making a difference

Yes, this is yet another election-year message. No, we are not asking you to vote for or against anyone.

One of the most difficult issues facing CCA families is dealing with health insurance companies. Too often parents are told they have inadequate insurance or no insurance coverage at all for their children. In particular, we have heard far too many stories of insurance being denied because the needed treatment is classified as “cosmetic.”

This does not have to be the case. Ten states have required that insurance companies cover reconstructive surgeries. No disastrous results such as statewide increases in insurance premiums have
Eleven-year-old Zachary Muller is one busy guy. This friendly, outgoing sixth-grader from Bayonne, NJ, enjoys school, with Reading, Social Studies, Math, Art and computer classes being his favorites.

He likes spending time with his friends, listening to Cher’s music and especially likes CCA. This will be his seventh retreat, counting this year. He’s a big Cher fan and has seen her five times at her concerts and had a chance to meet her backstage.

And he’s a TV star — he recently went to New York City to be on Maury, with Maury Povich! The show was about kids with differences, and featured Zach and three other kids and their moms.

He was a real hit with the audience and the staff of the show. Afterward, he was driven by a limousine to go on a shopping spree. He came back with, among many other items, lots of videos and video games. The show was taped back in December, but watch for the show to air soon.

Zach has had 21 surgeries so far in his life with “quite a few things more to do.” But that doesn’t stop him. His advice to anyone is to be positive and to not worry. “Keep smiling,” he said.
I’m Cindy De La Rosa. I’ve been a CCA kid for 13 years and enjoyed every bit of it. For my mom and me, CCA gives us chance to travel and lets us meet some pretty cool families.

I was born with cystichygroma. This is when a person has cystic tumors in their lymphoid system. I used to have a trach and a G-tube. I have had several operations and injections to decrease the tumors. I now have very few tumors, but I have a lot of scar tissue.

I’m an 18-year-old Wisconsin girl and a senior in high school. I graduate on June 10, and I’m counting the days. I’m not sure what I want to do with my future. Art is one of the biggest passions I have. I want to go to the University of Wisconsin Whitewater and become an art metals teacher for high school students. I plan to go to tech school and become a business major while I think about my future.

My mom is my best friend and I love her to death. She has always been there for me through thick and thin. My family is the best part of my life, even if they are a little crazy. I love all of them so much and thank God everyday for them. They are true friends, and I appreciate them very much.

I have many hobbies. Dance is my biggest passion in life. I have been dancing for fifteen years. Art metals and sculpture are new hobbies. I fell in love with art when I first walked through the doors of my high school art department. Art and dance help me get away from problems in life. I also love to hang out with my friends, go to school sporting events, watch movies and TV, listen to music and go shopping.

I have thought about what life would be like if I didn’t have tumors. I realized I wouldn’t like it. I would have never gotten adopted and I wouldn’t have a wonderful mother, friends or family.

I like being me. I’ve never really had a problem with people making fun of me, but then I have never let anyone make fun of me. I’ve always stuck up for myself, or my friends and family stuck up for me.

For me, beauty goes two ways…inside and out. I would rather be beautiful on the inside. And never let anyone tell you that you aren’t special! Everyone is special in some way and everyone makes a difference. Just be yourself and people will like you even more.
What is distraction?
Distraction osteogenesis is a technique in which a cut is made in the bone and a device is used to gradually lengthen the bone. Because of the slow rate at which the device is turned, new bone has time to form in the gap created. The first use of distractors on the lower jaw or mandible was in 1989 by Dr. Joseph McCarthy.

Which conditions of the mandible are treated with distraction?
Children are born with certain conditions that result in a small mandible. Depending on how small the mandible is, children may have difficulty breathing, feeding or speaking. The most common condition is craniofacial or hemifacial microsomia, in which either both sides or just one side of the lower jaw is small. Patients with Treacher Collins and Pierre Robin Sequence may also undergo distraction. Some children who have injuries to their mandible in childhood may also have small jaws from damage to the growth center of the mandible and may benefit from distraction.

At which age should mandibular distraction be performed?
The right timing for distraction depends on how small the mandible is, what problems the child is having and how the child’s mandible is growing. The smaller the mandible, the more the child will benefit from earlier distraction to lengthen the jaw in order to help with breathing, eating and appearance. Each child is different, and your child’s craniofacial surgeon should determine the need for and timing of distraction.

