

ccanetwork



newsletter of the children's craniofacial association

Cher — honorary chairperson

winter 2005

inside

cca kid meeka rowat.	2
cca grad amanda critchlaw	3
fundraising families.	5
calendar of events	5
microtia	6-7
holiday parties	8-9
fnms family conference	10
cca programs	11
3 cheers	12



Lauren, Ruben, Tricia and Gavin Trevino

gavin's story

by Ruben and Tricia Trevino

Raising a special-needs child is filled with anxiety and frustration, but it also brings a lot of joy and gratification. My wife **Tricia**, our daughter **Lauren** and I had no idea what to expect March 18, 1999, the day **Gavin Trevino** was born.

After learning of Gavin's challenges, we quickly researched to find out what we were dealing with. We had not been told anything by doctors, so I searched online until I found something about **Goldenhar Syndrome**. After taking my findings to the doctors, they diagnosed that that is what Gavin was born with.

We spent the next few years going from one doctor to another to decide a course of action for Gavin. We found ourselves still not satisfied with the answers we were getting and continued to get second opinions. Most of the doctors advised us to wait until Gavin was older to address the concerns of his jaw and ankylosis. So we decided to

see **gavin**, page 4



message from the chairman

Many people believe there is no such thing as status quo for an organization. If you're not getting better — you're getting worse. CCA has gone through some significant changes over the past several years, and they have all been for the better. We're reaching more families, we're developing closer ties with healthcare providers, our fundraising has matured, our educational materials are more expansive and we're taking a more activist role in advocating for patients.

The structure of CCA is also changing in order to continue this momentum. Board members and staff have a strategic plan for

see **chair**, page 11

2005 Retreat Info

The 15th Annual Cher's Family Retreat will be at the Gaylord Opryland Hotel in Nashville, TN, on June 23-26. For more information, contact Jana Butera at 800-535-3643 or JButera@ccakids.com.

If you make your own reservations, please let them know that you are with Children's Craniofacial Association or use Group Code X-CCA05.

meet meeka rowat

Who's warming up Elkhart Lake, WI, this winter with her sunny disposition? **Meeka Rowat**, that's who. In a recent interview, the bubbly third grader filled us in with what's going on in her busy life.

For starters, Meeka just turned nine January 10. She and her family and friends, about 10 people total, celebrated with a birthday bowling party. Everyone had a great time, especially the birthday girl, who bowled "lots of strikes!"

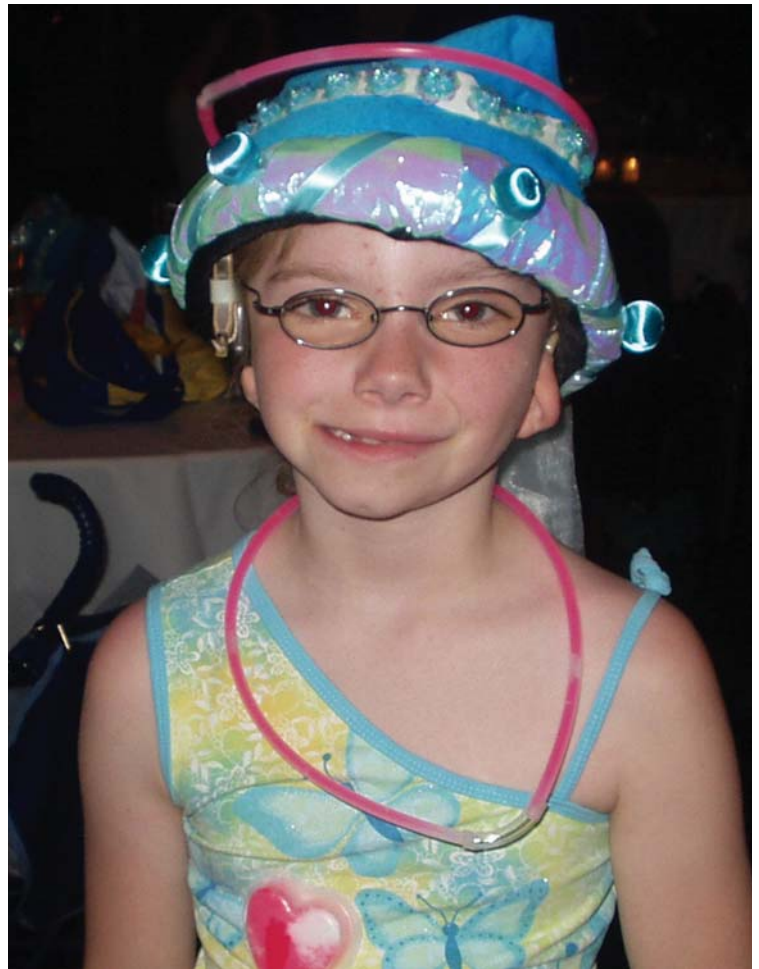
When it comes to school, Meeka's favorite subjects are art, music, writing, gym and "computers." Outside of school, she loves to draw and paint and likes to dance. She's also teaching herself to play the piano.

