ccanetwork

newsletter of the children's craniofacial association
Cher — honorary chairperson
summer 2010

inside

Nicholas Kifer blowing bubbles – quite an accomplishment for a child born with a cleft.

nicholas' story

By Carla Kifer

When **Nicholas** was born in 2004, we were so excited about the addition to our family. We already had a four-year-old daughter, **Taylor**, and she was so excited to be the big sister! My scheduled caesarean section went smoothly, and I remember thinking, "Thank God everything went okay."

Several hours went by and we still had not seen our baby boy. Finally, someone from the nursery came in to speak with us. She told us that Nicholas was born with a small hole in the roof of his mouth and was having some difficulty feeding. The nurses at the hospital told us that this was the easiest birth defect to fix.

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message from the program director

Well, another retreat has already come and gone. I honestly think the retreat weekend is the fastest weekend of the year! And, this year was one of our largest retreats to date. We had 92 families join us from 27 of the 50 states, Canada, and Switzerland! There were several first-time retreat families in attendance. For many of them, this was their first opportunity to meet another family who has a child with a craniofacial difference. To see a child finally meet

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

meet sydney rose ford

Sydney Rose Ford is already ahead of her time. She turned three this July, but for some reason tells everyone she is four years old.

She has an older sister named **Taylor**, who will be six in October. They are about the same size and are often asked if they are twins. They recently started sharing a room together and are the best of friends.

She and her sister have quite the pet collection: three dogs, Tori, Tiffy and Jasmine; a cat named Nala; a turtle, JJ and two hermit crabs (Syd calls hers Mr. Krabs, and Taylor named hers SilverNGold.) Sydney loves to have hermit crab races, chase the cat, and feed the turtle.

Up until she turned three, Sydney attended a Busy Bees preschool class through Early Intervention (EI), once a week for two hours. At 27 months, EI tested her, and she was so far advanced, she no longer qualified for the Busy Bees class. Her parents still wanted her in the class, and the teachers wanted her to be a peer role model, so she continued until her third birthday. She is so excited to start preschool in Ms. Foster's class this fall, where her big sister went.

Sydney has patiently watched her sister take dance lessons and be in the church choir last year. Now that she's three, she can start both this fall—and she can hardly wait. She loves all types of music. Just the other day she was listening to her daddy's hard rock, and was completely mesmerized dancing to Jimmy Buffett!

This summer, Sydney went with her family and grandparents to the Gulf Shores (before the oil spill). She loved the beach and doing cannonballs in the pool, but she was terrified of the ocean. She also spent a lot of time with her grandparents at the lake, and she loved riding around in the golf cart, making sure all the nearby farm animals were okay. Her grandparents are taking her to Disney World this Christmas, and she's thrilled she has a chance to meet Ariel, Flounder and Nemo!

Sydney recently returned from Boston with her parents, where she had her annual cleft clinic appointment. She loves to fly and is so brave—she held her parents' hands so they weren't scared!

Her favorite movie is *The Little Mermaid*, and she loves watching Dora and Spongebob on TV.

She has a favorite pink blankey that she has kept close to her since she was a baby and going through surgeries, she adores anything "mermaid or Dora." She also loves to play dress-up with her many costumes.

Sydney likes looking at books and painting things like mermaids, snakes and fish. She loves to swim and is looking forward to her first swim lessons this summer in her quest to become, you guessed it, a mermaid.

She also loves to make people smile and make sure they are okay. There isn't a day that goes by that she isn't making sure her mom has a smile on her face.

Sydney was born with a cleft lip and palate, and has had four surgeries so far: lip/nasal adhesion and partial gum closure, ear tubes, full lip/nose repair and palate repair. She will have a lip and possible nose revision in the next year or two, and she will possibly need a pharyngeal flap surgery around age five. She will definitely have palate expanders to prepare for the bone graft around age eight to ten. Then she will probably have a final revision around age 16 and possibly get teeth implants. Right now, she's enjoying being in the "no surgery club" since her palate repair at 8 months old.

When she grows up, Sydney wants to be Spiderman, despite never seeing *Spiderman* movies. Sometimes she also says she wants to be a doctor, a mermaid (of course) or a mommy.

ccakid

ccagrad

meet joseph brooks

hi, I'm **Joseph Brooks**. I'm 20 years old and live in Stafford, Virginia, which is about 40 miles south of Washington, D.C.

I am a freshman at the University of Mary Washington (UMW) in Fredericksburg, Virginia, which is another 20 miles south of Stafford. I am majoring in psychology. I am not really sure what I want to do after college, but it may have something to do with aviation.

In fact, my favorite hobby is anything to do with aviation, including aviation photography. I love to fly, and my favorite kind of plane is the Boeing 777. I am also a fan of the Boeing 737. In my spare time, I like to play Flight Simulator X, a pilot simulation game for the computer, and I like to listen to live air traffic control feeds from liveatc.net. I also enjoy watching airplane videos on YouTube. I have posted a couple of videos related to aviation on my YouTube page. My username is airplanecrazy1989.

I live with three sisters—Jerilyn, age 22; Carrie, age 15; and Cathryn, age 11. I also have an older brother and sister—Jenny and Jeremy. I love my family. We have had a lot of adventures together, such as getting our flight delayed from 10 p.m. to 2 a.m. in Honolulu, or driving across the country after landing in L.A. Disney World trips are also a fun family event.

I love music, and I play percussion in the UMW Concert Band. I was in marching band for all four years of high school, and I really enjoyed every minute of it. Marching band was a lot of hard work, but it was also a great experience. I enjoyed playing at the football games and going on the Florida trips in the spring. We marched the Spectro Magic parade at the Magic Kingdom both my sophomore and senior years—definitely something I will never forget.

I am also a diehard Dallas Cowboys fan. I got to see the new Cowboys stadium, and I watched my Cowboys triumph over the Redskins 7-6. The game was very boring until the last five minutes, but the stadium was like nothing I'd ever seen before. When I saw it for the first time from the outside and inside, I was in awe of how gigantic it was.