How does mandibular distraction work?
The child has the first surgery to make a cut in the bone and to place the device. Four to five days later, the device is “activated.” This means that the screw is turned twice a day, a total of one millimeter per day. When the desired amount of lengthening is achieved, distraction is stopped. The device has to stay in place for twice the amount of time that it was activated. This time allows the new bone to heal and strengthen before the device is removed at a second surgery.

What are the advantages of distraction?
Before distraction was used, surgery would be delayed until the child finished with mandibular growth. When growth was complete, cuts would be made in the jaw and bone grafts from other areas of the body would be used to fill the gaps. Now that distraction is commonly used, the need for bone grafts has decreased and problems in the areas where bone was taken have diminished. Distractors can be used in younger patients because less cuts and holes need to be made in the bone, which may result in damage to permanent teeth in the child. In patients who have very small mandibles, especially on one side, the growth of the upper jaw is also affected. By distracting earlier, the upper jaw is allowed to grow. Another big advantage to distraction is that it simultaneously stretches or expands soft tissue. Many children with hemifacial or bifacial microsomia and Treacher Collins have muscles and soft tissue that are also smaller and less developed. Distraction slowly stretches these and allows better coverage over the lengthened bone.

What are the disadvantages of distraction?
One of the main disadvantages of lower-jaw distraction is the risk to
mandible, from page 4

permanent tooth buds. Depending on the anatomy of the jaw, cuts and pin placements in the area of tooth buds can sometimes be avoided. Some children have a difficult time wearing an external device, but most adapt well and have minimal discomfort during distraction.

If a child has mandibular distraction, does he/she need to have more surgery on the mandible?

The need for further surgery depends on how small the mandible is and how early the child needs distraction. In general, the smaller the jaw and the earlier the need for distraction, the more likely the child will need jaw surgery in the future. During distraction, the jaw is “over-lengthened” slightly, understanding that it does not grow at the same rate as the rest of the face, in order to delay any future surgery.

KlubHouseKids

It's time! CCA is registering kids to participate in the KlubHouseKids project that will take place this April. So get a group of your friends together and sign up now. Together we will make a difference for kids who have craniofacial differences.

KlubHouseKids clubs want to make a difference in their community and invite you to join them. This group is dedicated to holding an annual fundraiser to raise awareness of kids with craniofacial conditions and raise funds to support CCA programs and services.

The charter chapter of KlubHouseKids invites you to be a KlubHouseKid for the month of April. The KlubHouseKids will spread awareness and sell raffle tickets for a trip for four to Disney World! The grand prize will include airfare, hotel and Disney World tickets.

Kids, do you want to help? Grown ups, do you know kids who might want to help? Get a few of your friends, nephews, nieces or neighbor kids together and form a KlubHouseKids club. You get the kids together, and CCA will show you what to do. If you enjoy the club, you can find out how to become a permanent club or if you just want to help CCA during the annual event, you can do that too.

But, don’t miss out. For more information or to sign up now, email Jana at JButera@CCAKids.com or call her at 800-535-3643.

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.

annual family retreat update

The 2004 Cher's Family Retreat will be held June 24–27, 2004, in Tempe, AZ. 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.

The retreat is for kids with craniofacial differences and their immediate families only.

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...any flat-piece media, to create an original work of your own art. All of you will get artistic exposure, so have fun with it. (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 Website next winter!
CCA hosted its 14th holiday party in Dallas, TX, on Saturday, December 13, 2003. The annual event was held in conjunction with North Texas Hospital for Children’s Craniofacial Center, Dr. Jeffrey Fearon, Dr. Kenneth Salyer and Dr. David Genecov.

More than 500 kids, moms, dads, doctors and other craniofacial team members gathered for a morning of holiday cheer. There were holiday crafts, cookie decorating and face painting, and the group was entertained by a ventriloquist and storyteller from Nana Puddin’. The partygoers received autographed pictures from the Dallas Cowboys Cheerleaders, a Texas Ranger Hall of Famer, and players and cheerleaders from the Dallas Desperados Arena football club. The Plano, TX, firefighters brought their hook and ladder fire truck and, of course, the jolly old man himself, Santa Claus (Mike Lorfing) was on hand to give out gifts supplied by Warner Brothers and have pictures taken with all the kids.