Meeka also attends hippo therapy classes every Tuesday, where she works with her horse, Zeus.

("Hippo" is actually the Greek word for "horse," and in hippo therapy, which is a type of physical therapy, the horses' movements help strengthen the patients' muscles and improve circulation. The one-on-one contact with the horse is emotionally therapeutic, too.) She's also taking dressage lessons, where she's learning riding techniques and how to care for Zeus.

When she's not busy with school or spending time with Zeus, Meeka takes care of her fish, Nemo, and kitten, President George, whom she claims is a "cutie."

Meeka and her family are relatively new to CCA. In fact, her first retreat was last summer in Tempe. She had a blast and made some good friends. Her favorite part was riding the camel in the desert just



Meeka Rowat at the 2004 Cher's Family Retreat in Tempe, AZ

outside Tempe. She also had a great time at the party on the last night. She and her family also participated in the CCA Midwest Holiday party in Kenosha.

And through CCA, Meeka had the opportunity to meet **Cher**. She went to one of her concerts and met her backstage before the show. Cher even had a picture of Meeka in her dressing room. At this concert, Meeka sat right in front of the microphone, close by the dancers. She had a great time at the show, and, of course, is now one of Cher's biggest fans. "It's

really nice that Cher helps families," she said.

Meeka has **Goldenhar Syndrome** and has had jaw surgery recently in Chicago at the Shriners Hospital. This will be her second surgery so far. She's doing well. Her advice to others going into surgery is "Don't worry or be scared, because everyone will take care of you."

She also has some great advice for questions curious people may have. She said, "Just answer the questions. When people stare, they just want to know 'why.'"

meet amanda critchlaw

my name is **Amanda Critchlaw**. I am 18 years old and live in Lake Hopatcong, NJ. When I was three years old I was diagnosed with **Crouzon's Syndrome**. Growing up was not always easy, but I had the help of my family and friends. My dad was my biggest help because he has Crouzon's Syndrome, too.

I've been teased and made fun of all through school. Luckily, I had an older brother and wonderful friends who were always there to stick up for me. When I was in fourth grade, my dad gave me advice I will never forget and still use today. He told me that when someone makes fun of you, to simply smile and say thank you. People never know how to respond. Most important, it shows them that they cannot hurt you.

I've also learned that you can't be mad at people for what they say; most of the time they don't know any better. When people ask me what is wrong with my eyes, I tell them about my disorder and surgeries.

I've had people tell me they will never make fun of another person again, some tell me I'm an amazing person and others ask me how I can still smile with all I

have been through. I tell them my disorder helped me grow to be a better person and also helped me decide what I want to be when I grow up.

Through my surgeries and hospital stays, I knew I wanted to be a nurse. Three years ago, after my last surgery, I had an amazing nurse who inspired me to be a pediatric ICU nurse. Currently, I attend Mount Saint Mary College, where I'm in their nursing program. I will graduate with my BSN, and then I plan to go for my Master's degree in pediatrics.

I want to be a nurse because I want to help children. I know how boring it is to be stuck in a hospital bed, but I also know how scary it can be. My nurse played games with me, got me McDonald's and also brought her own shampoo so I could wash my hair. I would like to be like her when I become a nurse and I only hope I can do as good a job making kids feel comfortable.

