

ccanetwork



newsletter of the children's craniofacial association

Cher — honorary chairperson

fall 2006

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Ava with her mom and dad at the Hershey CCA Retreat.

ava's story

"There's something seriously wrong with your baby."

These words were spoken to me and my husband, Malcolm, on February 12, 2003. I was in my 39th week of pregnancy, and our baby hadn't "dropped" into my birth canal. An ultrasound was performed to see what the problem was. Halfway through, the technician stopped, left and returned with the doctor, who looked very concerned and then said those horrible words. She tried to explain a condition called craniosynostosis, which we did not understand at all at the time. I could feel my stomach tie into a knot.

"Will she be brain-damaged?" The doctor replied, "I don't know." I whispered, "Will she live?" Again, "I don't know."

I cannot explain the feelings of grief, terror and dread that overtook us at that moment. We knew nothing

see **ava**, page 10



message from the development director

If you're reading this newsletter on our website, maybe you're a family touched in some way by a craniofacial condition and have just found CCA. Welcome!

If you've been around a while and receive this newsletter by mail or you check online now and again to see the latest news, thank you for your interest and support!

CCA has grown remarkably over the past decade—more so during the past few years alone. Thanks to the Internet, we provide access to so much

see **development director**, page 17



Janelle on her first day of preschool.

meet janelle joswick

Janelle Joswick is four years old and lives in Spring, TX. She attends preschool in the mornings, where she spends her time drawing, playing games and singing. Although there are 20 kids in her preschool class, Janelle especially likes to play with classmate and good friend, Olivia, and her best friend, Rachel. Outside of school, Janelle also likes to play with her friend Lauren.

She's a dancer, too. Janelle takes ballet, tap and gymnastics classes, and she performed last May in a recital. When she's not dancing, she plays with her Barbie dolls, and likes watching movies. Her favorite colors are pink and purple. When she grows up, Janelle wants to be a teacher or a princess.

Janelle was born with Goldenhar syndrome. She has had four surgeries so far, one of them being an open-heart surgery. She has no other procedures scheduled in the near future, but she will have to undergo more as she grows older. Sometimes people ask questions about Janelle's condition, or at times they just stare. Her mom says that Janelle tells anyone who asks, "That's the way I am."

Janelle and her family have been a part of CCA for the past two and half years. They had a great time at this year's retreat in Hershey, PA, where they had the opportunity to participate in fun activities and meet lots of new friends.



cca kid

meet taylor macut

hi, my name is **Taylor Macut**. My family and friends call me Tay. I'm 14. I was born on September 25, 1992, in Harrisburg, PA. I have Apert syndrome and have had about 10 surgeries so far, all at CHOP in Philadelphia. Hopefully, I don't have too many more in the future!

I live with my dad, step mom (but she's like a real mom to me), and my brother Keaton. He is 16 years old and bugs me a lot. Sometimes he's very funny but most of the time he's annoying. My grandparents (Nanner and Bop) live close to us and I like to visit them a lot.

I like to swim and ride my bike with my neighbors and play video games. I sometimes beat my brother in Mario Kart Double Dash. I also like playing with my friends, and eating—especially macaroni and cheese.

I like any kind of music except rap and country. I

really like The Beach Boys. I also go to see a lot of musicals with my parents. They even took me to New York City to see "Wicked." We went backstage after the show, and I got my program signed by all the cast!

I also like to play sports and play soccer, basketball, tennis, golf and football with my friends. I'm also a fan of the Philadelphia Eagles.

School is OK. I'm in eighth grade at C.D. East Middle School. Next year, I will go to high school, where my brother will be a senior. When he goes to college, I will get his room.

When I grow up I want to be a chef. I like to cook, and my dad lets me help make dinner at home.

I have to go and make sure all of my homework is done for school. See you all at the next retreat!



Eighth grader Taylor Macut



Taylor in 3rd grade.



Taylor in Kindergarten.



meet taryn macleNNan

Ryan MacLennan's big sister

hello, my name is **Taryn MacLennan**. I am eight years old and the big sister and best friend to Ryan MacLennan, who has Goldenhar Syndrome.

For my eighth birthday, I wanted to do something to help my little brother, so he wouldn't have to go through so many surgeries and see so many doctors. I found out that I couldn't really do anything to stop that, but I found a way I could help other kids. I cut 10 inches of my hair for "Locks of Love" to help kids who lose their hair to

cancer and leukemia and other medical treatments.

When I am not playing or fighting with my little brother, I enjoy playing softball and soccer and dancing. **I also enjoy going to the yearly CCA retreats, where I have met a lot of good friends. We have made the last three retreats: Tempe, Nashville and Hershey. I hope to see everyone next year in Salt Lake City!**

Jeremy Dale,
Tommy Dale,
Ryan MacLennan,
Lexie Adams, and
Taryn MacLennan



Taryn donated
her hair to
Locks of Love.

ccasupersib

spooktacular costume contest

We are happy to announce the winners of our Halloween Costume Contest.

Four-year-old **Jylian Bilbow** of Arlington, Texas was the winner of the 0-5 age group. She dressed up as a 50's girl and her little brother **Mikey**, was Elvis.

Six-year-old **Peter Dankelson** of Commerce Township, Michigan was the winner of the 6-12 age group. He was Captain Hook and his little brother **Jacob**, was Peter Pan.



Fourteen-year-old **Teeter Sears** of Columbia, South Carolina was the winner of the 13-18 age group. She dressed up as Queen Anne



and her Mom said she felt like a real Queen that night. Congratulations!



happy new year mon!

Attention CCA Families & Friends

We're kicking off the 2007 New Year with a raffle to win a trip for two to Jamaica!

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

We need all of our families and anyone else interested in helping to sell raffle tickets (you may have helped with our motorcycle raffles in the past) to get on board!

Tickets will sell for \$5 each or \$20 for 5 tickets (includes 1 free), or \$100.00 for 30 tickets (includes 10 free).

Participants will begin selling starting January 1st and the drawing will be held on the first day of spring, March 21st. Get in on the contest to see who can sell the most. There is going to be another fabulous prize for that winner!

Please contact CCA to join in and sign up to sell!

Watch our website for more details and/or to purchase tickets online.

regional volunteers

public awareness about craniofacial conditions is important on several levels.

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

CCA has formed a network of regional volunteers across the country who have banded

together in an effort to educate and inform the public. The regional volunteers and CCA will now turn to local areas to recruit volunteers who will distribute educational materials throughout their communities.

