ccanetwork

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

spring 2004

inside

2004 Retreat info

The 14th Annual Cher's Family Retreat will be in Tempe, AZ on June 24-27. For more information, see the article on page 7 or contact Jana Butera at 800-535-3643 or JButera@ccakids.com.

Freddie's group at 5th Grade Camp Fitch.

Freddie Seitz fits right in

by **Rose Seitz**

As a parent of a child born with a craniofacial difference, I have many concerns, ranging from health issues to socialization. My son also faced another challenge — hearing loss. He is profoundly deaf and uses sign language as his means of communication. I have spent many hours trying to determine the best way to help my son with all of the roadblocks I knew he would encounter.

What I have learned is that every child is different. There is no roadmap. There is no one else out there that can tell us what we need to do. We have to walk this road ourselves and figure it out along the way. Certainly we need to educate ourselves, listen to others who have been there and pick up bits and pieces along the way, but it is up to us to determine how to apply what we learn.

We made sure our son was always involved in extracurricular activities within his home school district, even though he attended school outside of our school district. We knew he was going to attend school within his home

see **freddie,** page 8

making a difference

One of the many great things about CCA is the relationships it often engenders. The headquarters may be in Dallas, but the support and spirit of the organization really exists within the communities of families and supporters that CCA creates. We have great examples coming in the next months.

Now is the time to register for our annual Cher's Family Retreat. This is a wonderful opportunity to meet other families in a supportive environment. And as any Retreat regular will tell you, it's also a time when the kids have a lot of fun. Check this issue of the newsletter for details and registration information.

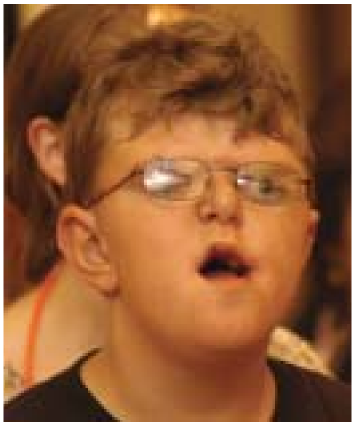
CCA is now being supported by a great group of kids who have formed a

see **chair,** page 14

Justin (right) with sister, Jessica (left) and Mom, Liz (middle), at the 2003 family retreat in Washington, DC.

meet justin prince

If you're looking for 11-year-old **Justin Prince,** chances are you'll find him outside playing sports. This fifth grader from Cheshire, CT, loves to play baseball and football. He's a big fan of the New York Yankees, Dallas Cowboys and Houston Rockets' Yao Ming. He's also got an impressive collection of baseball cards.



When he's not outdoors, Justin plays Nintendo and computer games and likes watching the TV show, "The Simpsons." As for movies, "Cheaper by the Dozen" is one of his favorites, but he admits he only sees movies "on a rainy day."

His favorite subject in school is social studies; he knows all the state capitals. Math and language arts are his least favorite subjects.

Justin also has some big plans for this summer — he's going to the 14th Annual Cher's Family Retreat in Tempe. He went to the retreat last year in Washington, DC, where he enjoyed seeing the sights and had fun at the pool party. He also met his good friend, Zach Muller. (Check out the article on Zach in the Winter 2004 issue of *CCA Network*.)

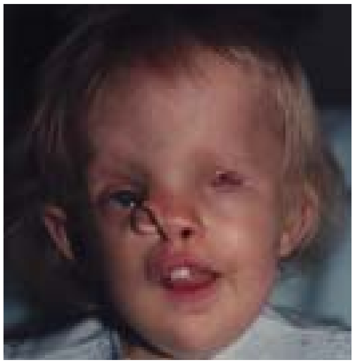
Justin was born with Apert Syndrome and has had 14 surgeries so far, with many more to go. He's got a positive, never-say-never attitude about it, though, which shines through in everything he does.

ccakid

ccateen

genevieve delong

m My name is Genevieve DeLong. I'm 16 years old and live in Florida. I was born with Amniotic Band Syndrome, which affected my facial features.



When I was born I didn't have bone over my right eye and my left eye didn't fully develop, leaving me with low vision and very little peripheral vision. Also, one of my nostrils wasn't developed fully and my jaw was crooked.

I've had nine reconstructive surgeries that have helped correct some of the maxillofacial and cranial problems. I've had three other surgeries in an attempt to correct my lack of a sense of smell. Most all my surgeries have been done at Medical City Hospital in Dallas, TX, where I feel safest about the care I'm receiving.

As for school, I'm a very good student. I've received a lot of awards for my grades and a first-place award in a writing expository. I received an award for best behavior and another for getting along with others. And in P.E., I received a gold medal for a track and field event.

I like to read and watch TV shows — "ER" is my favorite. The reason why I like the show is because I can relate to some of what the patients have to go through. And I like the dramatic storylines.

I also enjoy going to the mall with my family. Sometimes when I go people look at me, and I think of what they could be saying. For example, they might say, "Yuck, what happened to her?" I have to keep saying to myself, "Don't worry about it. Don't pay attention to them. There are other people out here that don't think that way."

I found out about Cher's Family Retreats, and my family and I are going to go to this year's retreat in Tempe. I'm hoping to make new friends and maybe even meet Cher in person.

Sometimes I get mad at the fact I don't have friends around the block to hang around with. My cousins come visit, though, and I hang with them and go to the mall. One of them in particular helps me out by giving me tips on how to deal with things that are troubling me.

Some kids make fun of me, but I don't let it bother me much. Sometimes I know how to deal with the problems I have, and, then again, sometimes I can't figure it out and need some help. Over the years I have met incredible people, friends and family, who have helped me and are there for me whenever I need them.

Most of all, I believe all of the things that I go through are just obstacles that can be moved out of the way or dealt with in some way. In other words, it may be in my way today — but it won't be in my way for long.

fibrous dysplasia

by Hrayr Shahinian, MD; and Milena Ocon, B.S.

What is fibrous dysplasia?

Fibrous dysplasia is a congenital, non-hereditary, progressive skeletal disorder by which normal bone is replaced by a variable amount of structurally weak fibrous and osseous tissue. It is characterized by the presence of woven bone. In normal bone formation, woven bone appears first and later matures into lamellar bone. Under concentrated light, lamellar bone trabeculae (rows of cells bridging an intercellular space) show widely spaced parallel birefringent lines, which are rimmed with osteoblasts and osteoclasts. In fibrous dysplasia, where bone development ceases in the woven bone stage, the trabeculae show random irregular birefringence and are surrounded by abundant fibrous tissue.

