

ccanetwork



newsletter of the children's craniofacial association

Cher — honorary chairperson

spring 2008

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message from the executive director

The annual planning meetings for the CCA Board of Directors and staff are always a very productive time, and this past January's meeting was no exception. We took an in-depth look at the accomplishments from 2007 and used that information to develop goals and objectives for 2008 and beyond.

Some of the highlights from 2007 include:

- **17th Annual Family Retreat.** 78 families from 32 states and Canada attended the retreat in Salt Lake City, UT.

rachel's story

By Alison Morrissey

fourteen years ago, Joe and I were expecting our first child. We had planned the pregnancy, and we were so thrilled about bringing our child into the world. We went to all the child-bearing classes, read many books, spent months discussing names, prepared the nursery and did all the glorious things expectant parents do.

I thought about the birth over and over in my mind, like a Hollywood movie, excited and nervous, replaying a million times what it would feel like to hold my brand-new baby for the first time.

Although it was a few weeks early, the night finally came and I knew my body was ready. After a long night of labor, our OB/GYN came in and said, "It's time." The room was filled with excitement, and I couldn't believe I would soon have a baby.

see **rachel**, page 10

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

meet olivia sanborn

Olivia Sanborn is five years old and lives in Richmond, VT. She attends preschool, where she loves to play with her good friends, Molly and Alexis. And while at school, she also enjoys painting and playing in the imagination corner, where she pretends to be a waitress and cashier. Olivia is looking forward to going to kindergarten this fall. She even knows who she's going to be for Halloween — Tinkerbell.

When she's not in school, Olivia plays games on the computer and spends time with her older sister, **Amelia**, who is in the first grade. Olivia likes to watch anything on the Disney Channel, and her favorite movies are "Alvin and the Chipmunks" and "Snow Buddies." Her favorite song at the moment is "Best of Both Worlds," by Miley Cyrus.

Olivia likes outdoor sports. She went skiing for

the very first time and found she was really good at it. She also is a very good ice skater. Olivia likes playing soccer and is part of an adaptive league.

She and her family have attended the last three CCA retreats and are hoping to attend this year's retreat in Myrtle Beach, SC. She's made a lot of friends with CCA, including best friend Ava. Both families meet up every few months.

Olivia has Pfeiffer syndrome and has had six surgeries so far, with at least two major ones left. All of this doesn't seem to faze her, though. And it doesn't matter even when people look at her. In her words, she "just smiles back." What a great way to handle potentially tough situations. What great wisdom from someone so young.

Ava Beeler (left) and Olivia (right) wave to their parents while enjoying time together.



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 AReves@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

Watch for New Programs in 2008

- Webinar
- Spanish booklets
- Kids Klub
- Website additions

meet derrick wolf

hello, my name is **Derrick Wolf**, and I am 17 years old. I was born in Cincinnati, OH. I have an older brother, **Kevin**, and an older sister, **Sara**.

For the first few years of my life, I had to go through various operations to fix complications. I believe my first surgery was putting in a trach when I was only a few days old. My most recent surgery was closing the hole in my neck from my trach. So, yes, I finally got my trach out on August 7, 2006.

I would tell you what type of syndrome I have, but I don't even know anymore. I was classified as having Miller syndrome, but at my last craniofacial team meeting, my genetics doctor told me I have a whole new unknown syndrome. I am basically my own syndrome! It is really cool! My doctor is even writing an article about me for a medical journal.

I am currently a junior at Oak Hills High School, although I'll be a senior in just a few months! I am looking at different colleges to apply for, to get the whole college experience. I would like to go into computer graphics,

or visual communication design, because I am a very artistic person and really good on computers.

Another plus for going to college is finally being able to live on my own away from home. With both my brother and sister away at college, I am the only child at my house and I love it! No fighting over who gets the computer or the television. It's just me and my parents.

I am in the workforce now and I love my job. I work at Best Buy as a customer service specialist, or cashier, for short. (I just like the fancier name better because it makes the job seem more important.)

Now you might think it would be hard to work and go to school at the same time. I work mostly on weekends and maybe two or three times during the week. I am good with balancing out my schoolwork with work.

I am on the honor roll at school and it just feels like such an accomplishment when I get good grades. Along with getting good grades in school I am also involved with many things as well, such as student council, Key Club, Spanish Club and even the



yearbook. The list goes on, but I can't mention them all for you because it is just way too much.

Now I know that I look different than all my friends, but I do all the same things they do. I don't let anything hold me back.

I am different even from the kids who have similar types of syndromes because of my arms and hands and because I have prosthetic lower legs. Even though I have prosthetic legs, I don't let it hold me back, because to me they are like my real legs, except it doesn't hurt if something hits them. They are heavier, but you get used to it after awhile.