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

fundraising news



aaron Goldman, a student in Kingwood, TX, held an art and music festival to raise funds for CCA in honor of his brother, **Evan**, who has craniofacial challenges. Here's what Aaron had to say:

"We had many people contribute in different ways by showing art, playing music, donating money and coming to support the event... At the show, I delivered a speech explaining what your association does, why it is important and how I discovered your organization. Everyone who attended got a better understanding of craniofacial issues, how difficult the lives can be for the people and families affected and how your association brings them together and puts smiles on their faces..."

Aaron ended his note by thanking CCA for "helping these people and bringing some sun into their lives.

...I will be planning more benefits." Thank you so much, Aaron!



darnell Menard of Lee Center, NY, hosted a Home Interiors party and donated her credit to CCA. **Home Interiors** gives 50 percent of the party sales to an organization if the hostess holds a benefit. To thank

CCA for helping her family, Darnell sent a check for \$162 instead of taking hostess credit for herself. Thanks for being so thoughtful and giving back to help others!



best wishes and a big thank you to newlyweds **Mary Beth (Ayres) and Jim King** of Scottsdale, AZ.

Instead of wedding gifts, they requested contributions to their favorite charities, among them CCA. These donations in honor of the couple added much-needed funds to continue and improve our programs and services.



Our families never cease to amaze us...they step up and help when they are able...following is a portion of a letter from **Angela and Ben Cronin** in Greenwich, NY who were also raising funds in observance of September's Craniofacial Acceptance month...

We had planned to do a small fund raiser for the month of September with just our family and friends, to

raise awareness for Craniofacial Acceptance Month. Sadly on August 21, 2006 my father-in-law, **Mike Cronin**, passed away. My mother-in-law wanted memorials to be made to an organization associated with our daughter **Megan's** syndrome. We decided on Children's Craniofacial Association to coincide with our fundraiser. We have been able to collect much more than we anticipated. About \$2,000 is in honor of our daughter Megan Cronin, and the other \$2,600 is in memory of Megan's grandfather, Mike Cronin.

We have been so fortunate to have the support of our family and friends and realize that not every family is so lucky. **CCA is an amazing organization.** We hope the donation will help. We are also hoping to attend the retreat in the future.

Thanks, CCA, for all you do.

Thank you Cronin family for all you do!



Suzanne Chiasson of Burbank, CA, is a "yogi" with a big heart. She became acquainted with CCA through the Cher Convention in Los Angeles this past July and came up with a great idea for raising funds. Suzanne offered two special yoga instruction sessions to benefit CCA. "Yoga for Charity" raised more than \$600 for CCA! Thank you, Suzanne, and all of those who attended and supported her efforts. Namaste!



Three Cheers for the **Waukesha West High School Cheerleaders** in Waukesha, WI who, under the tutelage of their co-coaches, Lindsey Richardson and long-time CCA supporter, JoAnn Kopshinsky raised over \$100 (even though it was raining!) at their "Cheers for Kids"

car wash for CCA during September's Craniofacial Acceptance month observance. You Rah, Rah, Rock!



Nick Wiese of Baden, PA, helped CCA kick off September's Craniofacial Acceptance month at his high school by informing students and educators about the challenges faced by a kid with a craniofacial medical condition.

Nick, 18, and his parents attended our annual family retreat for the first time this past summer and they immediately brought their enthusiasm to all of our efforts, contributing to other family fundraisers, making purchases from our web store and joining in whatever we propose. Nick's campaign to raise funds and awareness will run throughout the school year.

A big thank you to Nick, his family and all of his friends for raising funds and widening the circle of acceptance!



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Questions, email Rose Seitz at rseitz@directed-tech.com

These gifts cause no clutter, because they get used up!

pierre robin sequence

By Richard J. Redett, MD

In 1923, a physician named Pierre Robin described a newborn child with an abnormally small lower jaw (mandible), large tongue and breathing problems. Today, Pierre Robin Sequence (PRS) is a condition of facial difference characterized by severe underdevelopment of the lower jaw (retrognathia), a downward or backward-positioned tongue (glossoptosis) and usually a cleft palate (opening in the roof of the mouth).

A sequence, not a syndrome

The disorder is called a sequence and not a syndrome because the underdeveloped lower jaw begins a sequence of events, which lead to the abnormal displacement of the tongue and subsequent formation of a cleft palate.

During the normal developmental process, between nine to eleven weeks during gestation, the tongue moves down and away from the roof of the mouth, allowing space for the sides of the palate to shift to the midline and close. In PRS, the small

lower jaw keeps the tongue positioned higher in the mouth than normal, thereby interfering with the normal closure of the palate. This typically results in a wide U-shaped cleft of the soft and part of the hard palate.

The overall incidence of Pierre Robin Sequence is low, approximately one in 8,500 to 14,000 births, and equally common in males and females. The diagnosis of PRS is made by examining the infant and not by special diagnostic tests. The exact cause of PRS is not known. External factors, which crowd the fetus and interfere with the growth of the lower jaw, may contribute to PRS.

There is a higher incidence of PRS in twins, which may be due to crowding in the uterus, thereby restricting growth of the lower jaw. Certain neurological conditions, which lead to decreased jaw movement in utero, can also restrict jaw growth. If an individual has PRS because of the influence of external factors while in utero, his or her risk of passing on the condition is minimal,

because the genetic information governing jaw and palate development has not been altered.

Possible genetic basis

Some studies demonstrate there may be a genetic basis for PRS. PRS can be seen in other syndromes including Stickler and Velocardiofacial Syndrome.

Stickler is the most common syndrome associated with PRS, occurring in 10 to 30 percent of cases. Stickler Syndrome is a genetic malfunction in the tissue that connects bones, heart, eyes and ears. This disorder is associated with problems with vision, hearing, bones and joints, the heart and facial formation, including cleft palate.

Velocardiofacial Syndrome is associated with PRS in approximately 10 percent of cases. The most common features are cleft palate, heart defects, characteristic facial appearance, minor learning problems, and speech and feeding problems.

In isolated cases where PRS is not associated with any other syndromes, the risk of a parent having

another child with PRS is three to five percent. The risk of an adult with isolated PRS having a child with cleft palate is three to five percent. Genetic testing may be offered if a genetic syndrome is suspected. Chromosome analysis and testing for chromosome deletion (FISH for deletion of 22q11) can be performed.

Feeding difficulties

Nearly every newborn with PRS will experience some degree of feeding difficulty. This is because of a combination of factors, including the size of the lower jaw, position of the tongue and the cleft of the palate. Babies with minor degrees of PRS can learn to feed with specially adapted nipples and bottles such as the Haberman Feeder, the Meade Johnson Cleft Palate Nurser or a regular nipple with a larger opening. A feeding consultant can often help parents choose the right nipple/bottle combination through a course of trial and error.

