboard and her pink guitar. Miranda's favorite color is blue, and her favorite foods are cucumbers and strawberries (not together). Her favorite subjects at school are history and science. She also loves to vacation in New York City.

She has been fortunate enough to meet a few of her favorite celebrities: Kenny Chesney, Billy Ray Cyrus, Zac Efron and Jesse McCartney. She is hoping to meet Cher this year in Myrtle Beach!

We are so glad to be a part of CCA. Our first retreat was Salt Lake City,



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.org website
- Annual Cher's Family Retreats
- Public awareness
- Family networking
- Advocacy

calendar of events

date March 15	event Henry's March for CCA (5k Fun Run) CSU, Stanislaus, Turlock, CA	contact laurynhenry@sbcglobal.net myspace.com/henrysmarch 209.664.0500
April 30	Retreat Sponsorship deadline Corporate Exposure Opportunities	JGorecki@ccakids.com 800.535.3643
June 16	Heroes for Hope Gala Jorge Posada Foundation 583 Park Avenue New York City, NY	JGorecki@ccakids.com 800.535.3643.
June 26-29	18th Annual Cher's Family Retreat Myrtle Beach, SC	AReeves@CCAkids.com 214.570.9099 800.535.3643
August 4	Sixth Annual Pete's Scramble for CCA Prestwick Village Golf Club Highland, MI	www.petescramble.com
August 23	Third Annual Wendelyn's wendelynnyvonne@hotmail.com "Course of Dreams" Golf Challenge Country Club of Arkansas Maumelle, AR	
September 22	Jylian's "Links of Love" for CCA, Celebrity Golf Event White Stone Golf Course Benbrook , TX	JGorecki@ccakids.com 800.535.3643
October 4	4th Annual Friends of Jeremy Golf Tournament Country Club of Corning Corning, NY	gdale@stny.rr.com www.friendsofjeremy.com
October 11-18	Disney Cruise 2008	www.apert.org

craniofacial acceptance month



Angela & Megan Cronin

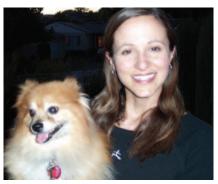
he September, 2007 observation of Craniofacial Acceptance Month included many families and friends raising funds for CCA with their own events as well as through sales of CCA web store and specialty items.

The first place prize for high sales during the CCA Sales for September went to the **Dornier family** of Baton Rouge, Louisiana. They chose a \$100 Target gift card. Second place went to the Seitz family who chose a set of five scented candles offered by CCA. In Third place the **Grathoff family**, gets a \$25.00 Target gift card. Thanks to everyone who joined the effort to sell items!

Among special efforts to raise funds for CCA during Craniofacial Acceptance Month were Tracy Overcash hosting a Southern Living show through **Rachel** Johnson; Arbonne by

Cheryl (Cheryl Swearingen) promoted sales and donated a percentage and pledge to continue right along whenever they have designated shows and sales; The Balentine **family** held a very successful Raffle / Bake Sale; Kim Rogers continued to pound the pavement for CCA, placing coin collection cans and testing sales of our "hanging cards" to commemorate the month; Nancy Fossee, held Fossee's CCA September Event which was an evening reception of shopping, food and fun organized by CCA Volunteer, Jana Peace (read more about it in this issue's 'Fundraising News'); and, you read about Seth's Stride for CCA in our last

Repeat help came from the 2nd Annual Wendelyn's 'Course of **Dreams' Golf Challenge** (which you also read about in the last issue); Hill **Elementary** school where



Yogi, Suzanne Chiasson with "Boo"



Angela Balentine, Crystal (family friend), Brittany Balentine, and Aunt Lori at the bake sale

they held their annual Denim Day in honor of former student, CCA kid, Justin Prince, taking up a collection from generous teachers and others;

Houston Katz's Deli again designated CCA to receive funds from their special table: **Brenda Siebert** of Fine Designs held another Open House; Suzanne Chiasson held the 2nd Annual Yoga for Charity event; the **Cronin Family** collected again for the cause in **Megan**'s name and big thanks go out to all who helped them! Cousin Pierrette Begent and her new husband, Chris Kirchoff, gave a generous check in lieu of wedding favors at their August nuptials. Michael and Brittany Colin at **Mae Communications** assisted in implementing an awareness campaign in the area; Jennifer Guerra's friends, Abigail De Los Reyes, Booz Allen **Hamilton** with WLC

Community Relations

Committee and Aldine

Apostolic Assembly Church again held a Tamale fundraiser in Natalie's name. The month's closing event was the Third Annual Friends of Jeremy Golf **Tournament**. Read about it on page 8.