I have been involved with CCA since I was three. My family and I have been to every retreat except one. CCA has been an important influence in my life. I grew up knowing there were kids like me.



Amanda Critchlaw

I've made many lifelong friends, and every year I make a couple more. I've also met the most amazing kids at the retreats. They are also why I want to be a nurse. CCA has helped me greatly growing up. I know that without them, I would not be the person I am today.

My family, friends and everyone at CCA helped me realize that I can do anything. I have never let people bring me down or hold me back. Growing up I did many activities like dance, softball and basketball. In high school I was also a cheerleader.

I know I wouldn't have ever done any of these things had I not had so many positive influences in my life. I've learned that no matter what people say, it's my life and I want the most out of it.

I'd like to leave you with my favorite quote by **Mother Teresa**. These words have helped me through so much, and my hope is that they will help you, too. **"I know God wouldn't give me anything I can't handle, I just wish he didn't trust me so much."**

cca grad

gavin, from page 1

wait, since we did not have much else to go on.

In August 2002, Gavin was admitted to the hospital for a sleep study. Soon after the study had started, the technician knew immediately something was wrong. Gavin was rushed into emergency surgery to have a tracheostomy performed, as he was severely oxygen deprived. We had noticed a few months back that Gavin's breathing had changed while he was sleeping, he was easily agitated, and his growth and weight were below normal.

After the trach was put in, we had to adjust quickly as a family. It was not easy in the beginning, but now everything is second nature. Gavin has done extremely well with the trach. To our surprise, he has handled it very maturely.

Once Gavin had the trach in, we knew we would need to push the doctors more to have a solid plan of action. We had been traveling to Miami for consultations and decided at the suggestion of Gavin's ENT to visit Jacksonville to get another opinion. After meeting with the surgeon, we knew this was the guy for the job. He had recommended an aggressive plan, but most of all, we were confident in his abilities.

On August 8, 2003, we started the first stage of surgeries for Gavin. The plan was to release his jaw and put in distraction devices to help give Gavin the room he needed to allow his upper and lower jaws to move.

After six and a half hours, Gavin came through the surgery without any complications. The doctors were able to insert the devices, release Gavin's jaw and were able to build a new TMJ, which he was born without.

The coming months were filled with painful therapy sessions and doctor's appointments. Gavin's jaw was moved 22mm down and 25mm forward. He had more movement than we could have hoped for but still not enough to allow him to chew normally. Gavin can close his mouth but not open it.

faith, love and patience go a long way.

With the first step behind us we moved to our next objective — getting the trach out. While the surgeon was confident, the ENT was much more skeptical.

On August 2, 2004, Gavin went in for an exploratory procedure to determine whether the trach could be removed. If the findings during this procedure were positive, then the next step would have been another sleep

study with the trach capped to ensure that he didn't have any lingering issues.

About 30 minutes after putting him under the ENT called for us in the waiting room. We immediately knew that this wasn't the news we were hoping for. The ENT had found that Gavin still had areas of concern in the back of his mouth and throat and said that they needed to be addressed before we moved forward.

This was heartbreaking for us but nothing we couldn't get past. We immediately called the surgeon in Jacksonville and sent him the information from the ENT. We are currently working with the doctors on a new plan of action for Gavin this year.

He is an amazing little boy. While he can't play organized sports, we have worked with him on developing his baseball skills with hopes that he might one day be able to play. He has shocked many baseball fans like his Grandpa and Uncle Tom, who have underestimated his abilities because of his size. They all have walked away wondering how could

someone so small hit a ball so far? Some still have the marks to prove it.

We have learned much from Gavin over the past five years. Faith, love and patience go a long way. As a family, we want to share what we have learned by telling our story and offering advice. We would like to thank CCA for allowing us to share Gavin's story with you.



gavin's dad helps raise \$600 for cca

One might say Gavin's Dad, **Ruben Trevino**, made people dig deep into their "denims." Only a short time after recovering from Florida's 2004 hurricane season, the good folks at **Fiserv** in **Lake Mary, FL**, held a Denim Day, raising **\$600** for CCA! During a **Denim Day**, employees donate to dress down for a day, wearing jeans or casual dress not otherwise allowed under their company dress code. It's a great way to raise funds — and fun! Another great thing about the Denim Day held by Fiserv is the awareness it created. Ruben found a number of co-workers are also touched by craniofacial conditions through family or friends. Gavin and CCA have many friends in Florida. Thank you all!

more friends help raise funds for family

When we appeal for funds, we know it's a fact people like to give to a cause they can somehow relate to. For CCA it's most often folks who know our kids personally who support us. CCA families and friends are often our most ardent advocates.