I can ride a bike, swim, play soccer, hang out with friends, oh, and I can even drive! I have had my license for more than a

year already, and I have never gotten any tickets or had any accidents, knock on wood. People always ask if it is hard for me to drive and I just smile and say, "Nope it's easy!" Just because we look different doesn't mean we can't push a pedal and steer left or right.

After reading this I am sure you can tell I don't like it when people judge me on my looks as to what I can or cannot do. If people think or say I can't do something I love to go out and do it just to prove them wrong.

Now, there are times where I lay in bed and wonder what my life would be like if I looked like everyone else, but overall I am glad to be different because I have a different story to tell.

ccateen



meet chase tomanski

The day we brought Brock home was one of the best days of my life. I knocked on all the neighbors' doors to let them know, "My brother's home today. He has a little bit of a problem with his lip. Its called a cleft and it is so cute!"

It was hard watching my brother go through the surgeries to repair his cleft. I thought he would be fine just the way he was. I was very sad when they repaired his lip. I cried and cried. I didn't understand why he could not just be him. My Mom and Dad explained it to me several times, but it was still so sad.

I was very sweet to my brother after each surgery. I used to play with him and hold him so he would feel better. I was always careful not to be too funny because I thought it would hurt if he smiled. He smiled at me anyway, and I loved his new smile too.

I sometimes notice people staring at my brother, and it really makes

me sad. I try to tell them that he has a cleft and that is just the way he is. I learned a lot about how to deal with my brother being teased when my family and I went to the North American Cranial Facial Conference. I also met Ben, a good friend that is my age with a cleft. It was a lot of fun. I cannot wait to go back again!

A message from Mom and

Dad: *Chase is so special to our family. We did not know that Brock was going to be born with a cleft. His instant acceptance and genuine unconditional love for Brock made it so much easier for us to cope. I'll never forget the first time I took Brock to the grocery store and people were staring at him. I was so heartbroken. Chase noticed people staring too and he just started to educate them. Telling everyone around him "He has a cleft. He uses a special bottle. He has a great smile too. Want to see?" His sweet innocence made me realize people were not staring to be mean, they were more curious than anything. So together Chase and I educated everyone we could. He is our hero!*

everyone was so concerned about Brock's cleft. I thought he was beautiful just the way he was. I was just so happy to have a brother. I didn't care what he looked like.

My brother Brock also had some trouble breathing and had to stay in the NICU for four weeks. I enjoyed going to the hospital to visit him. Every time I would leave, I would cry for him to come home with us. It was so hard to leave him there alone. The nurses assured me that they would take good care of him while we were gone.

hi, I'm **Chase**. My family calls me Chaser. We live in The Woodlands, TX. My favorite things to do are reading, swimming, riding my bike, fishing with my Dad and playing with my little brother **Brock**.

I am seven years old and in Second Grade. I am also a Cub Scout and just earned my Wolf badge. I also won third place in my first Pinewood Derby.

When Brock was born, I was almost 5 years old. Brock was born with a bilateral cleft lip and palate. I loved him immediately and could not really understand why

ccasupersib

2008 heroes for hope gala

Children'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 for Hope Gala has been 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 Randolph** 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.

donor in the spotlight



major donors, **Sheryl** and **John Paul**, are this issue's Donors in the Spotlight.

The Pauls' company, **Association Works**, is a consulting firm to nonprofit organizations, including CCA. As facilitators of our yearly board retreat, they've guided our board and staff to formulate and update our strategic plan, which is our framework for effectively implementing our programs and services. John and Sheryl truly believe in our mission, and we are grateful for their support, both in-kind and financial. We are proud to call them friends.



tommy Dale of Horseheads, NY, celebrates his 6th birthday on April 1st with a cupcake and milk in his CCA Mug. **Happy Birthday Tommy!**

financial assistance

do you travel to receive quality medical care? If you do, and need financial help, CCA has a financial assistance program that will help with food, travel and/or lodging. Call CCA for an application at **800-535-3643**. All we ask is that you apply at least four to six weeks prior to your next appointment.

types of craniosynostosis

By Natasha Shur, MD, and Dianne Abuelo, MD

Craniosynostosis consists of premature fusion of one or more cranial sutures, resulting in a changed head shape. As geneticists, we tend to categorize craniosynostosis into several subgroups: primary versus secondary craniosynostosis and syndromic versus non-syndromic craniosynostosis.

Primary craniosynostosis means that there is a defect in the formation process of the connective tissue of the skull. Secondary means that there is a problem with the brain and its growth, in turn leading to early suture closure.

Syndromic means that the reason the skull closed is that there has been a change in genetic material. Non-syndromic means that the factors are probably a combination of environment and genetics but without a clearly defined heritable cause.

The Genetics of Craniosynostosis

Here is a summary of a few major categories and some genetic testing that is available.

Chromosomal Disorders

The first major category of genetic disorders, which may cause craniosynostosis

or other major birth defects, is chromosomal disorders. Chromosomes are organized structures of DNA that carry our estimated 20,000 genes, which provide a map of our hereditary characteristics.