Once again Dallas businesses supplied wonderful door prizes. The Dallas Mavericks Basketball Team sent tickets to a game, and we gave out tickets to the Mesquite Championship Rodeo, gift certificates to area restaurants, Celebration Station Amusement Park and Adventure Landing Golf. Autographed sports items from the Dallas Stars, Texas Rangers and Dallas Cowboys were also given to lucky partyers.
And the Midwest chapter of CCA once again held its holiday party at the Parkway Chateau at the Brat Stop in Kenosha, WI. Kids and their families enjoyed lots of special time with Santa (Ron Luke) and we made handcrafted ornaments. Cookies and punch were served and everyone took home gifts — even parents happily chose from the door prize pile. Santa assured everyone he’d visit the group again next year as long as everyone is nice and not naughty. All agreed!

Everyone had a wonderful time, and we want to thank everyone that donated prizes and all the volunteers that helped make the parties such a success.
large family of 25 (all 23 of the kids were adopted, with 15 living at home), and all the new brothers and sisters were anxious to love on their new baby brother.

The kids gathered around to look at him. Soon a chorus of “Aw, isn’t he cute?” rang out. They examined his hands and commented that with his mitten-like hands, he looked like he was giving the royal parade wave. They took off his socks and examined his feet. They looked at the fused toes and soon decided that it was still possible to play “piggies” with them.

Matthew had difficulty drinking and would use a tremendous amount of energy drinking a bottle. He was burning up the calories even as he drank, and we were told not to give him a pacifier. The therapist got us a Haberman nipple, which allowed us to squeeze the shaft of the nipple to help him get the milk out of it. Finally, he started gaining a little weight.

When Matthew was six months old, he had a total cranial vault reconstruction. Basically they removed his skull from the brow up and cut it into “daisy petals” and sewed it back into place, lowering the top of his head and expanding the forehead and the back of the head to make them more rounded.

Those who have not experienced it cannot imagine the turmoil that a parent goes through with such a surgery. We had come to know Matthew with a pointed skull and lack of a forehead. I had memorized every centimeter of his face and loved him as he was.

When they brought Matthew out of surgery and let me go see him in the PICU, I sat for hours watching him as he slept, watching the swelling change his features even further. I would have been very frightened if Tamara LeCara and Brenda Siebert had not prepared me by showing me photos and video of their kids postop. A zigzag incision stretched over Matthew’s head from ear to ear, with 66 staples closing it. His forehead swelled alarmingly — I was not used to seeing a forehead there at all — and his eyes, which had turned down at the outer corners, were lifted, giving him a mischievous glint. His eyes swelled until they bulged like Elmo’s and the nurses covered them with ointment and plastic wrap to keep them moist.

The plastic wrap bothered me more than anything. I said it made him look like yesterday’s leftovers, so I took scissors and colored paper and cut out a pair of “glasses” frames and taped them to the plastic wrap. Every day I made him a new pair in another style, but the most popular ones were the ones with exaggerated eyebrows which made him look like a Furby. The incredible thing was, that even in the midst of all this, Matthew smiled. With his arms in restraints, he used his feet to kick at rattles that we suspended over his crib.

The swelling gradually subsided over the next few weeks. Gradually over the next few months though, Matthew’s development slowed. His speech declined. It was such a gradual change that we didn’t notice at first and then credited it to all he had been through.

In January of 2002, we went to Dallas for surgery to separate his fingers and toes. All the way to Dallas, I felt uneasy, and by the morning of surgery I was really nervous. Something was not right but I was not sure what it was.

Just as they were wheeling Matthew down the hall to surgery, I spotted our neurosurgeon, Dr. Kenneth Shapiro. I called to him and asked him to look at Matthew before they took him into surgery. He examined Matthew and measured his head. Within minutes, the surgery was canceled and we were on our way to a CT scan.

After the scan, Dr. Shapiro told me that after the cranial vault surgery, the fluid in Matthew's brain had moved to the outside of his brain and
was putting pressure on it. Matthew had Hydrocephaly and needed a shunt to relieve the pressure. We were transferred to Children's Medical Center, where the shunt was put in.