Robert Muller, Zach's dad, has friends who donated through **Bonner's Pub** in **Bayonne, NJ**. Patrons and **Pete** and **Danny Bonner**, the pub's owners, together with **Tommy Straus**, owner of **Ultra Contracting** who matched funds, raised a **\$100** donation for CCA to help kids like Zach, who struggle with the challenges of craniofacial conditions.

A big THANK YOU to all who pitched in at the pub!

cut-a-thon – dallas

Salon D and CCA are teaming up for a cut-a-thon fundraiser on **Sunday, April 3, 2005**, in **Dallas, Texas**. Salon D's top stylists are opening their calendars from **12:00 to 6:00 p.m.** to give you, your family and your friends the amazing new hairstyle you've been waiting for!

Please join us for an afternoon of wine, hors d'oeuvres, fabulous door prizes and fresh, new styles. We are asking for a minimum donation of only \$25 per haircut, with those donations going to help CCA kids and families.

Salon D • 13615 Inwood Road, Suite 160 • Dallas, TX 75244
972.788.0975 • www.salond.com



"stryking" up a wonderful friendship

CCA in the USA sends a heartfelt thanks to **Stryker S.A.** in **Europe**.

We were contacted by **Suzi Williams**, HR Coordinator and Events Committee Member to confirm a donation of **CHF 3,260** (Swiss Francs – approximately **\$2,700** US dollars)!

The amount was raised as a result of a tombola (a lottery drawing) held at their Fire and Ice-themed Christmas Event on Friday, December 17, 2004. **CHF 1,630** was raised through ticket sales, and Stryker kindly agreed to match the employee contribution. Needless to say, we were surprised and thrilled with such a generous donation. It speaks to the fact that craniofacial conditions are known all over the world, and it's apparent that generous, caring folks are too! We are grateful CCA is able to communicate worldwide for help representing and advancing CCA's mission and vision. On behalf of all our children and families, "Thank you to the employees and management at Stryker!"

2005 calendar of events

date	event	web site
April 3	Cut-a-thon Dallas, TX (<i>see article at left</i>)	www.CCAKids.org
April 9	American Cleft Palate-Craniofacial Association — Connections (conference for families) Myrtle Beach, NC;	www.cleftline.org 800-24-CLEFT
June 23–26	Children's Craniofacial Association 15th Annual Cher's Family Retreat Nashville, TN	www.CCAKids.org
June 24–26	NOVA Family Conference Conference concerning hemangioma and vascular malformations Triangle Park, NC	www.novanews.org
July 17–19	North American Craniofacial Family Conference Las Vegas, NV	www.cleftadvocate.org

microtia

by Burt Brent, M.D.

Microtia varies from the complete absence of auricular (outer ear) tissues (anotia) to a somewhat normal but small ear with a narrowed canal. Between these extremes, one finds an endless variety of vestiges, the most common being a vertically-oriented sausage-shaped nubbin (figure 1). Microtia is nearly twice as frequent in males as in females, and the right-left-bilateral ratio is roughly 6:3:1.

Children will discover that they are different at around age three to three and a half. Classically, the parents find their child comparing sides in front of the mirror. They begin to refer to the microtic ear as their "little ear" or "closed ear." It is best to agree with the child that they were born with one big ear and one little ear and, when they are older, the little one can be made larger to match the other. Then they should be treated absolutely normally, without making a fuss about the deformity.

The first big psychological trial manifests in about the first grade in school, when children are continually exposed to a large group of their peers for the first time. Self-awareness is

heightened as they begin comparing each other and forming a real concept of body image. This is when name-calling and teasing begins, and the microtic patient learns what it means to be "different."