We have 46 chromosomes in every cell of our body, except the eggs and the sperm. Eggs and sperm each contain 23 chromosomes, in effect waiting to join back into 46 again. Cells in our body make eggs and sperm by dividing from 46 chromosomes to 23. Sometimes mistakes happen. An extra chromosome may get put into a single egg or sperm before they join together, before conception.

The classic example is Down syndrome, which most commonly results when an extra chromosome 21 gets put into an egg or sperm; after conception, there is an extra chromosome 21 in virtually every cell of the baby's body. Since each chromosome has hundreds of genes, this can cause developmental changes in the formation of many organs, including the brain, heart, and face.

There are several known chromosomal disorders, which are less easily recog-

nizable than Down syndrome. In some of those chromosomal disorders, not an entire chromosome but rather a part of a chromosome is missing or doubled. For example, there are some patients with craniosynostosis who have been reported to have parts of chromosome 7 missing. This is suspected in children who may have craniosynostosis along with other problems such as failure to thrive, facial features that are different from their parents, or associated heart problems.

When a chromosomal disorder is suspected, a karyotype (a map of the chromosomes) is made from a patient's white blood cells. The chromosomes are viewed under a microscope and arranged with the help of a computer.

Under the microscope, it is possible to see that chromosomes have a p arm (standing for petite) and a q arm (the longer arm) joined together by what is called a centromere. Even in the best of circumstances, the limitation of a karyotype is the inability to see small parts missing or doubled.

Single-Gene Disorders

Craniosynostosis may also be caused by single

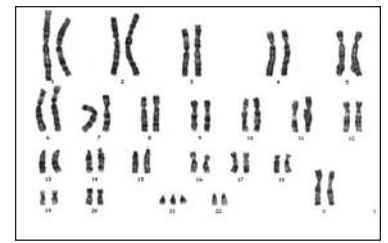


Figure 1: An example of Trisomy 21, with an extra chromosome 21 revealed on the karyotype.

gene disorders, in which a known change in one of the 20,000 genes causes a birth defect. An example of a single gene disorder is Crouzon syndrome. It has been discovered that a gene called the "fibroblast growth factor receptor gene," involved in controlling the timing of the bones coming together and hardening, is responsible for Crouzon syndrome. Special sequencing of the fibroblast growth factor receptor gene may reveal a change in the DNA code in patients with Crouzon syndrome.

Other craniosynostosis syndromes that are caused by changes in a single gene include Pfeiffer syndrome, Apert syndrome and Muenke syndrome. Children with any of these syndromes have features that are often recognizable by a geneticist.

Multifactorial Disorders

Sometimes, when a single suture closes early in a child, but there are no additional findings, a multifactorial inheritance pattern is suspected. In some cases, genetic testing

continued next page ⇨

of the fibroblast growth hormone gene is still indicated. In most cases of multifactorial disorders, there is no genetic testing available.

Microdeletion Disorders

Sometimes patients with craniosynostosis may have a small piece of a chromosome missing, which contains multiple genes, but the piece missing is too small to catch in an ordinary karyotype.

A new test has become available, called a microarray test, also known as “comparative genomic hybridization” and “array CGH.” DNA from a patient is isolated, mixed with control DNA, and it is placed over a chip. Areas that are missing look green, and areas that are duplicated look red.

Sometimes, syndromes with known clinical characteristics are diagnosed. Other times, syndromes are diagnosed with less known characteristics but clearly

causative of particular problems. Still other times, variants of unknown significance may be found. It turns out that a significant proportion of the “normal” population has some variation with duplicated or deleted areas of genes. This may explain variability between individuals.

It would be fascinating to perform microarray testing on Van Gogh and Einstein. Perhaps, deletions or duplications of genes can endow talents or other positive characteristics, like creativity.

Microarray testing is not a perfect test. It cannot detect when two pieces from the parent have changed places. It is more expensive and complex than a karyotype, often requiring insurance approval. Explaining variants and interpreting results remains challenging. Finally, there are other categories of genetic disorders that cannot be diagnosed with microarray.

Case Example

Giovoni came to the genetic clinic when he was 11 months old. He had failure to thrive (he was the size of a four-month-old), global developmental delay and facial features that did not resemble his parents. A genetic cause such as a chromosomal disorder was suspected.

Several tests were done, including a karyotype, which returned as normal. Then a microarray test was ordered. It revealed a small deletion, which included an estimated 10 or more genes, on the q arm of chromosome 1.