Monostotic disease is the most common type of fibrous dysplasia, occurring in 70% of cases and most frequently on the long bones — femur, ribs and skull. Polyostotic disease, afflicting 30% of patients, occurs in two or more bones and involves the head and neck 50% of the time. The third type, McCune-Albright syndrome, occurs in 3% of cases and is characterized by polyostotic fibrous dysplasia, skin pigmentation and precocious puberty in females.

Skull involvement occurs in 27% of monostotic and up to 50% of polyostotic patients. "Leontiasis ossea" is the specific name for fibrous dysplasia involving the facial and cranial bones. In its common form, one or more bones progressively increase, encroaching on the cavities of the orbit, mouth, the nose and its sinuses. Abnormal protrusion of the eyeball (exophthalmos) may develop and eventually cause complete loss of sight because of compression of the optic nerve. There may also be interference of the nasal passage and with eating.

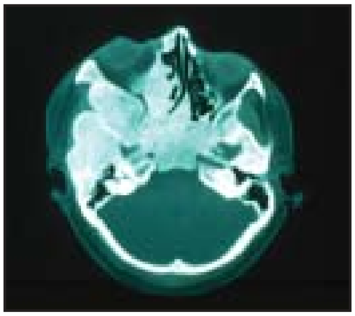
Fibrous dysplasia is a progressive disease, which typically occurs early in childhood and continues until skeletal growth ceases. It is first detected in young children, manifesting as a swelling of the jaw and a possible separation of teeth. It causes deformity and impingement, and if occurring in the frontal and sphenoid bones, it can eventually lead to deformation of facial features and skull shape.

Fibrous dysplasia of the skull base

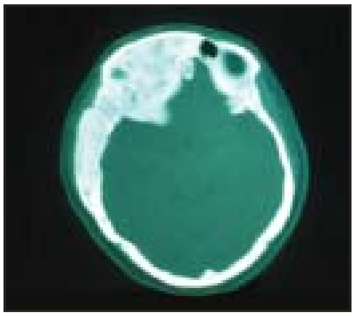
Fibrous dysplasia of the frontal and sphenoid bones eventually leads to distortion of facial features and skull shape as a result of the proliferation of thick, dense bone. Craniofacial fibrous dysplasia is different in that it ignores suture lines; more than one bone is usually involved. It can also result in cranial nerve impingement. Disease of the temporal bone may present a patient with 80% hearing loss because the inner ear canal narrows. It may also cause facial nerve (VII) paralysis or vertigo. Although any of our 12 cranial nerves and their cranial foramina can be involved with fibrous dysplasia, resulting in cranial nerve deficits, visual and hearing loss represent the more common and debilitating clinical presentations.

How does fibrous dysplasia present in radiographic appearance?

The radiologic appearance of fibrous dysplasia can appear as a lucent area with a sclerotic rim. In the skull base and facial bones, fibrous dysplasia manifests as marked sclerosis and bone thickening.



[Slide 1]



[Slide 2]

Treatment

It is estimated that patients with fibrous dysplasia are 400 times more likely than the general population to develop a malignant bone tumor. Therefore radiation is not recommended. Treatment involves management through observation first, then conservative measures such as surgical excision and shaving. A more curable treatment is by complete bone resection.

Surgical intervention is generally intended for cosmetic facial deformities and cranial nerve compressions. The abnormal bone must be completely removed. Surgery is usually delayed until adolescence; however, if the progression of the disease comprises

see **dysplasia,** page 5

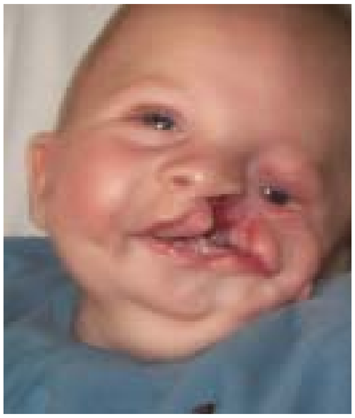
jeremy's story

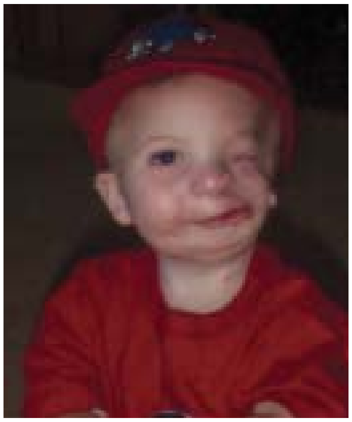
by George and Kristine Dale

Our son, Jeremy, was born on September 12, 1999. Like typical parents, we were very excited about the birth of our first child and were confident that the most perfect little baby would be coming soon. Our perfect little baby arrived seven weeks early and unbeknownst to us was born with a severe facial abnormality. Jeremy weighed 3 pounds and 10 ounces and was 16" long. He was diagnosed with Goldenhar Syndrome, which for Jeremy meant a large left facial cleft; extreme cleft palate; the absence of a left ear; an underdeveloped left eye and two hemi-vertebrae located in the middle of his spine and at the top of his spine, which caused congenital scoliosis. Jeremy was immediately admitted to the NICU and stayed there for almost six weeks.

Jeremy was a month old when he had his first surgery, a Nissen fundoplication and gastrostomy. The Nissen was done to prevent reflux, and the G-tube was placed so Jeremy could eat.


Jeremy right after being discharged from the hospital – 2 months old


Jeremy right before his facial cleft repair


Jeremy with his facial cleft closed

The first of many facial surgeries occurred in February 2000. Jeremy was five months old, and we were very excited and at the same time apprehensive. Although we knew that this was a major step toward his facial repair, we were sad that the face we loved looking at everyday was about to drastically change. The plan for the surgery was to place a rib graft in Jeremy's left cheek and to close the skin of the facial cleft.

Four hours into the eight-hour surgery, the team of doctors came into the waiting room to inform us that they had to abort the surgery because of complications. Jeremy's heart stopped beating, and they had to resuscitate him in the operating room. They said that he was okay and that no permanent damage was done.