The "second round" comes with adolescence, when everyone is conforming to peer pressure to be accepted. This is the era of our lives when looks become very important and everyone wants to "fit in." Teenagers with microtia are very self-conscious about being different and are particularly motivated to having the ear repaired. They are also very critical and may have unrealistic expectations of what can be surgically produced.

In addition to holding up our eyeglasses and funneling sounds towards our ear drums to improve hearing, ears make us look better and feel much better about ourselves as a whole person. This is the driving reason for surgical creation of the outer ear. Far from being cosmetic surgery, repairing a congenital deformity permits a person to have a normal self-image, a normal life and to be a normal, productive member of society.

The age at which an auricular construction should begin is governed by both psychological and physical considerations. Since the body image concept usually begins forming around the age of four or five years, it would be ideal to begin construction before children enter school. However, surgery should be postponed until rib growth provides substantial cartilage to permit a quality framework fabrication, which is rarely before the age of six.

Psychological and emotional benefit

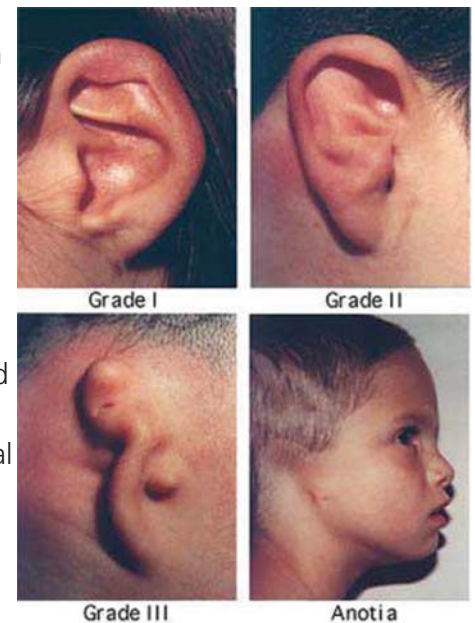
The impact of microtic deformity on patient and family sequentially becomes greater as the child enters school, approaches adolescence and reaches adulthood.

Before 10 years of age, 64.8 percent of families rated the deformity's impact as "moderate" to

"severe," whereas this figure jumped to 77.6 percent in ages 10 to 14 and 86.7 percent in patients older than 15. In ages six to 10, where 35.2 percent of families rated the impact as being only "mild," these same families often stated that the full impact had not yet been realized and that they sought surgery "not to solve a current problem but to prevent a future, anticipated crisis" as their child grew older.

continued next page ⇨

Figure 1
Variance of the microtia deformity. Grade I, II, III microtia and anotia (complete absence of any ear remnant).



Emotional Impact of Unrepaired Microtia			
<i>Rated by Patient and Family. Author's Series of 1,000 Cases.</i>			
Age (Years)	Severe	Moderate	Mild
5-10	18.6 %	46.2 %	35.2 %
11-14	16.3 %	61.2 %	22.5 %
15-20	26.7 %	60.0 %	13.3 %
21-62	44.1 %	41.2 %	14.7 %

Facial Deficiencies

A significant percentage of microtic patients exhibit deficient facial components. Appearing as a flattened side of the face, this condition is known as hemifacial microsomia, and is basically an underdevelopment of the bony jaws and overlying soft tissues.

Associated branchial arch deformities were common: 36.5 percent of patients had obvious bony and/or soft tissue deficiencies, making the side of the face appear flattened or distorted. Of these, the family perceived the facial deformity as “significant” in 49.4 percent of the cases. This obvious facial asymmetry is usually dealt with after the auricle is repaired.

From my years of long-term observation of many patients, this asymmetry doesn’t seem to worsen as the child grows but instead grows proportionally in its relation with existing facial features. This has been borne out by a recent growth analysis investigation.

Overt facial nerve weakness was found in 15.2 percent of my 1,000 microtia patients, causing a weak smile or inability to close one eye completely. Of these, 42.6 percent had involvement of more than one nerve branch (Table 2).