For infants with more severe PRS, the risk of aspiration during feeding can be high. In addition,

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the baby can struggle to move milk to the back of the throat and swallow while working on breathing, and significant calories can be lost.

To prevent aspiration during feeding and to allow the child to gain weight appropriately, a feeding tube (nasogastric tube or NG tube) may be inserted into the nose and down into the stomach. This is a safe procedure that will ensure the infant obtains the needed calories to gain weight appropriately. This is a temporary solution that can be used for up to a month.

Children who require long-term feeding assistance may need a gastric tube surgically inserted through the abdominal wall into the stomach. Many children with PRS outgrow their feeding problems by one to two years of age, when the mandible grows more sufficiently.

Respiratory problems

Breathing problems can be common in infants with PRS. A normal-sized lower jaw helps to anchor the tongue in a more forward position. Because of the small, recessed jaw found in children with PRS, the tongue tends to fall backwards and block off the throat and obstruct

breathing when the infant is placed on his/her back.

This is of great concern during sleep, when the tongue is more relaxed and prone to fall back into the throat. The majority of babies respond well to positioning on the stomach which helps pull the tongue forward during sleep. Other infants may require nasal tubes or surgery to pull or push the tongue forward.

At our hospital, we institute a trial of positioning the infant on his/her stomach. If this works to relieve the respiratory obstruction, infants can safely be sent home with an apnea monitor.

If stomach positioning does not work at relieving the respiratory obstruction, a nasopharyngeal airway may be passed through the nose into the upper airway to help with breathing. A nasal airway can be used for a short period of time. Occasionally a sleep study will be done prior to discharge from the hospital to insure the child is safe to be sent home without risk of significant apnea.

For those infants with more severe respiratory obstruction, surgical procedures may be required to improve breathing. For children whose breathing

obstruction is not relieved by prone positioning, we generally recommend a surgical procedure called a tongue-lip adhesion.

A tongue-lip adhesion is a safe procedure which temporarily sutures the tip of the tongue to the inside of the lower lip thereby pulling the tongue forward and out of the back of the throat. The tongue-lip adhesion stays in place for eight to ten months, until the lower jaw has grown enough to pull the tongue forward on its own.

Mandibular distraction

Some hospitals will perform a procedure called mandibular distraction (figure 1) if positioning on the stomach or a tongue lip adhesion fails to relieve the respiratory obstruction. Mandibular distraction is a procedure involving surgically cutting the lower jaw and placing either an internal (in the mouth) or external (through the skin) device which can be slowly adjusted to lengthen the jaw and theoretically pull the tongue out of the back of the throat.

Unfortunately, none of these procedures works all of the time, and a small number of children with PRS and severe respiratory obstruction may require a tracheostomy to help with breathing. Most children



An illustration demonstrating mandibular distraction. A cut has been made through the jaw. The device is secured to the lower jaw by pins, which pass through the skin. A screw is turned once or twice a day to lengthen the mandible and bring the tongue forward.

with isolated PRS experience enough jaw growth during the first one to two years of life to allow for eventual removal of the tracheostomy.

Children with PRS and other associated syndromes such as Stickler or Velocardiofacial may have a small lower jaw for life. For any child with PRS, it is important to have surgical procedures performed at a hospital where there are anesthesiologists familiar with the anesthetic difficulties in children with a small lower jaw.

Cleft palate repair

The cleft palate is usually repaired when the infant is between nine and twelve months old, depending on the health of the child. In PRS, surgery may be

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Ava at one year.

Ava spent the next two months of her life in the Neonatal Intensive Care Unit (NICU) at Connecticut Children's Medical Center. She was sedated with narcotics, head wrapped in a huge bandage, breathing on a ventilator. The tube for the ventilator and a feeding tube were taped to her face, so we couldn't even see all of her. I sat with Ava all day, mostly staring into space. Sometimes my parents would sit with me,

would ever be the same. We were right.

Ava Marie Beeler was born via C-section the next day. We had been told that she had a very rare form of craniosynostosis called a cloverleaf skull. All of the sutures of her skull had fused shut. They told us she most likely had Pfeiffer Syndrome Type II and that she had to have emergency surgery to "unfuse" the sutures of her skull. We had no idea what anyone was talking about. Who had ever heard of such a thing? A neurosurgeon talked to us about the surgery; he said he wasn't sure Ava would even live through it.

We had Ava baptized, and we prayed with all our might. Somehow our tiny baby, at 36 hours old, made it through the incredibly difficult surgery.



Ava at six weeks, looking at her mobile in the NICU.

sometimes my in-laws. Many times, the NICU nurses would take their time and sit with me.

I was angry, sad, depressed and frightened. A geneticist told me that if Ava survived she would likely be severely mentally impaired.

We had a family meeting with her doctors to discuss Ava's condition. She needed a tracheostomy to

breathe, a feeding tube to eat and surgery to help control her reflux. She also had a ventricular septal defect (commonly known as a hole in the heart), which would likely require open heart surgery. Her DNA analysis came back from Johns Hopkins, and we found that her condition was caused by the FGFR2 genetic mutation that causes many of the craniofacial syndromes. (Ava has never been diagnosed with a particular syndrome, as she has the features of several.)

This was all overwhelming. Each day felt like a battle.

One afternoon, Malcolm came to the hospital after work with an email from a woman he had contacted online. Her name was Jenny and her daughter, Kayla, had also been born with a cloverleaf skull. Her daughter had a trach, feeding-tube, shunt, and had endured many surgeries, but she was also a happy little girl who spoke sign language fluently, enjoyed school and seemed to be as normal as she could possibly be.

This was the first glimmer of hope we had. Jenny wrote to us a lot during those early days, and her words were incredibly helpful. I printed her emails and carried

them with me to the NICU each day, reading them over and over.

As Ava was weaned from the narcotics, she began to look around. She turned toward voices in the room and seemed to "check out" everyone who walked in. At one month of age, she was strong enough to undergo a tracheostomy, Nissen fundoplication, and insertion of a feeding tube.

Finally, all the tubes were removed from her mouth and we were able to see her pretty little face for the first time. Things began to get better. Ava began to receive breast milk and formula instead of IV feedings. She was weaned from the ventilator. We were able to hold her and even walk her around the NICU in a stroller. Eventually we made plans to bring her home.

This in itself was a challenge. Caring for Ava in the NICU with an army of nurses around was quite different from caring for her at home. We had a night nurse four nights a week, but it wasn't nearly enough.

During her third week home, Ava's eyelid fell behind the globe of her eye and she was readmitted to the hospital. She stayed for three weeks until our nursing agency found a nurse to stay with

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me while Malcolm was at work. Nurse Judy was incredible. She taught me how to care for Ava and how to be a mother to a special needs child. Our night nurse, Karen, worked six nights a week so we could sleep.