It was amazing how alert Matthew was after the pressure was reduced. When Matthew was 15 months old, we went to Dallas for the hand surgery. On the way there, both Matthew and I started to wheeze, and by the time we saw the doctors, his little chest was retracting with each breath. He was hospitalized and underwent tests and breathing treatments. The doctors learned that Matthew was aspirating (breathing in food) when he ate and drank. He was also having reflux and aspirating that. This was irritating his lungs.

After a few days of breathing treatments, he was breathing better and underwent surgery to prevent the reflux. They also put in a G-tube (a tube into his stomach that we could give him medicine and formula through and also relieve pressure when he had gas in his tummy, since he could no longer burp either.) They also stitched the corners of his eyes so that he could close his eyes.

After the surgery, they were not able to get him to breathe on his own, so he stayed on a ventilator until the next morning. They gave him breathing treatments continuously for another day, then took him back to surgery and separated some of his fingers and toes. This gave him three fingers and a thumb on each hand. He was soon sitting up in bed, batting at a balloon with his casts.

The casts came off three weeks later, and they bandaged his hands and feet for a few more days. When the bandages came off, Matthew looked at his hands with wonder. A huge smile came over his face and he held them up with a flourish as if to say, “TADAAAA!” He had the second surgery a few months later and has all his digits now. He uses them very well.

In August, 2002, Matthew underwent 10 hours of surgery, a monobloc mid-face advancement with internal distractor. For several months his sleep apnea had gotten progressively worse, and we were also worried about his eyes. Matthew knew that we were going for surgery this time. He cried and pouted for half the trip to Dallas before giving in and enjoying his favorite tape.

The long wait during surgery was so hard, but Jana from CCA, little Macy’s family and our friends, the Sieberts, were in the waiting room with me. That made the wait much easier. A few days after the surgery, we started turning the pins to move his mid-face forward.

The first time that I had to do it, my heart pounded and I was nauseated, but it got easier. When we had turned the pins for one week, the apnea stopped. His breathing was so quiet that we were happy to have a monitor.

The difference in Matthew since the mid-face surgery is tremendous. It improved his appearance, but more than that, Matthew is more confident and outgoing. He has more energy since he is not waking 20 to 30 times a night. He has gained a lot of weight and grown taller.

Matthew will turn three soon. He is sweet, although a bit spoiled, and has a wonderful giggle. He flirts outrageously with women, batting his eyes and blowing kisses to members of his “Fan Club.” He brings smiles to the faces of even the grumpiest people when he waves his arms to music and dances.

Yesterday, I talked with his birth mom. We talk about once a month and visit with her occasionally. I share all his landmarks with her and call her whenever he is having any surgeries, so that she can pray too. Yesterday, I told her that he is walking now and that he will begin school after his next surgery to remove his pins. She said, “School? Already? By himself?”

And that is exactly how I feel about it. Time has flown by, and it is hard to believe that my “little baby boy” is ready to walk into a classroom by himself.

Looking back on the last three years, there were some pretty stressful moments — and many beautiful moments. I know that the future holds more surgeries, but I would not trade Matthew for the world. In fact, I would like another one just like him, and David says that he would, too.
face-to-face: a poem for matthew
by Cheryl Whitten

I look into your eyes and you smile,
a smile that would light up the darkest night.
A smile creeps across my own face in response,
and we laugh together as if at some secret joke.
But our laughter rises from the deep joy and delight
of loving and being loved.
When I look at you I see past the differences
that strangers notice first when they meet you.
Instead of mittened hands,
I see your hand gripping my finger,
then reaching upward to lightly touch my lips for kisses.
Instead of fused toes, I see piggies,
ten of them, from the one that went to market,
to the little one that went wee, wee, wee, all the way home.
Instead of a small down-turned mouth,
I see the lips that curve into a smile for my delight,
the ones that said, “Mom, mom” just the other day.
Instead of big, bulgy eyes that rarely close completely,
I see eyes that brighten with excitement when I speak,
eyes that look at me at 4am and see past the imperfections
that a stranger would immediately notice.
Instead, you look past the puffy eyes,
lack of makeup, the extra pounds,
and messed up hair
and see exactly what I see in your eyes.
Love.

my name is Kim Idleman. When my son, Timothy
was six years old he was diagnosed with fibrous
dysplasia, a rare bone disorder involving his cranial bones.
By 1997, Timothy had undergone two cranial vault recon-
structions, as well as right orbit reconstructions. This left
him with half of his skull being comprised of titanium
mesh and more than 150 screws.