We were numb and felt so sad and angry and could not believe that Jeremy had a life full of surgeries ahead of him.

Two weeks later, Jeremy was back in the operating room, and the doctors were able to complete the facial cleft repair surgery. It was so amazing to see Jeremy after the surgery. The hole in his face had been closed, and he had a cheek and the cutest little lips!

Jeremy's first year flew by and we were so grateful for our perfect little baby who was growing up so fast.

Jeremy had just turned one when he started having reflux problems again. The doctors had determined that the Nissen that was done a year ago had herniated into his chest, so they needed to repeat the surgery. In January 2001, Jeremy had his second Nissen fundoplication. Little did we know how surgery-packed 2001 would be for him.

In March 2001, Jeremy had his palate closure surgery. The palate was closed with the help of a pharyngeal flap. The surgery went very well, but Jeremy ended up having a difficult recovery. After we were discharged from the hospital, Jeremy got very sick and ended up dehydrated. Exactly three weeks after the palate surgery, he began having breathing problems while he was

see **jeremy,** page 6

---

dysplasia, from page 4

neurological function, a decompressive procedure should be considered early in childhood to preserve normal function.

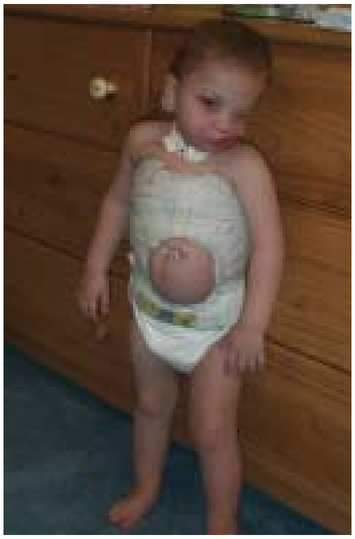
Fibrous dysplasia is a non-hereditary, progressive and benign disease, in which treatment options are symptomatic. Some lesions are amenable to resection for a cure by a single procedure. More often, most lesions can be managed through staged procedures with overall very favorable outcomes and good long-term prognosis.

jeremy, from page 5

sleeping, so he was admitted to the hospital again.

On his second night there he stopped breathing. It took the PICU team and a variety of other physicians to stabilize Jeremy and get him intubated. The palate closure and pharyngeal flap, in combination with Jeremy's other facial abnormalities, had restricted Jeremy's airway, and the stress was causing the airway to become obstructed. Jeremy needed a tracheostomy tube to help him breathe.

After Jeremy's palate surgery we felt like we had taken a huge step forward, now it seemed like we were taking three giant leaps backwards. The tracheostomy tube was overwhelming to deal with at first because of the dangers and added equipment and supplies. But like everything else, we did what we could to learn as much as we could, and we took everything day by day.



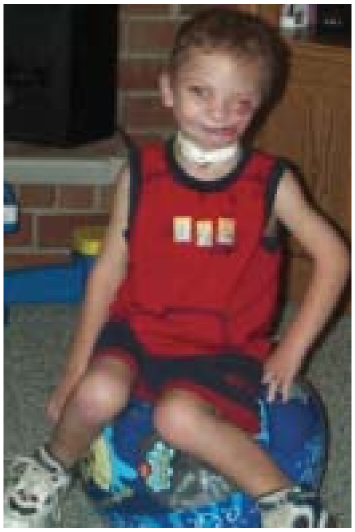
Jeremy in his body cast

A few months later we realized that Jeremy needing the tracheostomy tube was a true blessing in disguise. Jeremy was breathing better than he ever had since he was born. He was getting much better sleep and was growing and developing faster.

Every six months, from the time Jeremy was born, Jeremy needed an X-ray of his spine to check to see if his congenital scoliosis was progressing. The summer after his tracheotomy, it was determined that Jeremy was going to need surgery to correct the scoliosis. That fall, Jeremy had a spinal fusion — the doctors removed the hemivertebrae in his spine and fused his spine together. The surgery was 10 hours long, and there was a 10% chance of paralysis. Fortunately, the surgery was a huge success and Jeremy was wiggling his toes as soon as he woke up! The unfortunate part was that he was in a body cast for 4 months (127 days to be exact) after the surgery. The cast did not stop Jeremy. He was running around within a couple of weeks!

We had a little bit of a break after the back surgery, which was good because Jeremy was about to become a big brother. Jeremy's brother, Tommy, was born in April 2002 without any complications.

That summer, Jeremy was scheduled for a bronchial scope. The doctors decided that it would be a good time to divide his pharyngeal flap. The goal was to open up Jeremy's airway a little bit. While the doctors were doing the procedure, they removed his tonsils. This was a quick surgery and recovery for Jeremy, and one with a lot of benefits. A few weeks after the surgery, Jeremy was able to start passing air and was able to make noises. It was so nice to hear Jeremy's voice. It had been over a year!



Jeremy at 4 years old

After his tonsillectomy, Jeremy had a full surgery-free year, and it was wonderful! During that time he was a great big brother and he was learning and developing so fast. Even though he was able to make noises, he still could not speak, so he was learning sign language and picking it up very quickly!

The surgery break came to an end, and Jeremy was scheduled for a major surgery in August 2003. Now that Jeremy was almost four years old, the doctors felt it was time to continue with the facial repair. We were excited and apprehensive about the surgery because we knew that Jeremy's face was about to change. During the surgery, which lasted more than 10 hours, the doctors took bone from Jeremy's skull and used it to build the bone around and under his left eye and in his cheek. He had an incision from one ear, across the top of his head and over to where his left ear would be.

Again, this surgery was a huge success and we were so excited to see the results a couple of days later when the bandages were removed! The upper left portion of Jeremy's face was almost the same size as his right. It was unbelievable what the doctors had accomplished.

It felt like Jeremy had just recovered from surgery when we were headed back again. This time it was for a costo chondral graft in his left mandible. In January 2004, the doctors took one of Jeremy's ribs and grafted it

see **jeremy,** page 7

jeremy, from page 6

in his lower left jaw. The surgery was a success medically, but it was a hard one emotionally for Jeremy. He was very uncomfortable, sad and angry. It usually takes Jeremy little to no time to bounce back to his normal self, but this time it took a little bit longer. He was at an age where he didn't fully understand, but he knew he didn't like it!