I was born with a rare condition called Oto-Palatal-Digital Syndrome type II, and I have endured 42 surgeries because of this. Eighteen of those surgeries occurred between April and June 2009 when I went in for a Le Forte III procedure. All went downhill when the doctor cut my perfectly good VP shunt—I spent a total of about three months in the hospital.

I almost made it to the retreat in Dallas, but I got sick the day before I was to get out of the hospital, which was two days before my flight to Dallas. So the retreat in Boston was my first. It was amazing to meet everyone.

My advice for younger kids with craniofacial syndromes is to just be yourself. If someone is making fun of you, you should try to be nice to that person. If the teasing continues, then just walk away and tell someone, maybe a friend or a trusted adult.

If someone is continuously being mean to you, don't waste your time on them. Stick with your friends and the bully should not bother you. Also, a good way to make friends is simply by being kind to others.

ccasupersib

meet taylor ford

taylor Ford is five years old and starting kindergarten in the fall. She is very petite for her age but has a larger-than-life personality and is a born leader.

Taylor is just starting to read, and her favorite book is *The Human Body*. She got interested in it after her father was in EMT school, and now she can't get enough of it. Her favorite word is "phalanges" (finger bones), and she can recognize many parts of the body on sight.

She has a deep love of horses and all things princess! She took ballet and tap classes this past year, and loved performing on stage at her recital. Taylor is also in the preschool choir at church. She comes home from all her activities and loves to teach her little sister, who eagerly wants to do whatever big sis does. Now Taylor wants to try things like karate, soccer and whatever else she can convince her parents to let her do! Taylor is looking forward to camping at Disneyworld with her grandparents for the first time this next Christmas, and especially wants to meet Snow White!

Taylor was just two and a half when **Sydney Rose** was born. Since that day, Taylor has been there making Sydney smile the whole way. I worried before Sydney was born if Taylor would be scared when she saw the cleft, but Taylor acted like she didn't even notice anything different. Even though Sydney was always a happy baby, when Taylor walked by, the world stopped and Sydney's whole face lit up even more.

Taylor has taught Sydney so much more than her parents or any of the specialists she sees. She has not only helped teach Sydney her colors and shapes, but she has also taught her how to be brave like Madeline (a children's book character who often repeats "I can do anything" when a problem arises.)

Taylor went on her first plane ride at three years of age when Sydney (who was 6 months old) had her third surgery. As Sydney was recovering from surgery in the hospital, she had a Logan's bow across her face, hundreds of sutures, all sorts of wires and tubing attached to her and struggled to just eat. Taylor would show up with a princess costume on and dance and sing to her little sister, and Sydney would just smile hearing her voice.

When Taylor started preschool, she had to have some minor speech therapy. She would come home from school and teach her baby sister what she learned—this helped Sydney to have exceptional speech. She has also taught Sydney how to make friends and be outgoing and try new things.

Taylor has had her own struggles too. She has been dangling off the growth chart most of her life and struggling with feedings. But, having a baby sister who eats great and is steadily gaining in size has really helped Taylor push herself to overcome her feeding difficulties. She's also had a lot of dental work from the feeding difficulties that has helped prepare us for all the dental stuff Sydney will go through in the next few years.

I know both girls will have many ups and downs to come in their life, and I know they will get through it all just fine. That's because they will always have their best friend, each other, by their side. I never had a sister, but when I watch my girls together, I wish I had, and I am so blessed to be able to experience their sisterly love as their mom.

craniofacial acceptance month

This year marks the sixth year CCA will observe September as Craniofacial Acceptance Month across the nation. CCA families, friends, volunteers and related support groups will be widening the circle of acceptance for individuals with facial differences. The goal is to create awareness of craniofacial differences and to get people to see that "beyond the face is a heart."

As part of the 6th Annual Craniofacial Acceptance Month, CCA will hold its 3rd Annual National Picnic Day on September 11th (or other date in September of your choice). CCA families across the nation will hold picnics giving them a chance to get together with other families in their areas, while promoting awareness in the communities.

It's not too late; if you would like to hold a picnic contact CCA Program Director Annie Reeves. CCA will invite all of the families in your area and help you organize your picnic.

In addition to raising awareness and acceptance, CCA is raising funds to support programs and services available to all individuals with facial differences and their families. Contact CCA Development Director, Jill Patterson for materials about this year's fundraising events.

We hope you will join this important effort! Please call 800.535.3643.

free 2011 hotel stay!

Fundraising reward extended indefinitely!

For our 2009 20th anniversary year we had a special reward proposal to CCA families who helped with fundraising – any family raising $5,000 or more for Children's Craniofacial Association through December 31st of that year would be awarded one free hotel room for their stay at the following year's retreat (i.e. 2009 fundraising counted toward the 2010 retreat). This reward has been extended indefinitely!

This invitation is extended to all CCA families, including those already holding annual events throughout the year and it includes any type of effort. So all fundraising efforts for 2010 will go toward the 2011 retreat.

All families who wish to participate are asked to sign a confirmation form in order that we may track your success and budget for your room. Please contact the CCA office at 214.570.9099, toll-free at 800.353.3643 or email **JPatterson@ccakids.com** for more information.

Try creating your own Firstgiving page

A free CCA-customized "firstgiving" site is available for anyone who wants to help raise funds for CCA. Log onto **firstgiving.com/ccakids** and tell your personal story about why you support CCA or post an event you're having. Then, all you do is email your link to everyone you know and ask them to do the same! This is an especially easy way to "ask" for donations if you're uncomfortable with the face-to-face approach.

save the date

jylian's links of love

Monday, September 20, 2010
The Golf Club at The Resort on Eagle Mountain Lake

On Monday, September 20, 2010 Children's Craniofacial Association will hold its third annual "Jylian's Links of Love" benefit golf tournament, this year at The Golf Club at The Resort on Eagle Mountain in Fort Worth, Texas.

The tournament will begin with a shotgun start at 1:00, (registration begins at noon with lunch) and will end with dinner, awards, and auctions.