That first year was incredibly difficult. Our days were filled countless appointments and many speech, physical and occupation therapy sessions at our home. In the evenings, Malcolm and I would practice whatever skills her therapists had taught her and tried to be a normal family. At six months, Ava developed hydrocephalus and needed a VP shunt. At eight months she underwent her first cranial vault remodeling surgery to expand her cranium and bring her forehead forward.

At one-year old Ava learned to sit up! She also signed her first word, "shoes"! Ava could interact and play more, and she began to seem more like a normal one-year-old. At 15 months she began to crawl and eventually learned to pull to a stand. She walked around the house with a push toy.

The day after her second birthday party, she took her first steps on her own and

has not stopped moving since! By age two and a half, Ava could sign hundreds of words and eventually learned to stick

surgery in May 2006 to replace a blocked shunt, she finally underwent her second cranial vault remodeling at NYU that



Ava at three years, cheering with Dad. Go Longhorns!

her little finger in her trach and make sounds. Soon she began to say words and soon after, phrases and sentences. The hole in her heart miraculously closed to the size of a pinhole on its own and didn't require surgery.

In October 2005, we went to see the craniofacial team at New York University's (NYU) Institute for Reconstructive Plastic Surgery, headed by Dr. Joseph McCarthy. This team of doctors had seen many children like Ava and we felt they could give us the benefit of their experience and expertise. After an emergency

July. She was able to come home after only three nights in the hospital!

We attended our first CCA retreat at Hershey this year and met many more families who have endured the same things as Ava. For once, we felt like any other family on a vacation with friends, instead of the ones at whom everyone was staring. We had a terrific time!

Olivia Sanborn, Ava Beeler and Amelia Sanborn

We also have a very special friendship with the Sanborn family from Vermont. We met the Sanborns online, through a website for craniofacial families. Mark and Laurel have a daughter named Olivia who is only 6 weeks older than Ava. We met in person for the first time in May 2004. Our friendship with the Sanborns has grown. Ava loves Olivia and her sister Amelia, and we try to get together several times a year. These gatherings are very special to us and having friends who understand and experience the same things we do is so important.

Today, at three-and-a-half years old, Ava is a lively, happy, girl. She loves to sing and dance, act out stories, draw and make puppets and crafts. She attends preschool four afternoons a week. She has a wonderful, loving

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ava, from page 11

teacher and an excellent nurse who accompanies her to school.

We hope that this winter brings fewer illnesses than last year and that her immune system becomes stronger. We hope that she continues to learn and grow and become the best little Ava she can be. We are planning her mid-face distraction for late spring, after she does her duty as the flower girl in my brother's wedding.

We know that her mid-face surgery will be long and difficult and that she still faces many challenges ahead. We also know that Ava is strong and surrounded by a lot of love and prayers.

Life is not easy for us; we have to work harder than most parents. We are always worried about Ava. But we also have many truly happy moments and take joy in each milestone Ava reaches. We are a happy family. We are grateful for all the wonderful people who have come into our lives because of Ava. She is the light of our lives and the most beautiful, kind, clever and precious daughter we could have ever wanted.

prs, from page 9

postponed a month or two if the lower jaw and mouth are very small. Palate surgery takes about two or three hours, with the infant staying in the hospital one or two nights.

A child with PRS may spend his/her first night after palate surgery in the pediatric intensive care unit to monitor for signs of airway obstruction. A cleft palate can result in abnormalities with the middle ear, leading to persistent fluid, which is a primary cause of repeat ear infections. Hearing loss can be a consequence of repeat ear infections and persistent middle ear fluid. Tubes can be inserted into the ear at the time of palate repair to alleviate fluid build-up and restore hearing.

Most children have normal speech after palate repair, but some will require speech therapy or a second operation to improve speech later on. Because of the complexity of Pierre Robin Sequence and clefts of the palate, PRS should be diagnosed and treated by an experienced team of experts recognized by the American Cleft Palate-Craniofacial Association.



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Take a break from your regular search engine (Google, Yahoo, etc.) when surfing the Net and try www.goodsearch.com (powered by Yahoo). Add it to your "favorites" list, so you can go back to it easily each time you make a search.

Enter Children's Craniofacial Association as your beneficiary charity. (You only have to do this the first time.)



CCA will receive up to a penny each time you search. We've just begun and already we have tallied 800 pennies. Those pennies will add up—and that's good!

golf scramble raises thousands for cca!

Wendelyn Osborne hosted her first fundraiser ever, raising **more than \$7,000** for CCA! Her "Course of Dreams" Golf Challenge took place Saturday, August 26, 2006, at the Country Club of Arkansas in Maumelle, AR, just 10 minutes from Little Rock.

The event was a lead-in to September's National Craniofacial Acceptance Month. The **Honorable Burch Johnson, Mayor of Maumelle**, proclaimed the

represented a hole in the course but it also highlighted a particular craniofacial condition.

Wendelyn herself has craniometaphyseal dysplasia, a disorder with a life expectancy of 14 years. **Yet, she's beating the odds at 40 and believes it's important for folks to understand CCA is there for everyone affected as well as their families.**

"As we grow up, our looks may be improved with reconstructive procedures, but all challenges don't go away. CCA needs help with funding because many new families come to the organization while existing families continue to participate in programs and services, so the demand on resources is multiplied. I think people had fun while helping raise funds, but I trust they will also pass along some of what they've learned!"

Wendelyn extends her gratitude to her volunteers: **Roberta Long, Toni Thrash and Linda Osborne**; generous individual and corporate supporters, including **Lindy Blackstone** and her associates at the **BUZZ**



Wendelyn Osborne and Tim Jenkins, course owner

start of the scramble. Twelve teams (48 golfers) participated in the tournament and enjoyed lunch and a silent auction after the game.

The event also raised awareness of craniofacial concerns. The scoreboard, doubling as a teaching tool, was surrounded by 18 photos. Each photo



Neal Sharkey, Armour Bryant, Mike Coats & Ricky Carter, all from UPS; got a team together after hearing about the event on the radio.

sports radio (who talked up the event); **Timothy Morton**, owner and chef of **1620 Restaurant**, who provided the prize for **Scott Rykema** and his winning team; **Tim Jenkins**, owner of the **Country Club of Arkansas**, for offering his course; and **Sam Custer**, owner of the **Shackleford Road Sir Speedy Printing**, who donated all the printing for the event. Special thanks go to **Parker Cadillac** and **Golf Carts of Arkansas** for providing three Hole-in-One competitions.

Despite the tumultuous humidity and temperature, the golfers had a wonderful time riding in air-conditioned carts, and they plan to bring more of their friends with them for next year's tournament.