Brenda Siebert with son,

Thank you to all who helped Children's Craniofacial Association observe September's Craniofacial Acceptance Month, raising funds while spreading awareness that fosters acceptance.

fundraising news



Jana Peace and Nancy Fossee



The spread for Fossee's September Sale for CCA

CA Volunteer, Jana Peace was pleased to have her good friend, Nancy Fossee, graciously host Fossee's CCA September Event, a benefit for Children's Craniofacial Association which was an evening reception of shopping, food and fun to raise funds as well as awareness of Craniofacial Acceptance Month. The event was supported by generous donations and assistance of local retailers and friends including Susan Hassel, VP of Sales for The Transit Network, Jimmy John's Gourmet Sandwiches, La Madeleine, Whole Foods, Corner Bakery (Mo & Team), Chocolate Angel, and Margo's Collectibles. Margo, the rep for Mary Francis, also contacted Mary Francis, herself, who signed one of her collectible handbags especially for the event. The bag was raffled for

all attendees who contributed. Thank you Nancy and everyone for making it a smashing success that raised over

\$1,000 in one evening!

ana is always actively recruiting help everywhere she goes. Jana's friends at **Wolf Camera**, Preston Forest, help with many in-kind donations for CCA fundraising events as well as placing a collection can that fills and is replaced regularly. **Dallas Petals**, floral gift shop at Medical City Dallas Hospita,I does the same. Thank you to these supporters and to



CCA's good friends at Dallas Petals, Medical City

Jana for making many friends for CCA!!!

n October, CCA
Program Director,
Annie Reeves,
attended the 2nd
Annual White
Buffalo Bikefest,
held in her
hometown of
Snyder, TX. Annie
had a booth space



Annie Reeves at the White Buffalo Bikefest

donated by the **Snyder Chamber of Commerce** to distribute information about Children's Craniofacial Association and to raffle off several donated items. The raffle raised almost **\$1,000** over the weekend. Thanks to Annie, the rally organizers, and all who donated items and/or purchased chances to win and Congrats to all the lucky winners!

mily Tipton, Manager and Coffee Master at Starbuck's across from Medical City has embraced our CCA kids as the cause she promotes for her corporate allowance of six community fundraisers per year. CCA teamed with Emily for a community clean up day and picked up the litter along the bike path that runs down Medical City's Park Central and behind Starbucks.

fundraising news, from page 13



Jill Gorecki, Emily Tipton, Char Smith and Lauren Clowers

For every volunteer hour Starbucks will donate \$10 to the cause and with 50 volunteers working 2 hours each last November, we raised \$1,000 for CCA!

Thanks Emily, Starbucks and all the super employees and community volunteers!

Emily draws door prize winners with assistance from CCA kid, Brooklyn Nicholl

There's some big litter out there!



Emily's cheerful staff helped after work!

n November,
Jennifer Guerra
held "Nibblin' with
NattyCakes," an
afternoon of dessert,
wine and coffee, with
her daughter, Natalie
Wardlaw,

"Nattycakes" as guest
of honor, to raise
funds for CCA. Generous donors
who helped make the event a
success included Swanola
Chislum of Swanola's Tea Room,
Kevin Carpenter of of Kroger,
Bob Schwartz of Great Clips,
Christina Davidson of The
Davidson Gallery Photography,
Tropical Express, Boardwalk



Yummy spread at Nibblin' with Nattycakes



Guest of honor, Natalie Wardlaw, with her Mimi



Jennifer Guerra

Fudge, Gritman Essential Oils,
Joseph Kemble, Darlene
Tinsley of FMC Corporation and
C. Higa. The festivities raised over
\$750 for Children's Craniofacial
Association. Thank you ALL!

he Seitz family and friends participated once again this year in their local Simons Malls fundraising opportunity, Evening of Giving, garnering over \$100 selling tickets to shop at their mall on a night in November



Rose and Fred Seitz, with Freddie, Jonathan & Robbie

designated especially for charities to raise funds.