We do believe that making the diagnosis has helped Giovoni and his family. First, it prevented further tests to exclude other more worrisome causes for his medical problems. Secondly, his mother encountered some difficulties receiving adequate therapy. The diagnosis helped explain why he needed extra physical, occupational and speech services, and he received additional hours. Currently, Giovoni continues to make progress. He is a delightful boy with a lot of potential. His mother has enrolled in a rare chromosomal disorder support group. Summary of and additional features that may merit referral to genetics for testing

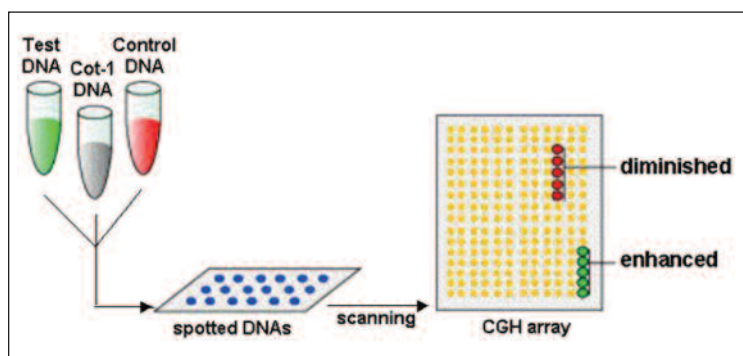


Case example to illustrate the how genetic testing may be used.

- Craniosynostosis alone or in combination with other anomalies
- Multiple birth defects
- Significant developmental delay or undiagnosed mental retardation
- Dysmorphic facial features (do not resemble the parents)
- Autism
- Micro or macrocephaly (head circumference very small or very large)
- Cleft lip and/or palate
- Deafness that is sensorineural (due to a nerve problem)
- Unusually tall or short stature

A special thanks to Susan Mello for allowing us to share Giovoni's story and inspiring us as a wonderful mother, artist and advocate for her son.

Figure 2: The Microarray Test



henry's march

It was a beautiful spring morning when our son Henry was born. The town was still sleeping as we drove to the hospital. Little did they know this baby diagnosed with Apert syndrome would be loved by so many in our community through an event we'd host nearly five



years later. Little did we know that the arrival of this same baby would stir so much passion in us that we would become advocates for children just like him. But we have found that not “knowing” and doing it anyway has been a common theme in our lives. And putting on Henry’s March without the experience of organizing more than a birthday party or garage sale didn’t stop us either.

Henry’s March was inspired by **Stacy Swihart** of Canton, OH, who held a 5K walk she and her brother Rick called **Seth’s Stride**. “We should do this. We’re going to do this” is how I remember Rachel’s comments to me.

“It can’t be done. You don’t have enough time.” Rachel and I heard this more than we care to remember. “They obviously don’t know Rachel,” I thought, “and they obviously don’t know me.” Last December, 90 days stood between us and March 15 — not much time to plan an event of any magnitude, let alone a charity event, run by 70 volunteers and fueled by personal donations and corporate sponsorships.

“It’s going to rain. No one will show up.” The rain never came, but people did come — more than 500 of them (more than 300 registered runners/walkers). They came from miles around, some traveled more than two hours to be with us, all to be part of something special. Some ran, some walked and all smiled through the 5K course on the Stanislaus campus of California State University. The only thing brighter than the sunshine was the yellow Henry’s March

T-shirts and the smiles of everyone who wore them. It was something we all had in common, every last one of us.

“People won’t donate. We’re in a recession.” In California’s central valley, unemployment runs high and foreclosures are on the rise. “Who will donate to a

cause they’re unfamiliar with and an organization many had never heard of?” People did donate. In fact, **we raised more than \$26,000!** While most was donated \$20 and \$30 at a time by individuals, several businesses believed in our mission of raising awareness for children with

see **henry’s march**, page 15



good news

CCA Mom, **Kendall Bilbow**, has been asked to serve on the board of directors for the **Loeys-Dietz Syndrome Foundation (LDSF)**. Kendall and **John Bilbow** have been active advocates since the birth of their daughter, **Jylian**, who was diagnosed with craniosynostosis and a closely-related rare connective tissue disorder that was finally identified as LDS.

The Loeys-Dietz Syndrome Foundation (LDSF) is a 501(c)(3) non-profit organization dedicated to:

- encouraging education about Loeys-Dietz syndrome and related connective tissue disorders to medical professionals and lay communities in order to aid in identification, diagnosis and treatment of Loeys-Dietz syndrome
 - fostering research about Loeys-Dietz syndrome
 - providing a support network, for parents and families affected by Loeys-Dietz syndrome (www.loeysdietz.org)
- CCA is the umbrella organization for all individual-syndrome causes and we welcome LDSF and



Kendall and Jylian Bilbow

all the families Kendall networks with.

Congratulations & best wishes Kendall!

See "More Good News" on page 12.

save the date

September 22, 2008
Whitestone Golf Club
Benbrook, TX

CCA will hold the first annual **Jylian's Links of Love** benefit golf tournament On Monday, September 22, at Whitestone Golf Club in Benbrook, TX. The tournament will begin with a shotgun start at 1:00, and will end with a dinner and silent auction. Visit www.jylianslinksoflove.com for registration and sponsorship details. Come join us!

chairman, from page 1

• 3rd Annual Craniofacial Acceptance Month.