Call the CCA office at 214.570.9099 or visit www.jylianslinksoflove.com for registration and sponsorship details.

what cca means to us

By Kim Trzanowski

When **Trevor** was born eight years ago, there was no preparing for his unexpected diagnosis of hemifacial microsomia with microtia. Everyone asks what that means, and I tell them "half the face small syndrome" and he's got what he likes to call a "little ear."

We have been using a wonderful team of doctors at **Children's Hospital of Philadelphia (CHOP)**, and we couldn't have asked for better care. We also found personal and emotional support through their patient liaison, **Diana Sweeney**, and she told us about CCA.

Our family sees some of the other families whose children are patients at CHOP, but there isn't time to make friends in a waiting room or really sit and share your stories with everyone. We recognized some familiar faces, but through CCA we can actually get to know them on a totally different level.

Trevor endured six surgeries in the first four and a half years of his life—the most traumatic being when he had his jaw distracted at four years old. He has been a trooper through every procedure.

Trevor has received all the therapies first through Early Intervention and then through school—speech, physical therapy and especially occupational therapy. He also has asthma and a life-threatening milk protein allergy. After his latest surgery he was diagnosed with anxiety disorder. Trevor was also blessed, however, with an amazing spirit, gorgeous blue eyes from Grandpa George, and a sense of humor that keeps me on my toes and laughing out loud daily.

My husband and I both come from very supportive, close families. They have been there through all of it, and so have our closest friends. No matter how close though, no one can fully understand the journey parents go through when gifted with a child like Trevor, or any one of these beautiful children. The CCA retreat finally brought that feeling of support and understanding home to us in a way that is hard to put into words. **The only way to truly understand what this retreat does, and what this organization does, is to see it for yourself.**

This year we attended our first CCA retreat. We had no idea what to expect other than knowing it would be a very emotional experience. Trevor is eight now, so he was pretty

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nervous to meet new people. He's used to his smaller circle of friends that don't ask him anymore "What happened to your ear?"

We arrived in Boston and were very proud to attend one of the symposiums on prosthetic ears, as **Mr. Barron** was the man we sought to do Trevor's ear a few years ago. During this symposium, Trevor attended a self-esteem session for children his age. It turned out that one of the families there happens to live about 20 minutes from us! Also, he hasn't stopped sharing his bag of "feelings" they made in that self esteem session since we got back home.

This retreat was amazing for all of us. Trevor met other children with hemifacial microsomia and also other anomalies. Never ONCE did we hear one child ask another child about their face—it was a complete comfort zone for everyone there. I have never before seen our son so comfortable and not worried about who is looking at his ear or face. Also, they were very accommodating with Trevor's food allergy too, which helped to ease his anxiety.

His dad and I got to share stories and speak to other parents who not only used some of the same doctors and facilities, but who also have had some of the same experiences and pain and heartbreaking moments. We spent those four days at the retreat crying—some were tears of release, some were tears of past pain buried deep inside and some were flooding tears of joy that we were not alone.

Every time we turned around Trevor was off somewhere playing with his new friends and smiling from big ear to little ear!

We have all made what I hope to be long-lasting friendships with other families both near and far who share our walk with us.

CCA and the retreat have profoundly impacted our lives—Trevor is already asking about play dates with his friends Zoe and Gavin. He is also excited about going to the retreat next year to see everyone again.

Everybody at the retreat was so friendly and warm. We now know a different sense of support and resources are available for our family, and it has become my new-found passion to help with fundraising for CCA—to help other families know that they are not alone.

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someone else "who looks like them" is priceless. One family saw our PSA during ***American Idol*** and decided to attend their first retreat. Their daughter attended the teen and young adult session during the symposium and instantly made friends. She and her new friends were together constantly during the rest of the retreat, which is what it's all about. Throughout the retreat, connections like these continued to be made.

This year, the **2nd Annual Craniofacial Symposium** was held on Thursday, prior to retreat activities. Healthcare professionals from the Boston area presented on various topics of interest to adults and children of all ages. Thanks so much to **Dr. Stephen Shusterman**, **Dr. Richard Bruun**, **Leah Ledgewood**, **Nicole DeMontille**, **Lauren Snelling**, **Robert Barron**, **Dr. Julie Snyder**, **Dr. Michael Detweiler**, **Dr. Lauren Mednick**, **Dr. Mark Proctor**, **Beth Dworetzky**, **Kara Jackman** and **Dr. Gary Rogers** for freely giving of their time and expertise to educate and enlighten our families. And CCA would also like to thank **Mairi Bleakie**, **Director of Foundation for Faces of Children**, for helping us organize the symposium.

The retreat activities started on Thursday evening with an ice cream social and an ice breaker. This year the families were broken into groups and asked to write on a piece of paper, an event, such as winning the lottery, making straight A's on a report card, running into a bear in the woods, etc., and then everyone had to place their piece of paper in a bag. Next, each person would pick a piece of paper from the bag and act out the event they chose, while the other people tried to guess what they were doing. We had people jumping up and down, running, dancing, making crazy sounds and laughing. Everyone seemed to really enjoy themselves, and it was a great way to get the families mingling!

On Friday after breakfast, we headed out to the New England Aquarium. Families were able to see all sorts of sea creatures, such as sharks, sea turtles, jellyfish, penguins and even some seals. We all wore our retreat T-shirts, to spread awareness in the community about CCA and craniofacial differences. Everywhere you looked, there were CCA T-shirts! What a neat experience! Special thanks to **Bruce Williamson** for giving us yet another creative shirt to add to our collections!

The Friday night events were loaded with fun and excitement! During dinner, "Professor Dan the Magic Man" performed a magic show. The kids lined the stage and watched his every move. Some of them even participated in the show. Everyone did a fantastic job! While the younger kids were enjoying the magic show, the teens enjoyed some time away from their parents, dancing the night away during Teen Night. **DJ Gary Leavitt** did a fantastic job getting everyone out on the dance floor. He started the night out by performing some of his character voices, which was shortly followed by line dancing, hula hoop contests and lots of young, fun and hip songs. The teens had a blast and I do believe this was the best teen night yet! Meanwhile, the rest of the group was frantically buying tickets to win their favorite basket in the fifth annual, family night chance raffle. The baskets were brought by the families and were filled with tons of goodies relative to their hometowns, cities and states. Once again, family night and the raffle in particular, were tons of fun and a huge success!