The second annual Wendelyn's Course of Dreams Golf Challenge is scheduled to be held **Saturday, August 25, 2007**, at the Country Club of Arkansas. Mark your calendars and help Wendelyn raise awareness throughout Arkansas—and the country!



Larry Crenshaw and Ronnie McKnight enjoy an air-conditioned golfcart in the Arkansas heat.

donors, january 1 – september 30, 2006*

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Marilyn & Keith Harrison
John J. & Arleen Heirly
Kelly Hernandez
Lora Higginbotham
Stormie Holguin
Barbara Hopwood
Richard & Judy Horn
Melissa & Donald House
Richard Howe
Clayton & Kathy Huck
Dorothy & Matthew Hunyadi
Dale & Joan Jennerjohn
Paul & Patricia John
Frances Johnson
A.E. Karpin
Brian Katz
Kathryn Kemp
Diane & Daniel Knockeart
Lee & Jenny Knutson
Thomas & Barbara Kochendorfer
Annette Kolodny
Elizabeth Krane & Marilyn Sutherland
Michael & Mary Lambert
Gregory Laney
Diane & Bruce LaRue
Nancy & Charles Lathrop
Karen & Charles Lee
Lexie Lermont
Diana Lesko
Christina & Mario Linarez
Damian Lively
Robin Longoria
Mary Lovell
Doris & Norbert Lustine
James Macaulay
Irene & Louis Macedo
Jennifer Madden
Joseph Malangone
Jessica Manzie
Anthony & Patricia Marino
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Jane Monell
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Mina Mulvey
Cynthia Nelson
Janell Nelson
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Janet Novick
Geraldine O'Reilly
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Mary & Anthony Pallante
Jana Peace
Joan Pedersen
Caroline Peterssen
Harry H. Porter, Jr.
Candace Powell
Joyce M. Prather
Debra Quattrini
Deborah Rader

Andrea Richard & Aaron Brenner
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Consuelo Ripstra
Aya Romero
T. P. & Heather Rose
Allan & Lisa Ross
Jim & Diane Rumbo
Carol Schatt
James Sebastian
Rose Seitz
Kimberly Shell
Ann & Anthony Silano
Tom & Jean Silva
Rand Sinanian
Marjorie Smith
Terrie Smith
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Richard Szulcowski
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Irina Temkin
Anthony & Rae Teta
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Patricia & Harold Timmer
Liz Tracy
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Elizabeth Vitez-Bainbridge
Alicia A Wadas
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Leslie Weisman
Robert & Anjelene Whaley
Joanie Winblad
John & Remy Wilcox
Francis & Heather Wills
Jeff & Linelle Wolpa
Michael Wood
Lynn Yetra & Ambrose Donovan

CCA Friends (\$100 +)

David & Judith Albers
Marie & Joseph Baniecki
Christine Barrett
William & Madaline Barry
Joyce Borsellino & Bill Masloski
Greg Briedenbach
Ann & William Burgin
Roger S. Chin, DDS, PS
Ann Connolly
G. M. Corzine
Diana Critchlaw
Roger Dalton
Anthony & Sandra Deakins
William & Karla Dean
Mark & Lania Deer
Eddie Edwards
Jerry Lynn & Dianne Erwin
Stephanie Floyd
John & Carrie Follett
Reynold Gravina

Kathy Guy
Robert Haley
Denyse Halperin
Kevin & Ellen Haugh
David & Ginger Henshall
Kathy & Stephen Hubbard
Saeed Kermani
Daniel & JoAnn Kopshinsky
Esther Krieger
Roger & Carolyn Lamb
S.F. Luhrs
Janis & Doug Macut
Richard & Beth Marsden
Chip & Kathy Michaelson
Alison & Joe Morrissey
John Moulton
Joe Neuhoof
Alland & Mary Karen Newstadt
Fred Paul
Mary, Conrad, Rebekah Perkins
Karin Perry
Rosalinda Pouya
Karen & Mark Proctor
Marie Quaranta
Tanya Rhodes
Alec & Kim Roark
Eric Ronczka
Jeff & Polly Rosignol
Paul Schmidt
Martin & Patricia Schweinhart
Stephen & Julie Shields
Rubin Solis for Tower Softball Team, Austin, TX
Karen Stott
Robert & Rosa Maria Vargas
Dwight Vaughn
David & Adrienne Weil
John & April Wharton
Leila Wiley
Dennis Wooden
Myrna & Ronald Zaccagnino
Donna Zavahir

CCA Extended Family (\$500 +)

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George & Kristine Dale
Conrad DePinto
Craig Dufresne, MD
Albert & Bunsiri Frazier
Fred & Judi Freeman
S. Gaylann Hicks
Mary Lytle
Mr. & Mrs. Thomas T. Soviero

CCA Sponsor (\$1,000 +)

Jeffrey & Beth Abel
Jane L. Goodman
Dan & Denise Paulson
Courtney Vincent

CCA Benefactor (\$5,000 +)

Robert & Maryellen Fettig
Greg Luetkemeyer

Memorials / In-Honor Gifts

David & Judith Albers, in memory of Kevin Dalton
Nancy Alexander, in honor of Heather Lermont-Pape's birthday
William & Madaline Barry, in memory of Kevin Dalton
Sheree Bishop, in the name of Taylor Bishop
Mrs. Oliver Bobsine, in memory of Gerri & Larry Reinherdt
Ron Birks & Kathi Douglas, in honor of the marriage of Marybeth Ayres & Jim King
Joyce Borsellino & Bill Masloski, in memory of Kevin Dalton
Boston JetSearch, Inc., in memory of Kevin Dalton
Jimmy & Beverly Butera, in memory of Bernice Peace
Jimmy & Beverly Butera, in honor of Janet Carter's birthday
Cher.com participants, in honor of Cher's birthday
Cher fans, in honor of Cher's birthday
Mary Cook, in honor of Heather Lermont-Pape's birthday
Leo Dalton, in memory of Kevin M. Dalton
Roger Dalton, in memory of Kevin M. Dalton
Sarah Delvento, in memory of Kevin Dalton
Conrad DePinto, in memory of Kevin Dalton
Cosgrove Aircraft Service, Inc., in memory of Kevin Dalton
Duncan Aviation, in memory of Kevin Dalton
Amy Escher & Donna Poyner, in honor of Heather Lermont-Pape's birthday
Mr. & Mrs. Robert Fallon, Jr., in honor of the marriage of Marybeth Ayres & Jim King
T.M. Farrell, in honor of the marriage of Marybeth Ayres & Jim King
First Grade Team at Bebensee Elementary, Arlington, TX, in honor of music teachers, Ms. Scott & Mrs. Atchley
Stephen & Marion Frost, in memory of Kevin Dalton