Over the past seven years we have had ups and downs,
but nothing major. I found CCA several years ago but
never utilized its services until recently. I found they had
much more to offer than I once had thought. I figured
that since my son’s disease was rare and the program had
few families in their database with the same disease that
CCA couldn’t provide the support I needed.

Wow, was I wrong! I quickly realized that families of
children with craniofacial disorders share a common bond.
We all have the same worries and though the diseases
may differ, our feelings and emotions are much the same.
We all go through the same grief and sadness. We all
need someone to share with, talk with and tell our stories
to in hopes that someone will understand what we are
going through.

Maybe new information or treatments are available that
we are not aware of yet. Maybe we just need someone
we can cry with that will cry with us, because they know
what we are feeling and going through.

This is where networking begins to work. Through the
sharing of others in similar situations, we can find what
we, as parents, need. Whether it is information, new
 treatments or support group information, CCA is there
to help families with craniofacial disorders.
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 black 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!

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?” Watch for our Take Five Campaign this spring.

Take Five is a way to contribute $5 monthly. You can donate almost painlessly using a monthly credit card deduction or just by saving your change in a jar each month. People who like the idea but want to get it over with can send $20 for three months. There will be an added incentive if you commit to Take Five for the year.

It’s about the cost of five cups of coffee (unless you go to the gourmet place, then it’s one cup!) each month, but when all of us do it together, the funds will add up quickly. If just four people commit to the Take Five plan, we can pay for airfare for one CCA kid to get to our family retreat. Multiply that by 10 (40 participants) and we can pay for six months of our toll-free helpline. Please consider the Take Five plan when your information arrives.

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!

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resulted. It is also not difficult to determine the difference between “cosmetic” and “reconstructive.” The American Medical Association has developed clear guidelines.

That’s the good news. The bad news is that families living in 40 states, the District of Columbia, Puerto Rico and the other American territories are still without adequate protection against insurance discrimination.

That brings us back to the importance of this election year for CCA families. All 435 members of the U.S. House of Representatives and one-third of the U.S. Senate are running for re-election. This means they will be spending considerable time this year back in their home states — getting out to meet the voters. Let them get to know you.

There is a measure before Congress to guarantee insurance coverage of reconstructive surgery for craniofacial patients. It was introduced by Congressman Mike Ross of Arkansas and co-sponsored by several other Members of Congress. Congressman Ross’s bill is not some far-out, unreasonable measure. It does not require any increase either the taxes or the deficit. It is also not without precedent.

The U.S. Congress has already passed similar legislation guaranteeing treatment for women who have suffered the effects of breast cancer.

But, as Congressman Ross told a CCA Forum last year, his legislation will not be passed unless we make ourselves heard. The insurance lobby on Capitol Hill is very powerful and will fight this legislation. Our CCA kids can gain much needed insurance coverage only if we make ourselves heard. If we don’t, the insurance industry will continue to deny coverage.

Please call your Congressman and Senator. It’s easy to get in touch. Or visit congress.org/congressorg/home/ on the Internet and enter your zip code. It will automatically provide information on how to contact your Senator or Representative, including the local office in your state. Tell them you support HR 1499 and tell them why. If at all possible, ask for a meeting with your Representative and Senators. Let them meet you and your family, particularly craniofacial patients. Make it personal for them.

Remember, they work for you and they want to hear your concerns.

Let’s make sure that it’s the CCA families who are the real winners this election year!

Best regards,
Tim Ayers
CCA Board Chair
CCA is so fortunate to have such a wide variety of volunteers. We have volunteers that donate their professional expertise, volunteers that help get our mailings out and others who serve on various committees.

About a year and a half ago, Lou Anderson from Wisconsin was enjoying Cher’s concert when she found herself sitting near a couple of CCA’s families. Lou was instantly touched by the kids and contacted CCA the next week. She told us her hobby was making quilts and that she would like to make some quilts for the kids.

Since then Lou has made around fifteen quilts for CCA “kidlets.” Program Director Jana Butera sends the quilts to new babies and children in the hospital who are having surgery. What a nice, warm surprise to cheer them up. So for her caring spirit, three cheers for Lou Anderson, CCA’s special volunteer!

Lou Anderson framed by two of her quilts.