The group met for breakfast again on Saturday morning and then headed to the pool for the pool party. After a day of getting to know each other better, sharing experiences and support and just plain having fun, everyone prepared for the dinner dance—our most popular event during the retreat. This year we had a special treat during the dinner/ dance. While everyone was

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eating a yummy dinner, CCA adult, **Zachary Bordonaro** and his dance partner, **Vicki Gilbert** wowed the crowd by performing several beautiful ballroom dances. Zachary, who was an attendee of the very first CCA Retreat at Disney World in 1991, now attends Tufts University in Boston, where he and Vicki compete on the Ballroom Dancing team. Their dancing was beautiful and really raised the bar for the rest of us. One of the little girls was sure they were a prince and princess!

Next in line to entertain us were the kids. They took over the dance floor shortly after dinner and stayed out there the the rest of the night. Several of our CCA kids, teens, siblings and adults performed dances and sang songs as well. The adults slowly started filling the dance floor and before you know it, there wasn't an open spot to be had. We had a very lively group this year!

The retreat ended with a farewell breakfast on Sunday morning and the tears began to flow as everyone had to say goodbye.

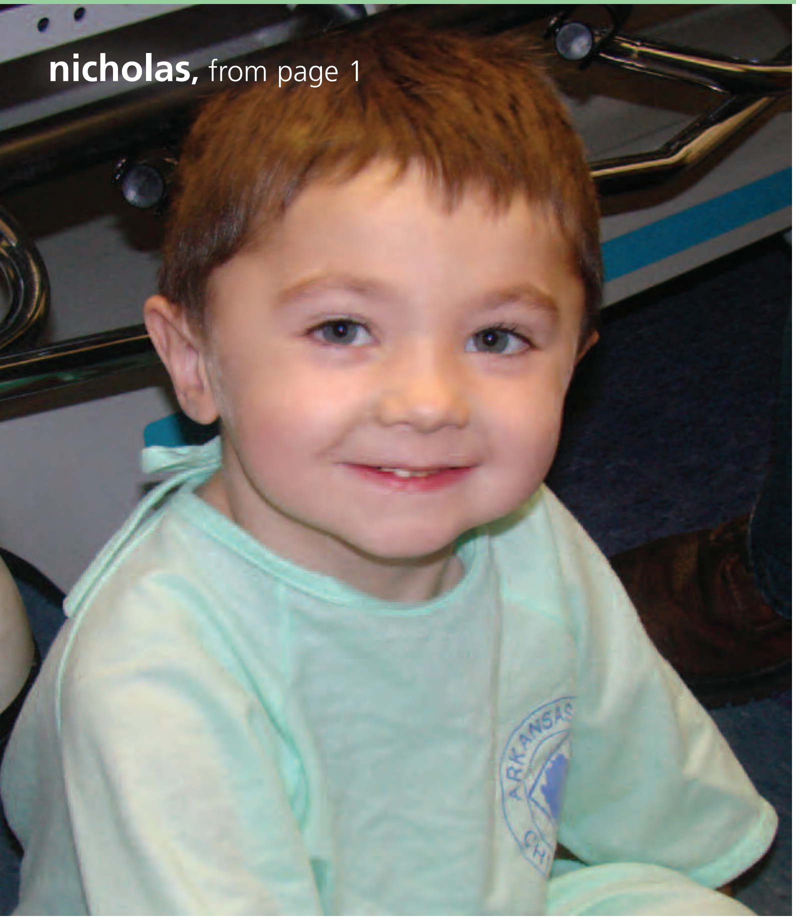
The families really connected and many friendships were made. And, they continued to form friendships in the weeks after by "friending" each other and posting tons of photos on Facebook, and joining CCA's Yahoo group. It's truly amazing! We even have several who are writing back and forth.

"We Are Family" is our theme song and it says it all! If you have never attended a retreat, I encourage you to try and attend next year. Words can't describe what a life-changing experience it is.

Please join us for our 21st Annual Family Retreat next June, in **Louisville, Kentucky**! Registration is officially open! See you next year!

Annie Reeves
CCA Program Director

nicholas, from page 1



When we finally saw Nicholas, he had an NG tube in his nose for feeding and a pulse oximeter to monitor his breathing. I looked in his mouth and, much to my surprise, there was no palate at all. A small hole? There was nothing! We were completely overwhelmed, and shocked.

Our pediatrician advised us to stay off the Internet and only read the information about clefts that he brought us. We were to also follow up with **Dr. Lisa Buckmiller** at **Arkansas Children's Hospital (ACH)** that following Monday. We were advised to feed Nicholas through the NG tube until seeing Dr. Buckmiller and were discharged four days after he was born.

We followed up with Dr. Buckmiller and left ACH thinking that maybe, we would be okay, although Nicholas had one of the largest clefts our pediatrician and Dr. Buckmiller had seen. This was only the beginning and we didn't know how extensive his problems actually were.

That following Wednesday, we removed the NG tube completely. Nicholas didn't do well, so we went back to the hospital to have the NG tube put back in. The next night, Nicholas was fed from the Pigeon feeder and he choked during the feeding to the extent of turning blue. He sucked his tongue back to the back of his throat and we didn't know if we would be able to save him. This was by far the scariest experience to date that we have had with him.

The next day, Nicholas choked again. Dr. Buckmiller's office recommended that we come right away to ACH through the ER. At that point, we were lost, thinking, "What are we going to do with this baby that can't eat or breathe?" I went to bed every night that week crying, afraid that Nicholas wouldn't wake up the next day.

This started our month-long stay in Little Rock. Nicholas was diagnosed with reflux. Also, Dr. Buckmiller told us about Pierre Robin Sequence (PRS). Nicholas had all of the characteristics: His tongue was displaced, causing the feeding and breathing problems. His jaw and chin were extremely small, contributing to the displaced tongue. He had dysphasia, which is uncoordinated or difficulty swallowing.

We were completely overwhelmed at this point.