Kidneys and Urinary Tract

Urogenital tract abnormalities increase in the

presence of auricular deformities [104], particularly when the patient is afflicted with other manifestations of facial underdevelopment [103]. Several of my patients have hypospadias or vaginal agenesis, and 4 percent have proven abnormalities of their collection systems, which include horseshoe kidney, ureteral duplication, unilateral renal agenesis and pelvic kidney.

However, because the body has enough “reserve” to easily live with just one kidney, I have yet to see any microtia patient suffer any life-threatening renal consequences from these system abnormalities. A routine screening of the urine may detect silent hematuria or proteinuria, but as likely will show nothing. Recurring urinary tract infections in microtia patients prompt renal function studies, and one should start with a renal ultrasound before considering more invasive techniques to detect these deformities. Because of the increased incidence of urogenital abnormalities in microtia patients, one might consider screening all of them with ultrasound.

Cervical (Neck) Spine

Cervical spine anomalies are more common in microtic patients if other “midline defects” exist, such as cardiac or renal dis-

orders or cleft lip and palate. Because associated neurologic symptoms are rare, the frequency of these vertebral abnormalities are probably underestimated in patients with microtia. Goldenhar Syndrome is a condition in which the microtia patient has an ocular dermoid and usually has cervical vertebral abnormalities.

When one notes an ocular dermoid or detects limited range of neck motion in any microtia patient, one should investigate the renal function and evaluate the cervical spine as well. Regarding the latter, CAT scans will provide useful information for any physician caring for these patients. It is particularly wise to bring this condition to the anesthesiologist’s attention during any kind of surgery, so that unusual neck manipulation is avoided during induction of anesthesia; the child’s

head should not be forcibly turned, but instead, the head, neck and body should be “log-rolled” as a unit for any turning maneuvers during surgery.

If there is any suspicion of neurological disturbances seen in these children, they should undergo CT scan, MRI and appropriate neurologic examination.

Other Associated Problems: Cleft Lip/Palate and Heart

Cleft lip and/or palate is seen in 4.3 percent of my patients, and 2.5 percent have cardiovascular malformations. The latter have included atrial and ventricular septal heart defects, dextrocardia, transposition of the great vessels, three-chambered heart and patent ductus. If any of these heart problems are noted, the pediatrician should consult with a cardiologist for appropriate steps in management.

Table 2 - Associated Deformities
Author’s Series of 1,000 Microtia Patients

Branchial Arch Deformities

A. Obvious Bony and Soft Tissue Deficit	36.5 %
Family perceives it as “significant”	49.4 %
B. Overt Facial Nerve Weakness	15.2 %
Of these, more than one branch involved	42.6 %

Macrostomia

2.5 %

Cleft Lip and/or Palate

4.3 %

Urogenital Defects

4.0 %

Cardiovascular Malformations

2.5 %

Miscellaneous Deformities

1.7 %

2004 holiday parties!

cca dallas

CCA, together with the **Craniofacial Center at North Texas Hospital for Children, Dr. Jeffrey Fearon, Dr. Kenneth Salyer and Dr. David Genecov**, hosted its fifteenth annual holiday party in Dallas, TX, on Saturday, December 11, 2004. Around 500 kids, moms, dads, doctors and other craniofacial team members gathered for an afternoon of holiday cheer.

Radio Disney DJs enthusiastically emceed the event and led partygoers through an afternoon of fun and games, including holiday crafts, cookie decorating and face painting. Partygoers met and received autographed



pictures from the **Dallas Desperados Cheerleaders** and **Texas Ranger Hall of Famer, John Wetteland**. The **Fort Worth Cats** and **Texas Ranger mascots** also treated them with a surprise visit.

Families went home with wonderful door prizes supplied by a variety of Dallas and surrounding area businesses. Prizes included **Imax, AMC** and **Cinemark** movie tickets as well as **Six Flags** amusement park tickets. Donated sports prizes included a baseball cap autographed by Texas Ranger



David Dellucci; Frisco Rough Riders shirts, tickets and caps; an autographed picture of the **Dallas Mavericks** and a **Nolan Ryan**-autographed baseball.

Of course, the highlight of the party was seeing the jolly old man himself, **Santa Claus (Mike Lorfing)**, who arrived on a hook and ladder fire truck brought in by the **Plano, Texas firefighters**. Each child had their picture taken with Old St. Nick and went

home with a special gift as well as a keepsake picture frame that they designed.