CCA mobilized families across the country to spread the word and raise funds. Radio interviews and PSAs were aired.

• Financial Assistance.

CCA provided funds for food, travel and/or lodging for 68 trips families had to make for medical care.

• Syndrome Booklets.

We published three new syndrome booklets: *A Guide to Understanding Microtia*, *A Guide to Understanding Moebius*

Syndrome, and *A Guide to Understanding Pfeiffer Syndrome*. Booklets on Pierre Robin Sequence and vascular malformations were written and will be published this year.

- **CCAKids.org.** We made updates and improvements to the CCA website.
- **Quarterly Newsletters.** We distributed 13,500 newsletters each quarter in 2007 and placed many more in hospitals and healthcare offices.
- **Family Networking.** We continued to broaden our network of families across the United States.

• Craniofacial Reconstructive Surgery Act (HR2820).

CCA advocated for fair insurance coverage by garnering support for HR2820.

• National Awareness Effort.

Nine regional volunteers led 119 local volunteers in spreading awareness across the country by distributing information to healthcare providers and facilities.

Another important part of the annual meeting is re-visiting our mission, vision and core values. Individuals who have facial differences and their families remain

our main focus, however, we felt our mission statement did not accurately reflect that, so we changed our mission statement to put people first:

Empowering and giving hope to individuals and families affected by facial differences

2008 is already off to a great start. We are looking forward to implementing even more new programs and services this year (see "Watch for New Programs," page 2).

Charlene Smith
Executive Director

rachel, from page 1

So far, the movie was playing out just the way I had pictured it in my mind. The head appeared and I thought, "Wow, this is amazing."

That's when our doctor simply and calmly said, "There is a problem. Your baby has a cleft lip and palate." She said it so peacefully, so naturally and so honestly that, as shocking as it was, Joe and I look back on that moment with gratefulness in our hearts that her bedside manner was so exceptional.



We couldn't have asked for a better doctor delivering our baby, but it was at that very moment that my mind went spinning out of control — as if I was no longer part of the birthing process.

I couldn't quite process the information, but I did want to know if it was a boy or girl. A moment later, Joe said, "It's a girl." Again, I was in a state of shock as my mind filled up with a million questions.

"What does this mean? Is she healthy? Will she be okay in life? What did I do wrong? Will I be able to care for her?" The questions went on and on.

We were so thrilled to have a daughter and we proudly named her **Rachael Kathleen**. In an instant, I had the deepest feelings of love, amazement and the overwhelming need to protect her, care for her and hold her forever. I marveled at this amazing creation of human life.

During the next 24 hours, we were flooded with information on how to feed her, when the surgeries would begin, how to connect with other families, what to expect over the next 15 years.

It was all so overwhelming. I just wanted to learn how to care for my newborn and go through all of the other emotions a new mom goes through. I didn't want to hear about surgeries, feeding issues, speech issues, ear infections, dental and orthodontia issues, breathing and snoring issues, etc. I just wanted to feed her, bathe her, love her and watch her grow.

I wanted all of us to feel "normal," but I knew that "normal" would take on a different meaning. Joe and I were determined to learn as much as we could, but to also enjoy being new parents. We were so proud of our baby girl. We did

not want the cleft lip and palate to define Rachael. We wanted Rachael to learn how to define herself with our love, support and guidance. We knew in our hearts it would be a long medical journey.

The first of many surgeries occurred when Rachael was three months old. As we prepared for that event, it seemed like three years. I knew I couldn't feed her 12 hours before the nurses took her out of my arms and I kept thinking, "How do I look into those beautiful blue eyes and not feed her."

The night before was an emotional roller coaster. I hated everything. I was mad at myself. I felt like I had failed her. She was happily just being a baby, and I couldn't explain the pain that she was about to endure.

During that first surgery, we watched every second on the clock. It was long and frightening. The second most shocking event, after being told that Rachael had a birth defect, was how Joe and I felt after her first surgery.

We had gotten so used to her facial features those first three months that we didn't want them to change. We hadn't anticipated the emotional aspect of all of this. We were so focused on the medical procedure. We loved her just the way she

was, and we didn't want her to change.

After each surgery, we were left dealing with the pain, discomfort, arm restraints, feeding issues, follow-up doctor appointments, infections, and hoping and praying that she would remain healthy. Immediately following each recovery, we would then begin discussing the next procedure. At times, it felt like it was too much.

After several failed surgeries, we just kept praying that we would find the right help for Rachael. We tried very hard to feel like normal parents, go about our normal business and have fun in the process.

People would stare and ask questions, and we never minded answering them. We felt that we were given an opportunity to educate people about facial differences, and that it doesn't matter what's on the outside.