Nicholas then had to have an NG tube, oxygen and pulse oximeter, and he had to lay elevated to help with the reflux. When Nicholas spit up (reflux), he aspirated it causing the choking incidents. It took a couple of weeks of observation and testing to determine that Nicholas would not be able to eat by mouth and his reflux was severe enough to require surgery.

He had surgery to insert a MIC-KEY button, and Nissen fundoplication to help with the reflux. At the start of the surgery, upon attempting to intubate Nicholas for this procedure, the doctors discovered that Nicholas had a very "difficult" and unstable airway. Therefore, he was left on a ventilator for eight days following his surgery to have the feeding tube placed.

We left ACH with a pulse oximeter and an oxygen tank. Once we arrived home in Jonesboro, a company came out and set up an oxygen concentrator. They also provided a food pump as well as all of our feeding and oxygen supplies.

This is not what you expect when you have a new baby, but that's what we had, so we made the best of it. We were so

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excited to be home with our daughter and son, nothing else mattered!

We made it okay without the need for a tracheotomy as long as Nicholas was positioned elevated and not laid flat. Nicholas slept his entire infant life elevated in a swing, bouncy seat or high chair. He never once slept in his crib.

I started researching his condition, trying to find out as much information as I could. I had never heard of PRS. I wanted Nicholas to be an exception for his condition and upon researching, found out that most kids with PRS have tracheotomy tubes and/or jaw distraction surgeries; most of them are able to eat normally, however, Nicholas was not.

I quit my job, so that I could focus strictly on Nicholas. I immediately began scheduling developmental, physical and speech therapies. At one point, Nicholas was cleared to get therapeutic feedings, but then that privilege was taken away once we realized that he was aspirating.

His first surgery was about a week after his first birthday when Dr. Buckmiller attempted to close his entire palate. Luckily, it went well and Nicholas didn't require a tracheotomy. He did come out with his tongue stitched to his lip, to hold it away from the palate, but that was removed shortly after the surgery.

The recovery was easy for us, because Nicholas was tube fed. We didn't have to worry about post-surgical eating and drinking, medications, etc. However, he did develop two fistulas (holes) in the repaired palate.

Four months later, we went for a swallow study, which showed that Nicholas was no longer aspirating. This allowed us to introduce him to baby foods. From that point on, Nicholas took well to eating.

We continued with all therapies and several follow-up visits to ACH. The feeding tube was removed in November 2005, and he was no longer dependent on oxygen for sleeping. We were able to get rid of all of his equipment. That was a happy day!

Dr. Buckmiller scheduled the second repair on his palate near his second birthday. The third repair came about 10 months later, along with some work on his sinuses. He frequently has sinus trouble because of the cleft, and he has had ear tubes since he was 10 months old.

For his fourth surgery, Nicholas had his palate lengthened. This was determined by a visit to the ACH where they did VPI (Velopharyngeal Insufficiency) scope. A tiny camera was inserted through Nicholas' nose to view the very back of his palate while he made specific sounds. **Dr. Charles Bower** performed the fourth surgery, which was a huge success. Now Nicholas can make pressure consonant sounds such as "p" and "b."

Since then we've followed up with Dr. Bower every six months, along with a visit to the ACH speech department. They have been so pleased with Nicholas' progress. He was receiving speech therapy three to four times a week. Now he gets speech lessons once a week after school. By the way, Nicholas will enter first grade in the fall, but he already reads and writes beyond his level.

You really can't tell just from looking at Nicholas everything that he's gone through. He speaks as normally as any other six-year-old child, just a little more nasally. He's made such tremendous progress so far with the help of the amazing medical team at Arkansas Children's Hospital and our local pediatrician.

I believe that Nicholas is an exception for the condition he has, and I can't believe, looking back at pictures, how far he has come. He truly is our little miracle, showing what lots of hard work and LOTS of prayer will do!

good news!

Miranda Larkin of Ocala, Florida was selected by the Miracle Network at Shands to tour the University of Florida's Gators football weight room, meet Coach Myer as well as several of the Gator players. Then she walked out with the Gators through the tunnel and onto the football field for the Orange and Blue game. They even announced her name on the loudspeaker! After all this excitement, she performed IMAGINE on stage to about 2000 people in the O'Connell center! How cool!

Stephen Wright of San Francisco is the recipient of a Volunteer Leave from Wells Fargo, which lets him begin a 10-week project supporting CCA while still receiving his regular Wells Fargo pay and benefits. Wright, a treasury service associate with Wells Fargo's Wholesale Banking group, is one of 30 Wells Fargo team members across the company to receive the award this year.

Stephen has volunteered with CCA for 17 years, serves on the board of directors and chairs the organization's audit committee. He plans to use his 12 years of banking experience and MBA with an emphasis in marketing to create marketing and financial plans for CCA.

Thank you for choosing CCA for this project, Stephen!

Elizabeth Moulton, mother to CCA adult **John Moulton**, had a very special day of pampering. The Masonic Home had a special Mother's Day celebration for all of the ladies living there. They had a beautician come in and do hair and make-up the Friday before Mother's Day. Then they took "Glamour Shots" and had a display of all of them. One of the ladies said "I feel like Mrs. Grandmother America." What a special treat for a special group of women! Elizabeth, you look beautiful!

big cca sisters!

▲ **Kate Rogers** and her baby brother, **Benjamin Lee Rogers**, born on 5.19.10.

◀ **Sophia Jane Weaver** and her baby brother, **Alexander Cole Weaver**, born on 7.8.10.

donor

in the spotlight

This issue we introduce our new CCA friend from abroad, **Mario Adamo**. Mario has been supporting CCA kids, adults and families for the past few years now.

He gives online, through Facebook, in person, for fundraisers, on Firstgiving, raffles, donations, webstore … you name it, if it supports CCA kids, Mario is all for it!

He first found Children's Craniofacial Association and ccakids.org on the Internet after striking up a wonderful relationship about eight years ago with **Teeter Sears** and the Sears family through **"Teeter's Page"** and **Apert International**. He says he had "a calling as a gift from God to find out about and do something more for rare syndromes" and he seems to be concentrating on "craniofacial" and the like.