Six weeks later, we were headed back to the operating room. This time it was an outpatient surgery. The doctors needed to remove the arch bars that were put in during the last surgery and to make a minor adjustment to the left side of his nose. During the surgery Jeremy also had his teeth cleaned and the doctors did a bronchial scope to examine his airway. Unfortunately, his upper airway still showed a lot of obstruction, so Jeremy will need his trach for a while longer.

Jeremy and his little brother, Tommy

Four years and 11 surgeries later, Jeremy has come a long way! It's amazing how quickly he recovers from surgeries and procedures. He has had wonderful doctors and therapists along the way and we are extremely optimistic about what the future holds for Jeremy. We are hoping that the day will come soon when the trach can be removed. Jeremy has many years of surgeries ahead of him, including continuing facial repairs and an ear reconstruction. Eventually, Jeremy will also need a prosthetic in his left eye.

Despite all of the medical needs, Jeremy is a typical kid who loves to play music and watch the "Wiggles" with his brother. He attends pre-school and is learning and communicating with sign language. Jeremy has a wonderful personality and has a lot of friends at school.

We are always so proud of him. We've all had our struggles with the looks, stares and comments of those people who don't understand, but we handle each one as they come, and we try to explain about Jeremy and educate as many people as we can. To those who know and love Jeremy, he is still that perfect little baby boy that was born four years ago.

klubhousekids

After a month of public awareness projects and raffle ticket sales, the KlubHouseKids from around the country participated in the KidsHelpingKids project. They educated children and adults and raised **$3,569.10** for CCA. **Jody Henry** of **Don Dillon Associates** of Dallas drew the winning ticket for the trip for four to Disney World, in Orlando. And the winner is… **Fred Freeman** of Tucson!

Congratulations to Fred and thanks to all of the kids and adults who helped spread awareness of children with facial differences and for raising funds for CCA's programs and services.

attention cca kids and sibs

Put your artistic talents to work and create a picture for us to display at the retreat. Send them to us or bring them along with you. Even if you are not attending the retreat, your work will be displayed.

You can use pencil, crayon, paint or any flat-piece media to create an original work of your own art. (No photos or copies, please.)

A dozen or so will be chosen for use in holiday items (like a CCA calendar) to sell on our Web site next winter!

So have fun and get creative!

annual family retreat update

The 2004 Cher's Family Retreat will be held June 24–27, 2004, in Tempe, AZ. The retreat is for kids with craniofacial differences and their immediate families only.

Activities will begin on Thursday evening with the annual ice cream party, and the dinner/dance will be held as usual on Saturday evening. We'll have planned outings that will include activities with a local flavor. And since we'll be in a state with beautiful sunshine, and a hotel with a beautiful pool, we'll have our pool party on Friday afternoon!

We hope you can join us. Please call CCA Program Director Jana Butera at 800-535-3643 or email her at jbutera@CCAKids.com for a registration form. We are looking forward to seeing all of our 2004 attendees!

freddie, from page 1

school district soon, and the children in our hometown needed to know about him and be educated about children with differences. Early on there were lots of questions, but as the years passed, the questions were fewer and we found that others were answering the questions for us.

I have had the pleasure of hearing children tell other children, "That's Freddie, he was born like that and has lots of surgeries. He likes cars, too. Let's play!" If I can stress anything it would be to get a child with a difference out there, doing what all of the other kids do. Soon you will find that people start to see past the differences and see the similarities.

Recently, my son went to our home school district for fifth grade. He had never attended school in our district past preschool, and the school district had never had a deaf child enrolled who used sign language. I would like to share with you a recent excerpt from an article in our community newsletter. *(See "An Exceptional Group of People at McKinley Elementary" on this same page.)*

more about freddie seitz…

an exceptional group of people at mckinley elementary

(L-R) Seated – **Nancy Moon, Pamela Yost, Irene Tunanidas, Freddie Seitz;** Standing: **Kelly Kerr, Ed Kempers, Fred Seitz, Rose Seitz**

Allow us to introduce you to an extraordinary 11-year-old and the special people at McKinley School who enable him to learn in the Poland Schools while he inspires all those around him, students and teachers alike.

Freddie Seitz is the young man. Fred and Rose are his parents. Freddie has craniofacial conditions and, according to Mrs. Seitz, also began to lose his hearing when he was about a year old.

Freddie began his education at St. Paul's Preschool when he was three. He moved on to Columbiana County for kindergarten, outside his home school district, where he remained through fourth grade. "They had a hearing impaired unit there with a special-ed teacher who was geared for hearing impaired children and interpreters were also provided," explained Mrs. Seitz. "We were hoping Freddie would get all his basic skills there, and it was always our desire to bring him back into the Poland school district, his home school district." Mrs. Seitz said that she actually had Freddie signed up for Columbiana's middle school but two weeks before the end of school last year Freddie asked her if he could go to the Poland schools. "I said, 'How about if we visit first? Let's not make any decisions until we visit,'" She related. "I was actually scared to death."

Ed Kempers, the principal of McKinley Elementary School, was informed that the Seitzes would be visiting. "While we were taking a tour of the building, Freddie asked, through sign language with his mom, very typical questions that any student would want to know," said Mr. Kempers. "When we went outside to look at the playground, he asked if he would be allowed to play football. The answer was 'No.' I remember, while we were walking through the halls, asking myself if there was any reason why this child should not go here. He's an intelligent boy and he's a nice boy. So that's where it all started." Freddie, of course, was thrilled with the visit and when asked if he wanted to come to McKinley, responded enthusiastically.

During the summer, Mr. Kempers, Sue Sause, the new director of special services and the Seitzes met to determine exactly what services they would need to make Freddie's school experience successful. "The team we put together is really unbelievable," Mr. Kempers enthused. "One of the first

see **mckinley,** page 9

mckinley, from page 8

people we needed was an interpreter. We found Kelly Kerr at the Youngstown Hearing and Speech Center and she's outstanding. She's here most of the day with Freddie," Mr. Kempers said. "Irene Tunanidas, known as "Miss Irene," is a retired teacher from the Youngstown City Schools and is also deaf herself. She works about three hours a day with Freddie, giving him extra help in some areas. Without her, this couldn't take place. She is one of the hardest working people I've ever met in my life."