Society taught my generation not to stare, not to ask questions, and to look away if someone had a physical disability. Society places a great deal of importance about what's on the outside versus what's on the inside. For this reason, I have always encouraged my children to ask questions, remain curious and to be kind.

We know it hasn't been an easy journey for Rachael.



said to me, “I feel so different here.” Talk about perspective.

Our journey is certainly not over. We travel to Dallas every six to eight weeks for orthodontist appointments and to prepare for the next round of surgeries. The financial and emotional expense can be overwhelming, but Joe and I want to look back and feel like we did the best we could for our child. We are so fortunate to live in a country where the medical care is outstanding.

The medical professionals and organizations such as CCA allow families to access the very best medical care. We have met many wonderful people on this journey and know the best is yet to come. We wish we could take away the pain that Rachael has endured, but we would not take away any of the life’s lessons that have been and continue to be graciously taught.

One of the best pieces of advice someone gave me in those first days at the hospital was to take as many pictures of Rachael as we could before her first surgery. This would show her how proud we have always been of her and the chance for all of us to have those precious visual memories of our beautiful baby girl born on April 13, 1994 — the Hollywood movie the way it was meant to be written.

She has undergone 13 surgeries with three different medical teams. And she still faces all the normal and “not so normal” issues that a teenage girl faces. Through it all, Rachael remains strong, confident, and focused. Joe and I see an incredibly beautiful young woman who has and will continue to accomplish amazing things in her life.

Through Rachael, we have learned to be more compassionate and kind. We also learned how to keep life in perspective. When I look back over the last 14 years, I feel incredibly blessed that we were lucky enough to bring her into this world.

Rachael is about to graduate from middle school with honors. She plays the violin, loves riding horses, roller skating and talking to friends.

Our second daughter, **Cali**, who is 12, has also been an inspiration and a source of strength to all of us. At the first CCA retreat we attended, Cali, who seemed a bit down,

calendar of events

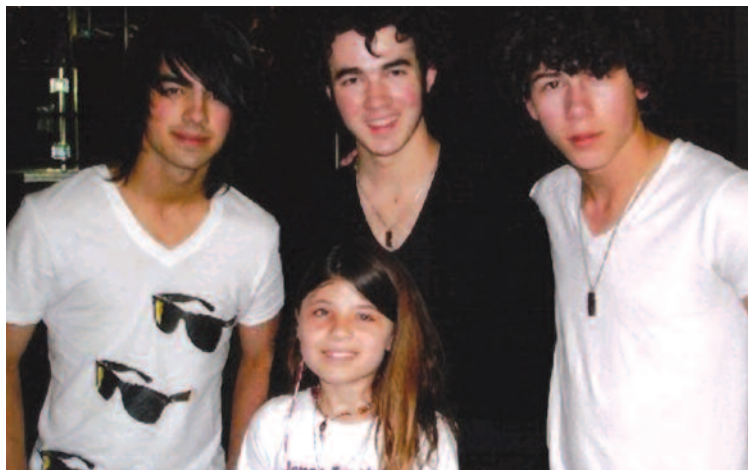
date	event	contact
June 16	Heroes for Hope Gala Jorge Posada Foundation 583 Park Avenue New York City, NY	JGorecki@ccakids.com 800.535.3643.
June 26-29	18th Annual Cher’s Family Retreat Myrtle Beach, SC	AReeses@CCAkids.com 214.570.9099 800.535.3643
July 11-13	Moebius Syndrome Foundation International Conference VIII Parsippany, NJ	www.moebiusnj.org
July 21-23	NACFC Tuscany Suites and Casino Las Vegas, NV	www.ameriface.org
August 4	6th Annual Pete’s Scramble for CCA Prestwick Village Golf Club Highland, MI	www.petescramble.com
August 11-12	Cher Convention Caesar’s Palace Las Vegas, NV	www.cherconvention.com
August 23	Third Annual Wendelyn’s Course of Dreams Golf Challenge Country Club of Arkansas Maumelle, AR	wendelynnvonne@hotmail.com
September 13	2nd Annual Seth’s Stride for CCA Canton, OH	mythreekids@neo.rr.com Stacy Swihart www.firstgiving.com/sethsstride
September 20	Alexa’s Appeal for Craniofacial Awareness, Dinner/Auction Center Plaza Modesto, CA	www.firstgiving.com/ ccaawarenessdinner
September 22	Jylian’s Links of Love for CCA, Celebrity Golf Event White Stone Golf Course Benbrook, TX	JGorecki@ccakids.com JyliansLinksofLove.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

more good news



Brandon Moore, of Bossier City, LA, recently received an Honor Roll Award. Brandon has excelled in school over the last four years and has been a straight "A" student since he entered First Grade. He is an amazing boy and continues to make great successes as he moves along. Brandon, we are proud of you!