Mario is a postman from Zurich, Switzerland. Two years ago, he went along on the Apert International Cruise, and this summer he joined our families in Boston for the Annual Family Retreat.

In his own words, Mario wants to do good for others and spread love and caring with an open heart. "In *The Bucket List*, they say, 'Have you found joy?' and 'Have you brought joy to others?' So then, I bring joy. I'm not a hero but I think I'm a winner!" He's not a wealthy man, money-wise, yet he's quick to fulfill every CCA birthday wish on our Facebook site! He ***is*** a very wealthy man if you count friends! Thanks Mario!

children's craniofacial association is on the road thanks to road scholar transport

Thanks to the generous activities of **Jim Barrett**, founder of **Road Scholar Transport**, you may see a truck rolling down the road raising awareness for CCA! Road Scholar is running the **10 Million Mile Awareness Program** and has chosen CCA as one of its charities.

The project started when Jim was introduced to CCA through a co-worker of **Marlene Deily**, grandmother to CCA kid **Jeremy Dale**. After hearing about the challenges that CCA kids must face, Jim was immediately energized to add CCA to his fleet of rolling billboards. CCA's own **Robin Williamson** collaborated with employees at Road Scholar to design the artwork on the truck and Road Scholar went to work on adding the CCA truck to its fleet.

Through the 10 Million Mile Awareness Program, Road Scholar customers can "sponsor" the CCA truck by utilizing Road Scholar Transport for their freight shipping needs. This helps to get the truck out on the road and bring awareness to all the communities where it travels. In addition to CCA, Road Scholar generously promotes awareness for 11 other charities.

With September being Craniofacial Acceptance Month, it is a great time to get this truck out on the road. If you are involved with freight shipping, or know someone who is, call Road Scholar Transport and request the CCA truck for your shipping needs.

You can find contact information for Road Scholar at **www.roadscholar.com**.

emily: a rare condition doesn't slow down this college-bound student

By: Mila Koumpilova, INFORUM

Emily Paulson's life started with a stint in intensive care, a string of surgeries and a nap on Cher's lap.

Emily Paulson's life started with a stint in intensive care, a string of surgeries and a nap on singer **Cher's** lap.

She's since endured more surgeries, hours of therapy and the occasional pitying stare. But Emily, 18, has refused to shirk attention. She's performed on a musical theater stage weeks after surgery. She's played the cello for a crowd at Pearl Harbor. She's appeared in a fitness video.

Last year, the Moorhead High School senior returned to volunteer at Fargo MeritCare's Neonatal Intensive Care Unit, where she spent weeks as a newborn. She's proof a feisty spirit trumps the snags a rare genetic disorder threw at her.

"It hasn't stopped me from doing anything," Emily says.

Emily was born with Treacher Collins syndrome, a congenital disorder one in 10,000 babies has. Infants with the condition have underdeveloped facial bones and difficulties speaking, swallowing and hearing. During her stay at the NICU, doctors inserted tubes in Emily's airway and stomach to help her breathe and eat.

After attending a Children's Craniofacial Association retreat as a toddler, Emily got an invite to appear on a national talk show with Cher. The singer had become active with the association after starring in *Mask*, a movie about a boy with facial differences.

Cher pointed out kids like Emily are just like other youngsters. As if to prove her right, Emily set out on an exploratory trek across the stage and then plopped on Cher's lap.

That was one early sign of Emily's fearlessness. At 18 months, she started pulling the tracheotomy tube out of her neck as a form of protest. That's how her parents figured out she didn't need it anymore.

Before jaw surgery at age four, Emily mostly communicated through sign language. Post-recovery, she amazed everyone with her sophisticated vocabulary. In grade school, she insisted her mom invent extra homework for her.

Treacher Collins can be a bit of a drag, Emily concedes. In her early teens, she had trouble breathing in her sleep and brought a sleep apnea machine to sleepovers. After surgeries, her dad, **Dan**, goes on a liquid diet with her.

Emily, who wears a hearing aid, has to focus to follow classroom lectures. Her teachers used to wear mics, but she cracked down on that her freshman year. "I hate having people do things especially for me. I can't stand that," she said.

But the disorder hasn't slowed Emily down; she's her class's salutatorian.

"You want your kids to do the best they can do," says mom **Denise**. "Emily has always put 100 percent in everything she does."

Emily recalls the tightness in her stomach as she was about to first step on stage before an unfamiliar audience. It was a sixth-grade musical called *Showstoppers*.

She's graced the stage many times since. **Patrick Kasper**, a Fargo choreographer, tapped her to appear in a hip-hop workout video in her signature pink tennis shoes.

"You are always nervous before you go on," she says, "but then you get on stage, and you see all these people watching with so much excitement."

Emily's traveled to Hawaii with the Moorhead High orchestra and to Scotland with the school's production of *High School Musical*. The show gave Emily her toughest stage trial: playing an "emo" girl.

"You have to be sad and mad, and that's completely the opposite of how I am," Emily explains.

To coax out the character, Emily conjured the pain of post-surgery recovery. She dyed her blond hair black, went heavy on the black eyeliner and shuffled across the stage in a cloud of teen angst.

"Emily auditions beautifully, and she's a fierce performer," says director **Rebecca Meyer-Larson**. "We don't notice she looks different from most girls. All we see is beauty and joy and confidence."

Meanwhile, Emily has cultivated a passion for youngsters with medical struggles. She's been baby-sitting a girl with cerebral palsy. She signed up to volunteer in the MeritCare NICU, where nurses still remember her and her unfailingly upbeat parents.

After her 11th surgery in June, Emily starts at Concordia College. She plans to go into nursing.

"She has so many great achievements, but we are most proud of who she is," says Denise. "She's always happy and positive."

cca 20th anniversary t-shirts

Our limited edition 20th Anniversary Logo T-shirts are still available for purchase, now on sale for just $15 each, plus shipping.

We still have the following sizes available: Adult sizes, S, M, 2XL, and 3XL. **And we're happy to announce youth sizes are still available:** XS (2-4), S (6-8), M (10-12), (L youth, order S adult).

bracelet sales continue!