Ken & Susan Godwin, in honor of Natalie Wardlaw
 Arthur Goldberg, in honor of the marriage of Marybeth Ayres & Jim King
 John J. & Arleen Heirly, in memory of Gene Zuk from Jim & Arleen
 John J. & Arleen Heirly, in memory of Bill Genthner
 John J. & Arleen Heirly, in memory of Tammi Kleis from Jim & Arleen
 David & Ginger Hershall, in honor of Jeremy Dale
 Richard & Judy Horn, in honor of the marriage of Marybeth Ayres & Jim King
 Kelly Hernandez, in honor of Cher's birthday
 Kathy & Steven Hubbard, in honor of Elizabeth Hubbard from Mom & Dad
 Dorothy & Matthew Hunyadi, in memory of Kevin Dalton
 Kathryn Kemp, in memory of Patrick Kemp
 Diane & Daniel Knockeart, in honor of Kieran Roehl, grandson
 Lee & Jenny Knutson, in honor of daughter, Nalani from the Knutson Family
 Daniel & JoAnn Kopshinsky, in honor of Robbie Gorecki
 Bruce & Diane LaRue, in honor of Scott Guzzo from the LaRue Family
 Nancy & Charles Lathrop, in honor of Natalie Wardlaw
 Karen & Charles Lee, in honor of the marriage of Marybeth Ayres & Jim King
 Lexie Lermont, in honor of Heather Lermont-Pape's birthday
 Robin Longoria, in honor of Matthew & Mitchell Herring
 Mary Lovell, in honor of Peggy McDannel
 Greg Luetkemeyer, in honor of mother, Betty Luetkemeyer
 Doris & Norbert Lustine, in memory of Ruth Cohen
 Janis & Doug Macut, in honor of Dr. Savi
 Janis & Doug Macut, in honor of Dotti Macut
 Joseph Malangone, in memory of Kevin Dalton

Greg & Patti Mathers, in honor of Katelyn Mathers
 Ellen McPadden, in honor of Jeremy Dale from Aunt Ellen
 Ellen McPadden, in the name of Jeremy Dale
 Ann E. Melendy, in honor of Dianna H. Allen
 Jane Monell, in memory of Tom Law
 Alison & Joe Morrissey, in honor of Rachael Morrissey
 Alland & Mary Karen Newstadt, in honor of the marriage of Jessica & Jeff
 MaryAnn Pallante, in honor of Freddy Seitz
 Fred Paul, in memory of Kevin Dalton
 Joan Pedersen, in honor of Heather Lermont-Pape's birthday
 Mary Perkins, acknowledged to Michael Perkins
 Karin Perry, in memory of Mom, Elaine Perry
 Harry H. Porter, Jr., in honor of the marriage of Marybeth Ayres & Jim King
 Joyce M. Prather, in honor of Frankie Prather from Mom
 Karen & Mark Proctor, in honor of the marriage of Marybeth & Jim King
 Tanya Rhodes, in honor of Max Abel
 Rib-X Pharmaceuticals, Inc., in memory of Kevin Dalton
 Alec & Kim Roark, in honor of Jylia Bilbow
 Aya Romero, in honor of Eric James Romero
 Jim & Diane Rumbo, in honor of the marriage of Marybeth Ayres & Jim King
 Carol Schatt, in honor of the marriage of Marybeth Ayres & Jim King
 Paul Schmidt, in honor of Peter Dankelson
 Tom & Jean Silva, in memory of Kevin Dalton
 Rand Sinanian, in memory of Kevin Dalton
 Tower Softball Team, Austin, TX, in memory of Kevin Dalton by John's Teammates
 Szaferman, Lakind, Blumstein, Blader & Lehmann, in honor of Avery Lytle

Tag Aviation (USA) Inc., in memory of Kevin Dalton
 Lucia & Scott Van Cleef, in honor of Avery Lytle from Emma Van Cleef
 Elizabeth Vitez-Bainbridge in honor of son, Thomas Vitez from Elizabeth J. Vitez
 Alicia A Wadas, in honor of the marriage of Marybeth Ayres & Jim King
 David & Adrienne Weil, in memory of Kevin Dalton
 Westchester Aircraft Maintenance Assn., in memory of Kevin Dalton
 John & April Wharton, in honor of Jake Wharton
 Michael Wood, in memory of Kevin Dalton
 Donna Zavahir, in memory of Mary "Ann" Davidson

Corporate / Foundation Gifts

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

AMT Internet Companies
 AT&T (Employee Giving)
 Alessi, S.C.
 America's Charities (Employee Giving Funds Management)
 American Express (Employee Giving)
 Association Works, by Sheryl & John Paul
 Bank of America United Way Campaign (Directed Donations)
 The Biella Foundation by Mart Bert
 Boston JetSearch Inc.
 Community Health Systems Foundation, matching gift of Martin Schweinhart
 Cosgrove Aircraft Service, Inc.
 Dean Painting / William Dean d/b/a.
 Dell USA (Employee Giving)
 Direct Strategies, by Dana Heter
 Dream Kitchens, Inc. by Keven & Terri Schmidt
 Duncan Aviation
 Fidelity Charitable Gift Fund (Matched Gifts)
 The Frugal Flower, Inc. (Purchases Percentage Incentives)
 Funding Factory (Rebates/Recycling Program)
 GE Foundation, matching gift of Beth Abel

Jefferson Lumber & Millwork
 Lockheed Martin (Employee Giving)
 Prudential Foundation (Employee Giving/Matching Gifts)
 Rainer & Anding & McLindon by George Anding, Jr.
 Rib-X Pharmaceuticals, Inc.
 SBC (Employee Giving)
 Safeway, Inc. (Purchases Percentage Incentives)
 Sarah Hall Productions
 Schoolpop (Purchases Percentage Incentives)
 Square D Foundation (John Eschmann, Matching Gift)
 Superior Bonding, by Victor Montoya
 Synthes Maxillofacial by Roger S. Chin, DDS, PS
 Szaferman, Lakind, Blumstein, Blader & Lehmann
 Tag Aviation (USA) Inc.
 Tweezerman Corp
 United Way of Central Maryland (Directed Donations/Employee Giving)
 United Way of Fresno County (Directed Donations/Employee Giving)
 United Way of Long Island (Directed Donations)
 United Way of Metropolitan Dallas, Inc. (Directed Donations)
 United Way of Metropolitan Tarrant County (Humanity Fund/Employee Giving)
 United Way of Tucson & Southern AZ (Directed Donations)
 The Weatherstrip Company, by Greg & Patti Mathers
 Wellpoint Foundation (Employee Giving/Matching Funds Management)
 Wells Fargo (Employee Giving)
 Westchester Aircraft Maintenance Assn.