Miranda Larkin, of Ocala, FL, recently had her wish come true. She had the opportunity to meet the Jonas Brothers at their concert in Orlando! She went on stage to watch them perform and do their sound check before the concert. She also went on their tour bus. They even gave her an autographed guitar! She was treated like a VIP! Her wish came true through New Hope for Kids, who grant wishes to children under 19 with a life-threatening or life-challenging illness.



how to raise funds for cca

CCCA 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 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.)

• **MonaVie**

Raise Funds for CCA with MonaVie, an amazing product packed with antioxidants. Four ounces per day has the antioxidant capacity of 13 servings of fruit and veggies!!

Contact CCA mom, Rachel Johnson to find out how you can help CCA and yourself with this outstanding gift from the rainforest. www.mymonavie.com/TJ and Rachel phone: 209.664.0500 or 209.505.1673

• **Buy Gifts from**

BeautiControl at www.BeautiPage.com/cc afriends and CCA gets the agent profit! Questions? Email Rose Seitz at rseitz@directed-tech.com. These gifts

cause no clutter, because they get used up!

• **Book all of your travel needs**

at 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.

• 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.

• **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.

New Ideas

New!

• **FirstGiving**

We're pleased to provide a free customized CCA 'firstgiving' site for anyone who wants help raise funds for CCA.

Log onto firstgiving.com/ccakids and tell your personal story or post an event you're having. You can even set a goal and track success! When you tell your own story about your CCA Kid or why you are involved with CCA, folks will respond because they know YOU!

• **Currentfun.com**

New!

-Go to currentfun.com
-Click on "start shopping now"
-Buy what you want
-Click "proceed to checkout"
-Choose Texas for the State
-Then click on Children's Craniofacial Association
-Then finish the order as you would any order
Folks can also order catalogs through that site if they want to go door to door instead of the internet. CCA receives 50% of what folks order this way. The catalog changes seasonally, so it's not a one-shot fundraiser ...people can go in at any time (as long as they go into currentfun.com (not the regular Current sight).
-Place and order and CCA will benefit from it.

Looking for ideas?

Contact Jill Gorecki at J.Gorecki@ccakids.com

fundraising news



The second **Make Your Mark Starbucks** team effort with CCA took place on Saturday, February 9th. Once again, **Emily Tipton**, Manager of the Starbucks across from Medical City Hospital held a community clean-up day. Volunteers picked up litter on the bike trail that borders the area. Afterward, everyone stayed to create valentines for our CCA Kids in the hospital. Starbucks will

potentially donate \$10 for each volunteer hour, up to **\$1,000**. You guessed it — we had 50 volunteers including **Starbucks employees**, our friends from the **Italian Club of Dallas**, and **Brownie Troop #8939** among others, who put in at least two hours each! Thanks again to Emily, her co-workers, our volunteers and, of course, Starbucks!



Our devoted volunteers from **The Italian Club of Dallas** invited our staff to the club for dinner — and a big surprise. They took up a collection for CCA and presented us with **\$250!** Grazi!



Mark and **Laurel Sanborn** of Richmond, VT, have embarked on a new idea for raising funds for CCA through Current. **Currentfun.com** is a sister site to Current (the well-known cards, paper goods and gift items catalog and website) made especially for fundraising efforts. When you shop from this site and indicate Children's Craniofacial Association as your charity, 50 percent of all purchases will come back in funds to benefit CCA! Laurel tells us since the catalog choices change regularly, this is an ongoing effort. Thank you!

donors, january 1 – march 31, 2008*

Gifts from Individuals

CCA Supporters (\$25 to \$100)

Anonymous
Mildred Bonneau
Ann Byrd
Sergio Dominguez
Mary Kay & Thomas Gardin
Sidney Goldman
Jennifer & Michael Hastings
John "Jim" & Arleen Heiry
John Hermanek & Mary Drill
A.E. Karpen
Domenica & Robert McKinnon
James J. & MaryJo Montalbano
Jessie & Theodore Morgan
Harlena Morton
Mina Mulvey
Sandra Peckinpah
Annie Reeves
Chris Riener
Iris Schell
William Schwerd
Mary Ann Silvestro
Stephen Smith
Erin & Crispin Stephens
Laura Talmus
John Zaengle

CCA Friends (\$100 +)

Mari-Jo & Paul Batchelor
Nancy Burson
Thomas Callahan
Diana Critchlaw
Kristine & George Dale
Robert Feinstein
Jill Gorecki
Margaret Grupp
Roger & Carolyn Lamb
Robert Nordness
Randolph Schaefer
Jessica & Frederick Schwerd
Kenneth Wilson

CCA Extended Family (\$500 +)

CCA Sponsor (\$1,000 +)

CCA Benefactor (\$5,000 +)