"Beyond the Face is a Heart" wristbands

The great response to our CCA bracelets has prompted us to sell them throughout the year!

Bracelets are $1 each

Available in the 5 colors of CCA's logo faces:
royal, orange, teal, purple, lime
Sizes: 8" (universal/adult) and 7" (small/child)

To purchase and/or sell, email or call Jill
JPatterson@ccakids.com • 800.535.3643

For a complete list of our programs and services, visit:
www.ccakids.org/prg.asp

goodsearch & goodshop

Every time you shop online at your favorite stores you could be saving money and earning a donation for Children's Craniofacial Association.

Our new toolbar, developed by **GoodSearch & GoodShop**, takes just a few seconds to download. More than 1,300 top stores including **Apple**, **Best Buy**, **Gap**, **PetSmart**, and **Staples** are pitching in and will donate a percentage of each sale to our organization. There's no extra cost to you and you may even save money as the merchants are providing us thousands of money-saving coupons!

The GoodSearch toolbar also includes a search box which is powered by Yahoo! Each time you search the web, about a penny is donated to us!

There's no easier way to help CCA. Please spread the word! Here's a link to the toolbar for more information: **http://www.goodsearch.com/toolbar/childrens-craniofacial-association-cca**

(Firefox seems to be the easiest browser to use.)

PERMISSION™
Skincare for Men

Giving Back

CCA is proud of our cause-related marketing alliance with Permission products, a line of men's skin care.

"Permission formulas help you face the world with new confidence, and you'll be helping others do the same. A portion of proceeds from each product go to benefit Children's Craniofacial Association…"

www.permissionskincare.com

testimonial

Our son **Sullivan** is nine years old and just underwent his fourteenth surgery. In the past we were able to have his procedure done locally; however, that was not the case for his last one, nor for his next one.

We live in Iowa and were able to get to Texas with the help of CCA. Without their help, I am not sure how we could have done it.

Their help did not stop with just *financial* support. They were also kind enough to come and offer us *emotional* support during his surgery. With our family so far away and our son in surgery, they were exactly what we needed at that moment!

Thank you so much CCA! You are an amazing organization, and we will always be grateful for your help!

Maylan, Amy, Hannah, Sullivan and Jonas Thomas

financial assistance

Do you travel to receive quality medical care? If you do, and need financial help, CCA has a financial assistance program that will help with food, travel and/or lodging. Call CCA for an application at **800.535.3643**. All we ask is that you **apply at least four to six weeks prior** to your next appointment.

new cca web store offerings

$15 each plus shipping

Millifiori glass heart
No two alike!
Leather w/CCA logo tag

Stainless steel w/ braided leather; round, heart or dogtag style;
"Beyond the Face Is a Heart" on reverse

"Swarovski-type" genuine Austrian crystal
stretch bracelets with stainless steel CCA logo tag

Alexandrite "Purple"

Apricot "Orange"

Chrysolite "Lime"

Gold Beryl "Teal"

Light Sapphire "Royal"

Multi "Limited Edition" for September

fundraising news

jammin' jeans week

Judy Kemler dropped off a check at CCA from her Jammin' Jeans effort at work, in honor of grandson, Luke.

Mathematics instructor at Flower Mound High School in Flower Mound, TX, **Judy Kemler,** is also grandmother to CCA kid, **Luke Bowen**. Last May, she got her faculty at school to hold a Jammin' Jeans Week for Luke Bowen which brought in **almost $1,000** for CCA! Special thanks to school principal, **Mr. Paul Moon** for allowing the effort to take place and to everyone who participated! Judy also plans to get the student body involved for September's observance of Craniofacial Acceptance Month! Go Judy!

boston retreat chance raffle

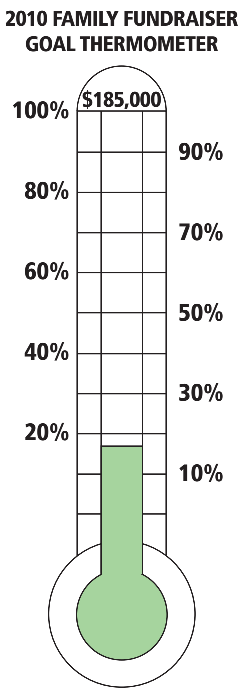
The "Chance Raffle" held at the Annual Family Retreat in Boston was another smashing success, raising about **$1,200**, $5 at a time, thanks to CCA family participation on both ends! Families first brought baskets and goodies from their hometowns and states to raffle and then purchased tickets in hopes of winning their favorites.

Another year of fabulous items, nail biting and fun ensued as Board Chair / CCA dad, **George Dale** announced winning names drawn by "Bill," the wait staff manager at the Hyatt, where the festivities were held. The only tense moment was when Program Director, **Annie Reeves** attempted to board her Boston flight with a huge New York Yankees basket. She was held up for a moment at security but it was all in fun as they let her to walk with it to her gate at her own risk! Hope the rest of you made it home okay with your goodies! Annie?

thinking about getting…

DirecTV ~ Clear ~ Wild Blue ~ ADT Service?

Use the **promo code 46063**, and you will get a great deal *and* help Children's Craniofacial Association at the same time! The promo code will get you 50% off for one full year—packages starting at $29.99 month. Call the CCA office for coupons you can use for lots of special offers.



cca mugshot

▲ Rachael Morrissey has left the building! Rachael & family visited the CCA office and posed for a post-operative mug shot!