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

A grant from the Dallas Jewish Community Foundation, recommended by Mr. & Mrs. Gerald Frankel
 A grant from 84 Lumber Company, Margaret Hardy Trust
 Guyuron Family Foundation, Inc.
 A grant from the David & Shirley Hubers Family Fund of

The Minneapolis Foundation, recommended by Travis & Christa Rymal
 A grant from the Staubach Family Foundation
 Wal-Mart

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

The Cher Charitable Foundation, Inc.
 A grant from Dreyfus Foundation
 A grant from the Jorge Posada Foundation
 A grant from The Lightner Sams Foundation, Inc.

Fundraising Events

Up to \$1,000

Cher's Birthday / Cher.com Fans
 Evan Goldman Honor Fundraiser / Aaron Goldman, Organizer/CCA Volunteer
 Highland Elementary School Denim Days Fundraiser / in honor of Justin Prince
 Home Interiors party for CCA / Darnell Menard, CCA Volunteer
 FServ Omaha Denim Days for CCA / Glen Peterson, Organizer/Trevino Family

\$1,000-\$5,000

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

\$5,000 or more

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

* Listed are monetary donations through 3rd quarter, 2006. We are extremely grateful for these and all prior donations. In-kind donations are not recorded here.

reconstructive surgery act

If you are happy with your insurance coverage for craniofacial conditions you are among the fortunate! Many families face a constant struggle with their insurance companies to receive coverage for medically necessary treatment. These families need your help!

Congressman Mike Ross introduced legislation to the US Congress to guarantee insurance coverage for craniofacial patients. This legislation (HR4022) was proposed because insurance companies often label needed reconstructive care as "cosmetic" and deny coverage for this or other reasons. The Reconstructive Surgery Act of 2005 seeks to guarantee that insurance companies meet their obligations to cover medically necessary care. Here's where you come in. Doing something as simple as making a phone call or copying a letter from www.aica-advocates.blogspot.com then mailing or emailing can make a huge impact! Please visit the website today and make a difference for many families who need your help.

craniofacial acceptance month



Craniofacial Acceptance Month fostered awareness and acceptance across the country as CCA families joined the effort. Throughout the month of September, CCA families nationwide mobilized to spread acceptance of children and adults living with craniofacial conditions. This was accomplished on several levels, including press coverage, proclamations and fundraising.

Since awareness leads to acceptance, several families were able to have articles placed in their local newspapers, and at least one family was interviewed on their local television station. Others were able to have CCA's link placed on prominent websites.

Janis Macut of PA worked with members of the State House of Representatives and Senate to declare Craniofacial

Awareness Day in her state. **Lisa Crawford** and **Wendelyn Osborne** contacted their governors' offices and were able to have September designated Craniofacial

Acceptance Month in AL and AR. In fact, **Governor Mike Huckabee** of AR, presented Wendelyn a proclamation of the designation. Wendelyn also had congressional records written by AR **Representative Mike Ross** and AR **Senator Mark Pryor** these are recorded in the Library of Congress.

Several CCA families conducted fundraisers during the month.

Jennifer Guerra of Dickinson, TX, whose daughter, **Natalie**, was born with Pfeiffer syndrome, raised funds with friends who held a tamale sale in Natalie's honor.

Angela and **Ben Cronin** of Greenwich, NY, raised funds in honor of their daughter, 19-month-old **Megan**, who was born with craniofrontonasal-

dysplasia (see more on page 6).

Wendelyn Osborne, who was born with craniometa-physal dysplasia, held a golf tournament in Little Rock, AR (see page 13).

Nick Wiese of Baden, PA, raised funds and awareness at his high school (see page 7).

Suzanne Chiasson of Burbank, CA, held "Yoga for Charity" classes (see page 7).

Darnell Menard from NY hosted a Home Interiors party, from which CCA received 50 percent of the total sales credit (see page 6).

The **Cheerleaders at Waukesha West High School** in WI held 'Cheers for Kids' and donated carwash funds (see page 7).

CCA produced the "Beyond the Face is a Heart" mail piece to help raise much-needed funds to support important programs and services and to raise awareness and acceptance by honoring children with craniofacial conditions.

CCA appreciates everyone who joined this important effort, and we look forward to even more participation in 2007.

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

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.

download the newsletter

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

development director, from page 1

more information and reach further in our efforts for awareness. We now serve many more children and families affected by craniofacial medical conditions. Along with that opportunity to help is the need to fund the increased demand for our programs and services.

We are aggressively seeking foundation and corporate grants and have established a direct mail campaign. Recently, you may have noticed more mail from CCA appealing for your help through contributions; this is our direct mail campaign in action. We respect our donors' privacy and do not distribute, rent or sell our database information.

CCA employs just four full-time employees serving the whole nation and parts beyond. We depend on a well-defined network of volunteerism. We adhere to a "Code for Fundraising Accountability," which includes Donors' Rights, and we encourage you to read them. They're posted

zones for this cause, volunteering, networking with new families and raising funds. Donors may feel gratified to know those they help are also striving to help themselves and others.

Craniofacial challenges aren't as widely recognized as other worthy causes, yet they affect many more individuals than people realize. And, many more are born each year, increasing the number affected.

In September, CCA proclaimed and observed National Craniofacial Acceptance month. Our goal was to spread awareness, recognizing that beyond the face is a heart, while widening the circle of acceptance.

Thank you all for joining our circle!

During this time of year, we're reminded of Charles Dickens' classic, *A Christmas Carol*, and how Scrooge was transformed overnight from stingy curmudgeon to generous philanthropist and Tiny Tim exclaimed, "God bless us,

No one is useless in this world who lightens the burdens of another

on our website and printed on page 19.

CCA is an association, and we are pleased to report that the numerous families connected with and being served by CCA are also those serving. Many families and friends of affected individuals reach beyond their comfort

everyone!" We wish everyone all the best this holiday and I leave you with another Dickens quote: "No one is useless in this world who lightens the burdens of another."

Jill Gorecki
Development Director

helping raise funds

As you can see from the "fundraising news" article on pages 6-7, there is no limit to the many ways our families and friends can help raise funds for CCA. On this page we have listed several ideas for fundraising. Please take a look and see if there's something you think is a good fit for you and let us know if you would like more information.

If you develop an idea that's easy to duplicate, please share it with us and we'll pass it along here.

- **www.goodsearch.com**

Enter Children's Craniofacial Association (only have to do this the first time) as your beneficiary charity and CCA will receive up to a penny each time.