The opportunity is offered each year across the nation, wherever Simons operates a mall.

continued next page ⇒



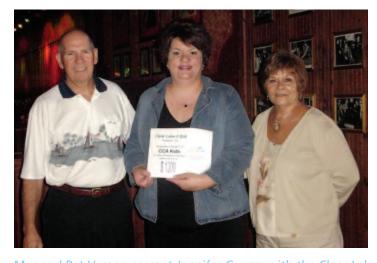
Margaret Jenna-Dalton & 2 year-old, Elizabeth Ivy Dalton

argaret Jenna-Dalton and her team of Christmas angels collected \$1,451 for CCA during her annual gift wrapping fundraiser held in cooperation with the Border's Books in Austin, Texas. They worked approximately 40 hours at two different stores gift

wrapping hundreds of gifts for Border's customers.

Tremendous thanks to Margaret, and we join her in thanking her "crew" of helpers: Marie Bevins, Holly Hillis, Stacy Reed, Patti Stone, Lori Anderson, Michelle Parker, Erica Alejandro, and Sandra Hamlett.

Margaret reminds everyone: the gift wrapping opportunity for fundraising may be duplicated at any Border's Books and suggests others to try it for CCA next Christmas!



Mac and Pat Vereen present Jennifer Guerra with the Clear Lake 8 Ball Donations

harles "Mac" and Patricia Vereen run a Thursday night pool league and each year in honor of their grandson, they select an organization to benefit from donations given by league members. This holiday season, they invited member David Guerra's daughter, Jennifer to speak about her daughter, Natalie and on behalf of Children's Craniofacial Association. Teams voted on donations to CCA and the Vereens also collected more from past players totaling a very generous contribution of \$1,200. Thank you ALL!

how to raise funds for cca

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 (Powered by Yahoo)

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.

In addition to "searching" for CCA, you can "goodshop" online by clicking thru to GoodShop.com, a new online shopping mall which features hundreds of great stores including Best Buy, Macy's, Apple, and Orbitz. It's easy, just go to GoodShop, click on the store's logo and then

shop as your normally would! You get the same prices, but a percentage comes to us!

• 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

how to raise funds, from page 15

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.)
- Southern Living at Home Run a Southern Living at Home catalog party and raise funds for

CCA. It's fun and easy to do!! 25% of all of the retail sales will be donated. Plus you will be rewarded with product for your efforts. Contact Rachel Johnson, CCA Mom and Director with Southern Living at Home email: southernrachel@sbcglobal .net (please also see www.laurynhenry.com) phone: 209.664.0500

- Buy Gifts from
 BeautiControl at
 www.BeautiPage.com/cc
 afriends and CCA gets
 the agent profit!
 Questions? Email Rose
 Seitz at rseitz@directedtech.com. These gifts
 cause no clutter, because
 they get used up!
- Book all of your travel needs at www.ytbtravel.com/ccaki ds 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.
- CCA supporter Dan
 Freeman is a Lifelock
 affiliate (the service that protects your identity from theft) and will generously donate
 \$15.00 per sale to CCA when buyers enter the promo code: CCA. See www.lifelock.com to find

- out how the service works and to help raise funds!
- Tupperware now has a formal fundraising program and you may contact CCA mom, Kathy Hubbard, zibadoo@juno.com to learn more about how to raise funds for CCA.

New Ideas

new!

www.itzybitzy.com

Itzy Bitzy sells infant and toddler squeaky shoes. Children love to wear these shoes that squeak when they walk, and they also serve as a great therapy tool in helping little ones learn to walk properly. These shoes also help parents keep track of their little ones. 10% of Sales go to CCA.

Looking for ideas?

Contact Jill Gorecki at J.Gorecki@ccakids.com

donors, january 1 – december 31, 2007*

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(\$25 to \$100)

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birthday

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Brian & Kathleen Dalton, in honor of our youngest daughter

John Dalton, in memory of Kevin Dalton

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We do our best to accurately recognize donors. If you notice an error, please let us know. CFC (Combined Federal Campaign, federal-employee giving)

^{*}Listed are Monetary Donations of \$25 or more through 4th quarter, 2007. We are extremely grateful for these and all prior donations, raffle ticket purchases, fundraisers and in-kind donations not recorded here.