Nancy Moon teaches Freddie science and social studies. "Freddie sits in the front and Kelly interprets everything that happens," Mrs. Moon said. "He's wonderful to have in class." Pamela Yost teaches Freddie math. I'm very fortunate because I have his strongest area. He's very strong in math. He works very, very hard and is probably one of my best role models as far as when other kids are struggling with a concept, they see Freddie not quitting so they don't quit either," Mrs. Yost said. "I think the children we have in class have learned more from Freddie than we have ever taught Freddie," she added. "I honestly believe that. They want to be involved. They want to learn how to sign to him. We've had so many kids sign up to be a part of an interpretive sign language class, I don't see how Kelly is going to do it all."

"For them to be exposed to somebody that they otherwise wouldn't be, and to learn about them, and to discover that he's basically just like them, and to get past the barriers of the differences and to see the similarities has been a marvelous experience for the children. It totally cuts out whining, too!" added Mrs. Moon. "Fifth grade is such a big jump from fourth grade and students sometimes feel that they can't do the work, but when they see Freddie succeeding they know they can, too."

By signing with his mother, Freddie said that McKinley is better than his other school because it's in his hometown and is easy to get to. "Mrs. Moon's class is my favorite and I have six friends who I spend time with. Football is my favorite sport, and I like riding my dirt bike in my back yard," he said. Freddie's dad said Freddie also entered the All American Soap Box Derby, the first deaf child in our area to do so.

"Our teachers have been wonderful," said Mr. Kempers. "Freddie is a bright boy and he doesn't need a lot of modifications or accommodations. He's very well liked and he likes being here. It's been a pleasure having him."

"I think Freddie, more than at any other time in his life, feels that he's accepted and that he's a real part of the class. I think that's a real tribute to the principal and the teachers," said Mrs. Seitz.

"He just totally fits in," added Mrs. Yost.

Freddie (right) with his younger brother, Jonathan.

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 Jana Butera at 800-535-3643 or email jbutera@ccakids.com

Programs we offer

- Toll-free hotline
- Doctor referral
- Information and support
- Educational booklets
- Financial assistance
- CCA newsletter, *CCA Network*
- www.ccakids.com Web site
- Annual Cher's Family Retreats
- Public awareness

cleft palate foundation annual conference

by **Deb Oliver**

As time marches on and the many phases of patient care present themselves, we find that each offers new challenges, both medically and socially. Families across the country often note one of the most important things they can do throughout the cycle of care and beyond is seek support — not only from their craniofacial team and other experts, but also from other families facing those same challenges.

One such opportunity for education and family networking came in March at the Cleft Palate Foundation's Connections Conference. The annual event, which this year convened in Chicago, brings parents, professionals, and teens and adults with clefts and other facial differences together to share experiences, address concerns and gain valuable information from medical professionals on a variety of topics.

This year's focus was on the psychosocial issues individuals and families face — education, social mainstreaming and the fine art of communication.

Georgette Couvall and Diane Nadelhoffer (both from IL) met for the first time at the CPF Wine and Cheese Reception Friday night.

Lynn Richman, PhD., keynote speaker and professor and director of the Division of Pediatric Psychology at the University of Iowa College of Medicine, presented the results of many years of research, offering statistics on retention rates of school-age children with facial differences. Oftentimes a child who is being held back is quite intelligent, even above-average intelligence. However, misconceptions an educator may have about a child with a facial difference (e.g., appearance versus intelligence) or even dysnomia (a language processing dysfunction making it difficult for an individual to name people and objects in rapid succession, even though they are recognized) may be contributing factors in evaluating the academic successes of these students.

Dr. Richman also stressed the importance of teaching our children coping skills, pointing out that different is not always negative. It is important to recognize that difficulties in social situations may actually have nothing to do with our child's facial difference. We all have a physiological make-up that pre-disposes us to being an internalizer or an externalizer. A child perceived as depressed or shy may actually be a reflective thinker and just quiet by nature. A child perceived as aggressive or acting out may actually be a leader who is maturing socially more quickly than his school-age counterparts.

Learning to process tone of voice, interpret facial expressions and read body language all assist us in understanding the multiple meanings of speech and social interaction. Recommended reading included *The Unwritten Rules of Friendship: Simple Strategies to Help Your Child Make Friends*, by Natalie Madorsky Elman and Eileen Kennedy-Moore.

Then conference-goers split into two groups, with some attending the Blessings in Disguise panel presentation, featuring individuals of all ages born with facial differences who shared their experiences and insights. Jared House, age 11 from Ohio, spoke to the group about his own experiences growing up with a cleft lip and palate. "Doctors can tell you the technical information, but families get to the heart of it all… the human side," his mother Melissa noted. She is very proud of him and knows that by sharing his story, her son will be helping parents understand what their children are going through.

Some attendees joined several hundred doctors and other professionals for the ACPA Advocacy Forum. A panel of medical professionals shared their experiences with reimbursement and billing problems as well as how medical professionals and families can work toward passage of health mandates such as the Treatment of Children's Deformities Act and the Reconstructive Surgery Act.

see **cleft palate,** page 11

Lynne and Mark Riley of Illinois and Gerald Degerstedt of Wisconsin.

cleft palate, from page 10

Afternoon breakout sessions divided the 120 participants into small groups to discuss the psychosocial issues and challenges at different life stages. Dr. Margot Stein, PhD., facilitated the discussion with an extremely large group of parents of pre-school and school-age children, while Kathy Kapp-Simon, PhD., led the dialogue for teen participants and their parents. Betsy Wilson, Executive Director of Let's Face It (www.faceit.org), who acquired her facial difference after battling cancer and losing a portion of her face and jaw to the disease, spoke with adults about birth and acquired anomalies and the issues they face in the workplace and in public life.

Additional roundtables were held on genetics, insurance and legislative issues and starting and maintaining support networks. The afternoon ended with a physician Q&A session. Several professionals from varied disciplines answered questions from parents and adult patients, with topics ranging from surgical procedures to an explanation of velopharyngeal insufficiency to pediatric dentistry and speech/language pathology.

Kristi Canul of Munster, Indiana, said, "I heard about the conference through the Family-to-Family Connection," referring to the on-line support network sponsored by cleftAdvocate (www.cleftadvocate.org).