calendar of events

date	event	contact
Sep 1, 2010	**Beginning day of 6th Annual Craniofacial Acceptance Month**	
Sep 2010	**3rd Annual Ryan's Road** Big Flats, NY	ngulich@yahoo.com
Sep 5, 2010	**Raegan's Rally/Walk for CCA** Deerasic Park, 3 PM Cambridge, OH	Ashley Daugherty adaugherty@mvesc.k12.oh.us
Sep 11, 2010	**4th Annual Seth's Stride for CCA** Canton, OH	mythreekids@neo.rr.com Stacy Swihart www.firstgiving.com/sethsstride
Sep 11, 2010	**3rd Annual National Picnic Day for Craniofacial Acceptance Month** Sandy Lake Amusement Park 10:00 AM – 1:00 PM Carrollton, TX	areeves@ccakids.com www.ccakids.org 214.570.9099 800.535.3643
	Hilton State Park 11:00 AM Dover Point, NH	shwmz@comcast.net
Sep 19, 2010	**Smiling Through the Mask – A dinner to benefit CCA** Restaurant 1620 Little Rock, AR	wendelynyvonne@hotmail.com
Sep 20, 2010	**Jylian's Links of Love** Golf Tournament The Golf Club at The Resort on Eagle Mountain Fort Worth, TX	JPatterson@ccakids.com www.ccakids.org 800.535.3643
Sep 25, 2010	**Little Fire, Big Heart Dinner/Auction** Melwood Art Center Louisville, KY	TarynSkees@gmail.com www.littlefirebigheart.com
Sep 25, 2010	**Rock'n Bowl with Kayla Smith** Riverside Lanes Warren, PA	msmith@nwbcorp.com 814.723.1221
Oct 2, 2010	**6th Annual Friends of Jeremy Golf Tournament** Corning Country Club Corning, NY	gdale@stny.rr.com www.friendsofjeremy.com
Oct 10, 2010	**3rd Annual Chocolate Festival for CCA** Aventura Mall Aventura, FL	ChefRick2@aol.com
Nov 7, 2010	**BaseBowl** **Jorge Posada Foundation** 300 New York at Chelsea Piers 12 PM – 4 PM	JPatterson@ccakids.com www.ccakids.org 214.570.9099 800.535.3643
Dec 3, 2010	**Center for Courageous Kids Family Retreat** Scottsville, KY	info@courageouskids.org www.courageouskids.org 270.618.2900
Dec 11, 2010	**CCA Holiday Party–Dallas** Southfork Ranch Parker, TX 10 AM – Noon	areeves@ccakid.com 214.570.9099 800.535.3643
Dec 2010	**CCA Holiday Party–Midwest** Brat Stop/Parkway Chateau Kenosha, WI	JPatterson@ccakids.com 214.570.9099 800.535.3643

donors, january 1 – june 30, 2010*

Gifts from Individuals

CCA Friends

($100 +)

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($500 +)

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($1,000 +)

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*Listed are **monetary donations of $100 or more through 2nd quarter, 2010**. We are extremely grateful for these and all other fees, purchases, fundraisers and in-kind donations not recorded here. (Note: For space consideration, 2010 donations under $100, CCA "Supporters," will only be published in our year-end list. Cumulative $100+ donations and all In honor or In Memory dedications will continue to be published in each quarterly issue.)

We do our best to accurately recognize donors. If you notice an error, please let us know.

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($5,000 +)

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($10,000 +)

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May Klein, in memory of Rick Dornier
Jo Koelz, in memory of Rick Dornier
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Adam Lamar, in memory of his "beloved father, Roy Nickola Lamar
& blessed Patti Welch who went to the Lord at the age of 9"
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Jill Patterson, in honor of Char Smith's birthday
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Caryl Rabedeaux, in memory of Rosaleen Egan
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Michael Rice, in honor of JoAnn Kopshinsky
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Jilly Bean Bunch

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CCA Corporate / Foundation Friends

(up to $1,000)

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Fifth Third Bank for Little First Big Heart
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Pfizer (United Way Campaign Employee Giving)
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Reed Realty for Henry's March
Rodig Smile Design for Henry's March
Rolling F Credit Union for Henry's March
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United Way Mile High (Donor-Directed Donations)
United Way New York City (Donor-Directed Donations)
United Way of Tucson & Southern Arizona (Donor-Directed Donations)
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Fundraising Events

Up to $1,000

Cash Can / Kim Rogers, CCA Volunteer
Janis Cazare's Firstgiving Page
Ink / Cell Recycle for CCA / CCA Families & Friends
Jewelry Sale / Peggy McDannel
Jammin' Jeans Week in honor of Luke Bowen for CCA / Judith Kemler, CCA Volunteer
Lily's Dinner for CCA / Firstgiving Page /Tosha Walker, CCA Volunteer

$1,000-$5,000

CCA 20th Annual Family Retreat "Chance Raffle" proceeds / CCA Retreat Attendee Families
Clear Lake 8 Ball / Raffle & Donation Collection for CCA in honor of Natalie Wardlaw
Little Fire, Big Heart Dinner Auction for CCA / Taryn Skees, CCA Volunteer
Wendelyn's Course of Dreams Golf Tournament / Wendelyn Osborne, CCA Volunteer

$5,000 or more

$10,000 or more

$20,000 or more

3rd Annual Henry's March for CCA / Johnson Family; Rachel, TJ, Lauren, Henry

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13140 Coit Road, Suite 517 • Dallas, TX 75240

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3 cheers for volunteers!

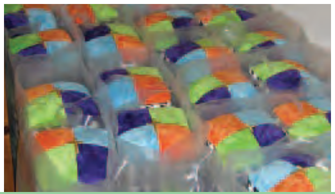
CCA was honored to have a new volunteer join our community this year showering us with prayer pocket pillows for our families. **Laurie Haese** is a wife and mother who considers herself blessed to have the time and talent to make such a unique gift that touches families who may be experiencing a variety of circumstances.

Laurie put her ideas into action when her daughter **Hannah** went off to college in 2006. It started out with cross pillows, and the next year she expanded her efforts with the prayer pocket pillow. She wanted to find a way to give a gift that would lift people up and let them know she was praying for them. She loves hearing how her customers have used them in so many creative ways and how it has encouraged friends and families.

When Laurie heard about CCA, she volunteered to donate pillows for families that have children in the hospital. She carefully considered each piece of fabric for the pillows. We call her our "pillow angel."

We asked if it might be possible for her to make them for the CCA Family Retreat. She asked how many families and didn't even bat an eye when she heard it would be about 115 pillows. She said "I loved doing the ones for the CCA retreat and hope they felt the love and prayers that went into making each one."

We think they definitely felt the love, Laurie, and we are so thankful and lucky to have you be a part of our family of volunteers.



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