Mark Hagen

Memorials / In-Honor Gifts

Kevin Alicbusan, in honor of
Aaron Nocum's 1st Birthday,
by Caroline Mingoa
Renee & Wayne Baxmann, in
honor of Robbie Gorecki
Doug & Ann Burgin, in honor of
Rick Dornier
Alexandra Chambers, in memory
of John Michael Chambers
Thomas & Shelley Flores, in
honor of Braxton Flores
Jim & Arleen Heiry, in memory
of Margaret Lux
Jim & Arleen Heiry, in memory
of Lois Witkowski
Law Offices of Steve Howen, in
honor of Brian Scott Cook
Sarah Erb & Andrew Keller, in
honor of Olivia Sanborn
Donald & Ann Lucas, in honor of
Brody Lucas on our 43rd
Anniversary
Jim & Maryjo Montalbano, in
honor of their daughter,
Jennifer's 33rd birthday
Jessie & Theodore Morgan, in
honor of Morgan Baldwin
from Nana
Ralph Nuckols, in honor of
Jeremy Dale
Andrea Richard, D.O., in memo-
ry of Ram Nath Pathlak
Jere Robertson, in honor of Jane
Monell
Jessica & Frederick Schwerd, in
honor of Megan Cronin
William Schwerd, in honor of
Megan Cronin
J.B. & Cynthia Wills, in honor of
Reed Wills

Corporate / Foundation Gifts

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

America's Charities (Employee
Giving Funds Management)
American Express Foundation
(Employee Gift Matching
Program)
Bank of America (United Way
Campaign Employee Giving)
Century Lodge No 492, Order of
Odd Fellows
Cher Convention
CFC Chicago Area
CFC Coachella Valley Twentynine
Palms Area
CFC Eastern Massachusetts
CFC, Fresno County
CFC Global Impact, Overseas
CFC LA Area
CFC New Orleans
CFC Niagara Frontier
CFC Southwestern Idaho
CFC Yellowstone County
Dream Kitchens, Inc. by Keven &
Terri Schmidt
Funding Factory
Gonser & Gonser by Cleo Gonser
Justgive (donors listed separately)
Network for Good (donors listed
separately)
Pfizer (United Way Campaign
Employee Giving)
The Prudential Foundation
(Employee/Matching Gifts)
The Prudential Foundation
(Matched Gift of Diana
Critchlaw)
Safeway, Inc. (purchases percent-
age incentives)
United Way of Brevard
United Way of Cedar Valley
Wellpoint Foundation Funds
Management

CCA Corporate / Foundation Sponsors (\$1,000-\$5,000)

The Redwoods Group (Matched
Gift of Bill Mecklenburg)
Matching Grant funds from
Sam's Club
Vivo Brothers, Inc.

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

Association Works by John &
Sheryl Paul

Fundraising Events

Up to \$1,000

Italian Club of Dallas Collection
for CCA
Cash Collection Cans placed for
CCA / Kim Rogers, CCA
Volunteer
Cher Convention
"Current" Catalog Fundraiser /
Mark & Laurel Sanborn, CCA
Volunteers
Sarah Orne Jewett Collection for
CCA/ Mary Zimmer, CCA
Volunteer

\$1,000-\$5,000

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

\$5,000 or more

\$10,000 or more

\$25,000 or more

Henry's March / Johnson Family,
Rachel, TJ, Lauren, Henry

henry's march,

from page 8

a facial difference and raising funds for those families through CCA.

What began as a planned walk in the neighborhood, Henry's March (as named by our 10-year old daughter, **Lauryn**) ballooned into a full-scale community event, complete with racing mascots, a 100-meter dash for kids, a 5K fun run, booths of local vendors, a face painter, raffle prizes and uplifting music to set the mood.

We are very thankful to our volunteers and sponsors. Their willingness to give their time and money when others created reasons why it wouldn't be successful is so appreciated. We hope our determination to make Henry's March a success will inspire others to face the "unknown" in their own lives and act upon their passion and their love for their child.

For more pictures and details about the race visit www.myspace.com/henrys march

TJ Johnson
Henry's dad



*Listed are **Monetary Donations of \$25 or more** through 1st quarter, 2008. We are extremely grateful for these and all other donations, fees, purchases, fundraisers and in-kind donations not recorded here.

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

3 cheers

for volunteers!

CCA would like to thank **Dr. Rick Redett**, a pediatric plastic surgeon at Johns Hopkins Hospital, for his hard work and dedication to CCA. Dr. Redett has written our Pfeiffer syndrome, Moebius syndrome and Pierre Robin Sequence booklets (new booklet) and will be writing a cleft lip and palate booklet for us later this year. He has also contributed an article for our newsletter and serves on our Medical Advisory Committee. He is always willing to help, and we truly appreciate his kindness.



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Cher

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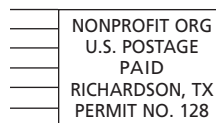
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URL CCAKids.com or CCAKids.org

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



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