"The conference was an absolutely amazing opportunity," she reflected. "I was able to meet other parents from all over the country who have either gone through or are now going through exactly what we are experiencing." Kristi's son Christopher sees the cleft/craniofacial team at Children's Memorial Hospital in Chicago and receives speech therapy on a weekly basis. In addition to speech and surgical intervention, Kristi recognizes there are other issues that need to be addressed.

"I was truly inspired by the young children, teenagers, and adults in attendance who were born with clefts and other craniofacial anomalies. They so bravely shared their personal insights and stories for our benefit. I now feel so much more prepared as a parent in order to help him reach his full potential."

In addition to Saturday's event, cleftAdvocate hosted the Pathfinder Outreach Workshop on Sunday at Shriner's Hospital in Chicago. The Pathfinder Program is a national network of families and individuals offering support and resources on a variety of fronts: newborn outreach, education of professionals, one-to-one family support and more. The workshop covered basic outreach skills and offered materials to assist local Pathfinder coordinators in contacting local families, birthing hospitals, nursing schools, early intervention teams and more. While most Pathfinders are casual or occasional peer counselors, some have addressed speech/language pathology students, local counsels and teams, and are working diligently to educate the general public about cleft/craniofacial issues.

Also addressed were the roadblocks to outreach, from time constraints to the degree of willingness of families to seek assistance outside their own

Catie Myers of Missouri and Robin Gibson of Alaska after the Pathfinder Workshop on Sunday.

see **cleft palate,** page 12

cleft palate, from page 11


Jana Butera, CCA's director of programs… clowning around!

family support system or cleft/craniofacial team. Annette Woods of Amarillo, TX, said she attended to "…learn more about networking families of children with special health care needs here in our home town. We want to make sure other families know they are not alone."

Working with members and directors of all cleft and craniofacial organizations — including the Cleft Palate Foundation (www.cleftline.org), CCA (www.ccakids.org) and AboutFace USA (www.aboutfaceusa.org), just to name a few — the Pathfinder Program was designed to bridge the real and perceived gaps between families, medical professionals and service providers by providing access to resources as well as social opportunities to families across the nation. A live teleconference overview and training is conducted on the second Monday of every month. For more information on the Pathfinder Program, contact Debbie Oliver at 702-769-9264 or at debbie@cleftadvocate.org.

Many new friendships were sparked in Chicago, and many "family" reunions occurred as well between attendees of earlier Connections conferences. We all look forward to future educational and networking opportunities across the country and appreciate the hard work and dedication of so many who made the conference a reality.

financial assistance

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

cher convention 2004

If you are a fan of CCA's National Spokesperson, you won't want to miss the third biennial Cher Convention July 16 and 17, 2004 at the Riviera Hotel in Las Vegas. The Cher Convention originators Judy Didelot, Jody Cantwell and Kim Werdman, joined by Linda Alamprese, Brad Wright, Mike Werdman and Fred, Edna, Robyn and Marina Fisher, are planning an event-packed convention.

The fun begins on Friday evening, with a dinner that includes "A Tribute to Cher — Spanning Five Decades in Concert" and dancing into the wee hours! Saturday's events include live and silent auctions, karaoke contests and a variety of seminars led by Cher career experts.

The convention coordinators are a group of very dedicated volunteers who spend countless hours to raise funds for CCA programs and services.

Apart from the conventions, these ambitious volunteers also conduct Internet auctions and sell Cher fan merchandise through CherConvention.com. To date, the convention foundation has raised more than $60,000 for CCA kids!

To register for the convention, or for more information visit the website or email JodyCantwell@hotmail.com.

take charge for CCA

Now's a great time to get a VISA credit card from Schoolpop. For every purchase you make — whether or not it's a participating Schoolpop merchant — Schoolpop will make a 1% donation to CCA!

Four people have already racked up more than $200 for CCA — and that's just since January! Think of what can be done if families and friends used the Schoolpop VISA card for groceries and gas as well as for shopping at participating merchants. Visit www.schoolpop.com to sign up for your Schoolpop VISA credit card now!

save those cells!

Please save your old cell phones for CCA as well as empty laser disk and ink cartridges from your computer printers. CCA can turn them in for rebates! Send them to us or bring them along if you're coming to the family retreat. All families turning in rebate items will get extra door prize tickets for each item they turn in!

If you think you can fill a whole box, call us and we will send you a collection box, ready to go with the UPS shipping charge already covered. Thanks for participating!

another "giving" idea for all cca supporters, friends, family:

take five

If you weren't able to contribute during our Annual Campaign at 2003 year end because you were putting all your hard-earned dollars toward Christmas and taxes, why not "Take Five" now?

"Take Five" is contributing $5 monthly to CCA. You can donate almost painlessly using a monthly credit card deduction or just by saving your loose change in a jar each month. If you are not inclined to use a credit card, we've included a dozen coupons (on the back of this page) to help make it simple to contribute at the same time you write all those other checks each month.

When you commit to "Take Five," you help CCA fulfill its mission to empower and give hope to facially disfigured individuals and their families. Some of these children will endure 20 to 40 surgeries to restore their heads and faces, in many cases, just to function for speaking and eating. Perhaps you know one of our children. The incidence is much more common than you might think. Thankfully, the days of ignorance when these people were locked away or hidden in shame are gone. However, awareness is one of our most important endeavors. We envision a world where people are accepted for who they are, not how they look.

When all of us do this together, the funds will add up quickly. If just four people commit to this plan, we can send a craniofacial child to our family retreat. Eight people helps pay airfare for a parent and child to get to a qualified craniofacial center for consultation or surgery. Multiply that by ten (80 participants) and we can pay for our toll-free helpline for another year.

As a parent of a child with craniofacial differences, I am witness to the invaluable help CCA provides. Whether it's needing information about finding a qualified surgeon to help my child, being networked with another family whose child has been through the same type of procedure my child is about to endure, or meeting that family and experiencing the comfort of knowing we are not alone, CCA has been there for us over the years. Please understand the need for Children's Craniofacial Association to continue these programs for the many new families who reach out daily for help. This non-profit organization needs your help. I am here to tell you, you can make a difference.

Your commitment to give just $5 per month will make a huge impact for many. We will keep you posted, here in the newsletter, about the strides made and you will read about many of the children and families you are assisting. They will also read about you, as we list the participants of this campaign with respect and gratitude (with your permission).

When you join this campaign, you will receive a very special "thank you" from one of our CCA kids.