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newsletter sponsorship

the name of Sharon Allbright

Foundation, recommended by

Travis & Christa Rymal and

Gift of Bill Mecklenburg)

A grant from WalMart, Garland

A grant from WalMart, Salt Lake

Foundation

Beth Abel)

Charities

City

CCA Corporate / **Foundation Partners** (\$5,000 or more)

A grant from Horace C. Cabe Foundation A grant from Fed Ex A grant from W.P. & Buela Luse Foundation A grant from Edmund & Alice Opler Foundation

A grant from the Perot Foundation Border's Books Gift Wrapping for A grant from Jorge Posada Foundation

A grant from the May & Stanley Smith Trust

A grant from the Max & Victoria Dreyfus Foundation

Fundraising Events

Up to \$1,000

Arbonne by Cheryl Sales for CCA / Estate Sale / Catherine Romero, Cheryl Swearingen Balentine Bake Sale/Raffle for CCA Fossee's CCA September Event / / Balentine Family BeautiControl / Rose Seitz, CCA Volunteer CCA Chance Raffle Cheers for Kids, 2nd Annual Carwash / Waukesha West Cheerleaders, Waukesha, WI Chores for Charity / Black Elementary 3rd Grade / Wendy Salin-Valle, CCA Volunteer

Dean Bingo Fundraiser / Olivia & Karla Dean / CCA Volunteers Evening of Giving / Seitz Family Fine Design Christopher Radko ornament sale / Brenda Siebert, \$5,000 or more CCA Volunteer

Helena's Book Sale for CCA / Moriarty Family

Katz's Deli Fundraising Table / Jennifer Guerra, CCA Volunteer Nibblin' With Nattycakes / Jennifer Guerra, CCA Volunteer

Rogers' Candy Sale for CCA / Kim Rogers, CCA Volunteer

Sarah Orne Jewett / Mary Zimmer, CCA Volunteer

Smiley Face email campaign / Peggy McDannel, CCA Volunteer

Tamale Sale for CCA in honor of Natalie Wardlaw

Valley View School Staff "Dress Down Day" for CCA in honor of Ava Beeler

Voorhees Center Genesis Healthcare, in honor of Eric Ronczka and Suzanne Ronczka White Buffalo Bikefest Raffle / Annie Reeves

Willamette Christian Center / Brenna's Raffle Fundraiser / Robyn Johnston, CCA Volunteer 2nd Annual Yoga for Charity / Suzanne Chiasson, CCA Volunteer

\$1,000-\$5,000

CCA / Margaret Jenna-Dalton / CCA Volunteer / Organizer CCA September Sales / CCA

Families selling special Web Store offerings

Clear Lake 8 Ball Billiard League, in honor of Natalie Wardlaw / suggested by David Guerra

Cronin Family Fundraiser / Angela Cronin

Denim Day in honor of Maya Rodriguez, CCA Kid / Christine Rodriguez, CCA Volunteer

CCA Volunteer

Jana Peace, CCA Volunteer

Girl's Night Out / Rose Seitz, CCA Volunteer

Starbucks Community Clean-Up for CCA / Emily Tipton, Organizer w/Jana Peace, CCA Volunteer

Tony's Wine Warehouse "Cher the Love" Event / Wayne Smith, **CCA Volunteer**

Voorhees Middle School Drama Club / Amy Ronczka-Cosmay, CCA Volunteer

CCA Jamaica Raffle Pete's 5th Annual Scramble for CCA / Dankelson Family Wendelyn's 2nd Annual Course of Dreams Golf Challenge / Wendelyn Osborne, CCA Volunteer

\$10,000 or more

3rd Annual Friends of Jeremy Golf Tournament / Dale Family Seth's Stride for CCA / Stacy Swihart, Rick Chiavari CCA Volunteers

3 cheers!

f you don't already know her, you have probably seen her name mentioned in our newsletters. Jana Peace has been involved with CCA for five years, starting as a staff member and for the past three years as a volunteer. She serves as the Regional Coordinator for the West South Central region, helps with fundraising events in the Dallas area, contributes many great ideas, and is an enthusiastic cheerleader for the CCA families we serve. Three Cheers for Jana, CCA's Dallas dynamo!



children's craniofacial association 13140 Coit Road, Suite 517 • Dallas, TX 75240

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