CCA thanks all the volunteers and donors who made the party special.





cca midwest

Once again, a group of CCA kids and their families gathered in Kenosha, WI, at **The Parkway Chateau/Brat Stop** for a visit with **Santa (Ron Luke)** — and with one another. The good folks at the Parkway Chateau provided the hall at no cost, and we received generous donations from **Erma Gorecki** (Robbie's grandma) for toys and from **Orvind & Susan Solvang** and **Hillcrest Plymouth LLC** (in honor of **Meeka Rowat**) for refreshments and other expenses. **Wendy Niemi-Zastrow,**

Meeka's mom, helped **Jill Gorecki** with the party planning, and everyone there joined in with craft-making and assisting Santa in giving out pre-Christmas surprise bags. Special thanks too to "Mrs. Santa," **Pat Mehigan** for taking photos. Nurse clinician **Peggy Buchholz** from **Children's Hospital of Wisconsin** lent her support by attending as well. Jill reports the CCA group in the Midwest is growing in numbers and that everyone had a great time together!



we are family

2004 FNMS Family Conference

For three glorious days in July, 28 of the families that make up our extended FNMS Family were gathered at the **Flying L Guest Ranch** just outside of San Antonio, in beautiful Bandera, Texas. Our members came from all over the globe, from places as far away as New Zealand, Germany, Poland and Greece, to renew old friendships, form new ones and share our collective stories.

The official kickoff was Friday morning at breakfast, and the wonderful sight that greeted me that morning will stay with me always. Many of the young children were wandering through the large dining area, sizing up new friends and greeting families. Little **Maria-Nefeli Athanasiou** of Greece was walking around and shaking hands with nearly everyone, even though she does not speak a word of English. Watching all of these little people become so animated together in such a short period of time was truly amazing.

Breakfast was followed by one of the weekend's main events, the FNMS Cowboy Olympics! Everyone loaded

up on the hay wagons for the ride out to the arena. These fun team events were modified by the wonderful staff of the Flying L just for our group.

Saturday's schedule was designed to give our families time to enjoy all the ranch and surrounding region had to offer. Some families chose to enjoy a trail ride, some chose to play in the pool and some went into town to shop. Others used the opportunity to sign their children into the kid's activity camp in order to attend the parent mini-conference on medical issues. This roundtable discussion enabled parents to freely exchange ideas and information on new procedures, medical equipment and issues that concern our children.

Saturday afternoon offered another of the weekend's highlights, the FNMS Karaoke and Ice Cream Social. I must tell you that although it did take some persuading to get our first participants up to the stage, once they had finished their outstanding performance, there were no longer a shortage of volunteers.

The Foundation for Nager and Miller Syndromes

(FNMS) is an international support group dedicated to

helping those affected by these two similar genetic

conditions, which involve severe facial and limb anomalies.

For more information, visit their Web site at

www.fnms.net or email at ***fnms4u@ameritech.net***.

The fun kept on rolling on Saturday night, as everyone caught the hay wagons down to the creekside barbecue for dinner. The food was delicious, the setting was gorgeous and the company was fabulous. Dinner was followed by another special treat.

Mr. Kevin Fitzpatrick, the most extraordinary trick roper, held audience on the tennis courts. This man not only possesses amazing roping and horsemanship skills but also a charming wit that kept the crowd laughing and thoroughly entertained for more than an hour. I will never forget little **Callie Dahl's** great pleasure at being tricked by Kevin; the laughs and smiles that poured out of her were absolutely contagious.

The day came to a close around the campfire with

s'mores and good conversation.

Sunday morning brought the festive weekend to a close with our farewell breakfast and photo escapade. It was an amazing, life affirming experience for me, and I was very sad that it had come to an end.

However, I now feel a greater sense of community and connectedness with all of our member families, both those that were present and those that were not. I feel so thankful for all of our terrific volunteers like **Alexa Larsen, Andy Van Quill, Beth Russell, Eileen Atkins, Peter McNulty** and **Nina Restivo**. I now know the importance of what **Margaret Ieronimo** – along with the help of each of you – has created in FNMS. Thank you all.