Warm regards,
Jill Gorecki, Robbie's mom

P.S. For those who like the idea but want to get it over and done sooner…

- Send three checks/charge three times for $20 each or six for $10 each.
- Consider a one-time or annual contribution of $60 to fulfill the commitment immediately!

Take Five – June 2004
Please accept my Contribution.
☐ My check is enclosed.
☐ Please charge my credit card: ☐ Visa ☐ MC

Credit Card Number

Expiration Date

Name on Card

Take Five – July 2004
Please accept my Contribution.
☐ My check is enclosed.
☐ Please charge my credit card: ☐ Visa ☐ MC

Credit Card Number

Expiration Date

Name on Card

Take Five – August 2004
Please accept my Contribution.
☐ My check is enclosed.
☐ Please charge my credit card: ☐ Visa ☐ MC

Credit Card Number

Expiration Date

Name on Card

Take Five – September 2004
Please accept my Contribution.
☐ My check is enclosed.
☐ Please charge my credit card: ☐ Visa ☐ MC

Credit Card Number

Expiration Date

Name on Card

Take Five – October 2004
Please accept my Contribution.
☐ My check is enclosed.
☐ Please charge my credit card: ☐ Visa ☐ MC

Credit Card Number

Expiration Date

Name on Card

Take Five – November 2004
Please accept my Contribution.
☐ My check is enclosed.
☐ Please charge my credit card: ☐ Visa ☐ MC

Credit Card Number

Expiration Date

Name on Card

Take Five – December 2004
Please accept my Contribution.
☐ My check is enclosed.
☐ Please charge my credit card: ☐ Visa ☐ MC

Credit Card Number

Expiration Date

Name on Card

Take Five – January 2005
Please accept my Contribution.
☐ My check is enclosed.
☐ Please charge my credit card: ☐ Visa ☐ MC

Credit Card Number

Expiration Date

Name on Card

Take Five – February 2005
Please accept my Contribution.
☐ My check is enclosed.
☐ Please charge my credit card: ☐ Visa ☐ MC

Credit Card Number

Expiration Date

Name on Card

Take Five – March 2005
Please accept my Contribution.
☐ My check is enclosed.
☐ Please charge my credit card: ☐ Visa ☐ MC

Credit Card Number

Expiration Date

Name on Card

Take Five – April 2005
Please accept my Contribution.
☐ My check is enclosed.
☐ Please charge my credit card: ☐ Visa ☐ MC

Credit Card Number

Expiration Date

Name on Card

Take Five – May 2005
Please accept my Contribution.
☐ My check is enclosed.
☐ Please charge my credit card: ☐ Visa ☐ MC

Credit Card Number

Expiration Date

Name on Card

chair, from page 1

group called KlubHouseKids. They held a fundraising raffle for CCA. The prize is a trip for four to Disney World in Orlando, FL. (See page 7 for the winner announcement.) A big thanks to everyone who helped to make this raffle a success.

And come on…deep down, who doesn't want to own a Harley? Each year, CCA sponsors a raffle for a brand new Harley Davidson motorcycle AUTOGRAPHED BY CHER! Call the CCA office and get your tickets to sell. You'll find it's fun, and family, friends, co-workers, and strangers will appreciate the chance to live out their biker dreams. The drawing is in August — so hurry!

This summer and fall there is also another very important way you can support the craniofacial patients. Incumbents and candidates for the U.S. House and Senate are out looking for votes. They are in town hall meetings, picnics and other gatherings of voters. Let them know that their support of HR 1499 is absolutely critical to our kids. This legislation is designed to end the unfair practice of insurance companies reclassifying needed reconstructive surgery as "cosmetic."

As always, thanks for your support. Hope you have a wonderful summer.

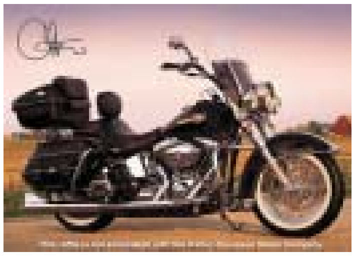
Best wishes,
Tim Ayers
CCA Board Chair

2004 harley raffle ticket sales underway

CCA's annual summer fundraiser — raffling off a new Harley autographed by national spokesperson, Cher — is on the roll.

A Lava Red Heritage Softail Classic® (including saddle bags) is this year's bike, and tickets are available once again.

Purchase tickets online at ccakids.com or from any CCA representative (1 for $5.00, 5 for $20 — 1 free, and 30 for $100 — 10 free!) Families, a "CCA representative" means you! Call or email for a stack of raffle tickets to sell. The family or friend of CCA selling the most tickets this year will win a scale replica Harley from Franklin Mint!



donors, october 2003 thru march 2004*

Gifts from Individuals

CCA Supporters
(up to $100)

Julie Adams
Karen L. Angell
Max Baer
Joseph & Marie Baniecki
Eugene Barbles
John & M. Kathryn Barrett
Mary Ann & Robert Beck
Alison Beeaker
William & Arlene Blumenthal
Richard & Joyce Bohannon
Mike Bosko
Karen & Phil Bova
Ann A. Byrd
Karen M. Calcote
Larry Carpenter
David & Virginia Carroll
Robin & Joey Chapurtinov
Beatrice W. Cooper
Barbara S. Chernetz
Nellie Arlene Coudare
Janice M. Damico
Greg & Tama Dierks
Louis & Donna Drouhard
M. L. Elrod
Richard P. Ferle
Angela & John Freeman
Victor Galvan
Valentina Garcia
Frank & Maryann Gilson
Donna & Ed Granados
Donald & Louise Gray
Maurice T. Gutzler
Kevin Eugene Haugh
Edwards Horwitz
Dale & Joan Jennerjohn
Paul & Patricia John
Jeffrey & Sherry Kaifesh
Marilyn Knueve
W. Mark & Karen Kram
Beverley Krolnik-Henry
Gregory Laney
Harley Lawrence
Diana Lesko
James M. Macaulay
Joan Maddock
Don Meier
Robert & Barbara Mellendorf
Drew J. Mills
James & Mary Jo Montalbano
Anthony & Marie Musumeci
Paul Niebruegge
Ann Patterson & Howard Langner
Greg Patterson
Doug & Anne Peterson
Bobbie E. Pogrow
Edward & Debra Quattrini
Connie Ripstra
Joseph & Marilyn Roche
Harold Roth
Murray & Shirley Rubinstein
Durward & Pat Schuetz
Cindy & Marc Seelye
Steven & Lisa Sharp
Michael Slusher
Claudia Smith
Melvin & Temmie Smith
Ronald & Deborah Smith
Andrea Stewart
Daniel & Carolyn Strack
Patricia & Harold Timmer
Dominic & Rebecca Ugolini
United Way Directed Donations
United Way of Fresno County
United Ways of New England
Margaret Upton
Robert Vargas
Barbara J. Wiedenman
Steve M. Yancy
Joseph & Beatrice Zabloudil
Randal K. & Pamela J. Zapp