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

- **Matching Gifts** Many companies offer a matching gift program, and will match your gifts, the gift of a spouse or retired employee. This could double or even triple your gift to Children's Craniofacial Association! For a matching gift form or

more information, please contact your Human Resources office.

- **Year-End Giving** There's a 2006 tax savings if you give prior to December 31st. This includes a donation by credit card that won't come due until your January bill!
- **Planned Giving** Tax preparation time is also a good time to consider long-term tax savings. It pays to plan in advance. When you consult an attorney or investment professional regarding your wishes for distribution of your assets in your will, consider a provision for CCA.

Help enable the charity you have embraced to continue good works in your name. 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 Christmas and Chanukah gifts! T-shirts, mugs, caps and a holiday ornament are the perfect gift for everyone on your list. So shop now and shop often!
- **Clubs / Hobbies** Raise funds by doing your thing; 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 according to company preference, a special day or days for employees to make a designated donation (cash or check) to CCA in return for the privilege of wearing denim (blue jeans) to work. Usually \$1 to \$5 (depending on how often the event takes place...i.e. weekly \$1, monthly \$5) 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** Write a letter to raise funds for CCA. Draft a letter to family, friends and acquaintances; anyone who has met or encountered your affected family member (CCA has a sample letter if you wish). The letter should include: Children's Craniofacial Association (CCA), a request for funds, your name (signature) and if you are providing a return envelope, it should be addressed to CCA.

- **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 donate meals / coupons. This same idea could be used for a family week of entertainment or any variation getting movie rental businesses and theatres or other attractions to donate. Call for more information.

- **Collection Cans** Place CCA collection cans for contributions. Ask local businesses to place a can or box (provided by CCA) to collect donations or take a can around to collect donations. (children must be adult supervised)
- **Get On Board!** Participate in the events, raffles and funding efforts of CCA and our supporters. Read CCA Network newsletter cover to cover and learn more about what's happening. If there's a donor envelope you cannot use, pass it along to someone you know who may not have yet embraced a charity. When you are finished with your copy of our newsletter, pass it along or leave it in a waiting room to spread the news! (remove your address label)

children's craniofacial association's code for fundraising accountability

Children's Craniofacial Association (CCA) adheres to the following policies in its fundraising activities:

Donors' Rights

1. All donors are entitled to receive a charitable donations tax receipt.
2. Donors and prospective donors will never be subjected to coercion or undue pressure.
3. Donors will be encouraged to seek independent advice concerning any proposed gift that might significantly affect the donor's financial position, taxable income or relationship with other family members.
4. All reasonable efforts will be taken to honor any request by a donor to be excluded from lists that the charity uses or shares with other organizations.
5. All reasonable efforts will be taken to honor any request by a donor or prospective donor not to be contacted in future fundraising campaigns.
6. All reasonable efforts will be taken to honor any request by a donor not to be contacted at home by telephone or other technology; also, all reasonable efforts will be taken to honor requests from donors who are contacted by telephone to receive printed material concerning the charity.

7. Any confidential information from or about donors that is obtained by, or on behalf of, CCA shall not be disclosed without the express consent of the donor.
8. All fundraising appeals by, or on behalf of, CCA will disclose CCA's name, its status as a registered charity and the purpose for which funds are requested.
9. Donors and prospective donors are entitled to the following, on request and at no charge other than cost of reproduction and distribution:
 - CCA's most recent annual report and/or audited financial statements;
 - CCA's most recent Charity Information Return (T3010) as submitted to Revenue Canada, (except the confidential schedules);
 - A list of the names of the members of the CCA governing board;
 - A copy of this Model Code and information about the process for registering complaints about violations of it.
10. Donors and prospective donors are entitled to know, on request, whether the individual asking for funds is a volunteer or a paid fundraiser.

tie one on for cca

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

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

The first 100 CCA logo ties were produced to



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

Month" and some are still available.

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

www.vineyardvines.com

calendar of events

date	event	contact
December 7	"CHER" the Love 7-10 p.m. Tony's Wine Warehouse & Restaurant 2904 Oak Lawn Ave., Dallas, TX	tonyswinewarehouse.com 214.520.9463 ask for Mary or James
December 9	CCA Dallas Holiday Party Medical City Dallas, TX	ARees@CCAkids.com 214.570.9099 800.535.3643
December 16	Midwest Holiday Party The Brat Stop/Parkway Chateau, Wisconsin Room Kenosha, WI	JGorecki@CCAkids.com 800.535.3643
May 19	Fifth Annual Pete's Scramble for CCA Beacon Hill Golf Club Commerce Twp., MI	Dede@perceptiondesigns.com
June 28-July 1	17th Annual Cher's Family Retreat Salt Lake City, UT	ARees@CCAkids.com 214.570.9099 800.535.3643
August 25	Wendelyn's "Course of Dreams" Golf Challenge Country Club of Arkansas Maumelle, AR	wendelynyvonne@hotmail.com
October 13	Second Annual Friends of Jeremy Golf Event Willowcreek Golf Club Big Flats, NY	gdale@stny.rr.com www.friendsofjeremy.com

3 cheers for volunteers!

The Internet has become a vital vehicle for delivering CCA's programs and services to families affected by craniofacial differences. Many charities employ full-time IT staff. Others designate a large chunk of their annual budgets to contracting webmasters. Children's Craniofacial Association prides itself on providing a professional, informative, interesting and easy-to-navigate website.

CCA is able to maintain CCAKids.org without a huge expense. We can do it thanks to the generosity of **Directed Technologies, Inc.** (www.directed-tech.com). **Fred and Rose Seitz** have donated their company's services since 2000. In addition to the website, **Steve Dunch** from Directed Technologies also assists CCA with its computer maintenance issues.

Fred and Rose became involved with CCA after their 14-year-old son, **Freddie**, was born with Goldenhar syndrome. The

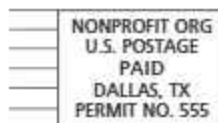
Seitz family lives in Poland, OH, and has two other sons: **Jonathan**, 10, and **Robbie**, five. Rose has also served as a member of CCA's board of directors since September 2004. She serves on the program committee and is the chairman of the national outreach (regional volunteer) committee.

Three cheers to Fred and Rose Seitz and Steve Dunch!



Steve Dunch, Rose Seitz and Fred Seitz

children's craniofacial association
13140 Coit Road, Suite 307 • Dallas, TX 75240



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Cher

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The views and opinions expressed
in this newsletter are not necessarily
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VOICE 214-570-9099

FAX 214-570-8811

TOLL-FREE 800-535-3643

URL CCAKids.com or CCAKids.org

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newsletter, please email your wishes to
KSilverman@CCAKids.com or mail the
label to the CCA office and ask that it
be removed from the mailing list.

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