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

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.

download the newsletter

If you are currently receiving the newsletter by mail, but would rather download it from CCAKids.com, let us know. The online version is in full color!

Watch our web site for the next CCA Motorcycle Raffle! If you would like to sell Harley raffle tickets call Annie at 800-535-3643

chair, from page 1

the organization that lays out specific goals and steps to reach those goals. The mechanism for implementing that plan is a much expanded committee structure.

Working within the committees, volunteers are asked to concentrate on areas in which they have expertise. This approach allows a group of volunteers to concentrate on a specific area and take ownership of the results.

Here are our current committees:

Programs: This is the committee that touches families most directly. It develops informational materials, such as our series of syndrome books. The Annual Family Retreat and other events around the country are the responsibility of this committee. Forming affiliations with other groups that share our issues is also a focus. If you have a little time and want to help families directly, this is the committee for you.

Development: We can't publish booklets, hold events or even keep our Web site functioning without money. Do you have experience in fundraising? If so, the Development Committee needs you. Fundraising can take place on the local, regional or national level. What are your ideas?

Marketing: This is the committee that takes CCA's vision to the world: "All people should be accepted for whom they are, not how they look." The Marketing Committee provides the words and images to tell the story of craniofacial patients and their needs. If you are a natural marketer or communicator, join up!

Governance, Finance & Audit: CCA is an organization with a heart, but it is also an organization with a brain. We must run our operation like a business. These committees are focused on efficiency, effectiveness, and responsibility. If you have experience in the business world or other associations, we want you.

Advocacy: Are you angry that craniofacial patients often have to fight tooth and nail to get adequate health insurance coverage? Well, stay mad and join this committee. We're pressing forward on several fronts to bring fairness to families who so frequently are denied the benefits they need and deserve.

We are grateful for all of our volunteers and look forward to moving CCA to a higher level with their expertise. With **your** help, 2005 will be a banner year.

Tim Ayers, *Board Chair*

If you feel you have skills that would benefit CCA, please call 800-535-3643 and ask for a volunteer application.

3 cheers

for volunteers!

K-K-K Katie...

Three Cheers for **Katie's Clothes Bin**, a thrift store in the small town of Hallstead, PA. Named for their daughter **Katie, Laurie and John Bovenkamp** saw a need for a shop in their town where gently used items could be purchased at reasonable prices, helping everyone involved.

In 1996, the Bovenkamp family including Laurie, John, Katie (now 16), her older brother John (18) and younger brother, Andrew (13) attended the CCA Cher's Family Retreat in Chicago, IL. They had a great time and still value the experience.

Since the store opened they've been "giving back"

to CCA through a 10% donation (more than \$500 in 2004, even when there are sometimes no "profits" to draw from). Laurie explains to customers why there is a photo of Cher in the shop and how their lives have been touched through CCA. Everyone seems to know Katie, who runs the register for her mom from time to time. Katie, born with Apert Syndrome is an active teen and an inspiration. The Bovenkamps raise funds for CCA while helping others make ends meet. We appreciate their generous donations.



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

RETURN SERVICE REQUESTED

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



Honorary Chairperson:

Cher

Board of Directors:

Tim Ayers, CHAIR Washington, DC
Tony Davis, Tuscaloosa, AL
Donna Gossett, Cullman, AL
Heather Lermont-Pape,
Indianapolis, IN
Dan Paulson, Fargo, ND
Rose Seitz, Youngstown, OH
Bill Sims, CPA, Dallas, TX
Robert Vargas, Dallas, TX
Robin Williamson, Carrollton, TX
Stephen Wright, San Francisco, CA

Medical Advisory Board:

Jeffrey Fearon, MD, CHIEF ADVISOR

CCA Network Editor:

Kelly Liszt

CCA Network Design and Production:

Robin Williamson, Williamson
Creative Services, Inc.

Executive Director:

Charlene Smith

Program Director:

Jana Butera

Development Director:

Jill Gorecki

Office Administrator:

Annie Reeves

Business Manager:

Cathy Evans

The views and opinions expressed in this newsletter are not necessarily those of CCA.

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.