CCA Friends
($100 +)

C. Barrett
Paul & Margaret Bordonaro
Jim & Beverly Butera
Joe W. Cherry
Harold & Gail Cohen
Elgin & Gwenith Corzine
Judy & David Didelot / Donation Can Contributions
Dion Flannery
Jill Gorecki
Renee Grasty
Reynold Gravina
Robert G. Haley
John & Arlene Heirty
Kathy J. Hubbard
William & Darlene Hunter
James & Kathryn Kemp
Roger & Carolyn Lamb
Jess Levya
James Lucas
Mary Lytle
Michael & Vita Montalbano
Patsy Ng
Steven L. Page
Marie Quaranta
Margaret Salvioli
Morton & Eunice Teitelbaum
Ronald & Myrna Zaccagnino

CCA Extended Family
($500 +)

Diana M. Critchlaw
United Way of Metropolitan Tarrant County Humanity Fund
Stephen Wright

CCA Sponsor
($1,000 +)

Roger S. Chin
John & Charlene Smith
Jeffrey A. Fearon, MD

CCA Benefactor
($5,000 +)

Anonymous
Cher
Lorettamarie Katsafouros bequest
Hazeldeane Pritchard bequest

Memorials / In-Honor Gifts

Max Baer
Jim & Beverly Butera
Larry Carpenter
John & Arlene Heirty
Kathy J. Hubbard
Dale & Joan Jennerjohn
Robert & Cathleen Johnston
James & Kathryn Kemp
Kathryn W. Kemp
Robyn E. Lapiana
Patsy Ng
John & Patricia Paul
Edward & Debra Quattrini
Patricia & Harold Timmer
Richard S. Ward Lumber Co.
Joseph & Beatrice Zabloudil
Randal K. & Pamela J. Zapp

Corporate / Foundation Gifts

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

Albertsons
Central Collections, Inc.
E.B. Sponseller, Inc.
Esther Krieger Foundation
Greenscapes Landscaping, Inc.
Hiznay & Associates
Jefferson Lumber & Millwork
Katie's Clothes Bin
Merrill Lynch & Co., Foundation
Prudential / Matching Employee Giving
SBC Employee Giving
Safeway, Inc.
Sarah Hall Productions Inc.
Schoolpop
The Frugal Flower

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

The Brotman Foundation
The Intuit Foundation
May Department Stores dba Foley's

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

Edmond & Alice Opler Foundation

The following are corporations donating a portion of the ticket proceeds for Cher's farewell tour since October, 2003.

Bill Graham Enterprises
Cellar Door Amphitheatre
Cellar Door Concerts of Florida
Cellar Door Productions of Michigan
Cellar Door North Central
Cellar Door Productions of Virginia
Charleston Civic Center
Chronicle Pavilion
Clear Channel Entertainment
Contemporary Group Acquisition Corp.
DLC Corporation
Denver Concert Promotions
Electric Factory Concerts
Evening Star Productions, Inc.
Journal Pavilion
Magic City Productions
New Avalon, Inc.
Oakdale Theatre Concerts, Inc.
Pace Concerts
Pace Music Group
Pavilion Partners
Peoria Civic Center
SFX/Core, Inc.
SFX Music Cleveland
SFX Target Center Arena
SMG Agent for Historic Boardwalk Hall, Op
Selma Amphitheatre, LLC
Sunshine Concerts
The Carolina Center
The Entertainment Group Fund
White River Amphitheatre

---

*Listed are monetary donations since last October. We are extremely grateful for these and all prior donations, raffle ticket purchases, fundraisers and in-kind donations not recorded here.

3cheers for volunteers!

Stephen has been a valuable asset to CCA and a shining example of what a child with a craniofacial condition can overcome. He's a successful, kind, happy, intelligent adult who gives hope and promise to young parents who have an affected child. Stephen is one of CCA's networkers who talks to parents all over the country.

This year he has been involved with the Annual Harley Raffle. During the past few months, Stephen has contacted hundreds of motorcycle-related websites across the country to get them to provide links to CCA's site. So, three cheers for super volunteer, Stephen Wright!

Here's a special message from Stephen:

Hello from San Francisco! My name is Stephen Wright, and I have Crouzon's Syndrome. My association with CCA goes back to 1989, when *Parade* magazine wrote about my Lefort III procedure (which basically means that I had my entire face reconstructed).

I work for Bank of America in downtown San Francisco's financial district, where I have been for almost seven years. I have also been busy getting my master's degree in business, which I completed in August 2003. Education has been my salvation in learning how to deal with life as a person faced with craniofacial issues.

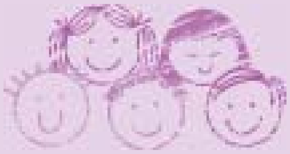
I have 23 nieces and nephews who keep me very busy as their uncle. Whenever I visit them around the country they invite their friends over to see me, and they tell them about all of my surgeries and how important it is to be kind to people who are different.

CCA has been very good to me throughout the years. The network of families and professionals has been very helpful when dealing with various medical and social issues. I look forward to the retreats, where I get to see friends I have had for 14 years now. Many of the children have grown up, and it's very inspiring to see how they have become so strong from persevering through the years.

Well, I look forward to seeing everyone in Tempe in June. — Stephen

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

NONPROFIT ORG
U.S. POSTAGE
PAID
DALLAS, TX
PERMIT NO. 555



VOICE 214-570-9099
FAX 214-570-8811
TOLL-FREE 800-535-3643
URL CCAkids.com

If you no longer wish to receive this newsletter, please email your wishes to JButera@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.