

ccanetwork



newsletter of the children's craniofacial association

Cher — honorary chairperson

fall 2004

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chase's story

by Carrie and John Ingram

The evening of December 23, 1999, was shaping up to be a typical Christmas holiday night — sitting by a warm fire, enjoying a nice dinner and watching Chevy Chase's antics in *Christmas Vacation* (an Ingram tradition). Already primed to celebrate the arrival of a Special Child during that time, we suppose it was appropriate for Chase to make his appearance as well, seven weeks early. We rushed to the hospital and on Christmas Eve 1999, John Charles Ingram, III — Chase — was born.

Just days prior, we had a scheduled ultrasound that revealed nothing out of the ordinary, so other than complications that may arise from his being premature, we had no expectations of other health problems or complications. Given his positioning in the womb, he was born by C-section and immediately encountered some serious medical issues. We spent the next 10 weeks in the NICU addressing issues associated with his being premature, primarily growth and lung development, as well as airway problems.

From day one, his nasal passage was blocked by bone. In his first weeks, his doctors and we were hopeful that he would just grow out of it — this was not to be. A trach was placed when he was six weeks old. (Note: It was also during this time that we became "addicted" to pulse-ox machines, always checking his oxygen "sats" and never understanding why all parents wouldn't want one.) We were concerned about his eating by mouth with the trach, but he did fine.

It was about this time that his head was beginning to appear slightly misshapen. His doctor described this as craniosynostosis (premature fusion of the plates in the skull) and after

Chase at 4 months old with a misshapen head.



see **chase**, page 4



meet our new board members

We often hear the phrase "it's a privilege and an honor" when people are introduced. Sometimes that rings hollow, but in the case of the men and women who have joined our board of directors those words are absolutely accurate. Our five new members not only bring a wide range of personal talent to the board, they also bring a level of commitment to craniofacial issues that is very personal. Allow me to tell you a little about each one of them.

see **new board members**, 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.

meet brevin klemann

As you read this article, **Brevin Klemann** may be out shooting hoops. This outgoing first grader from Fort Pierre, South Dakota, recently got the OK from his doctor. He can now play all the sports he wants!

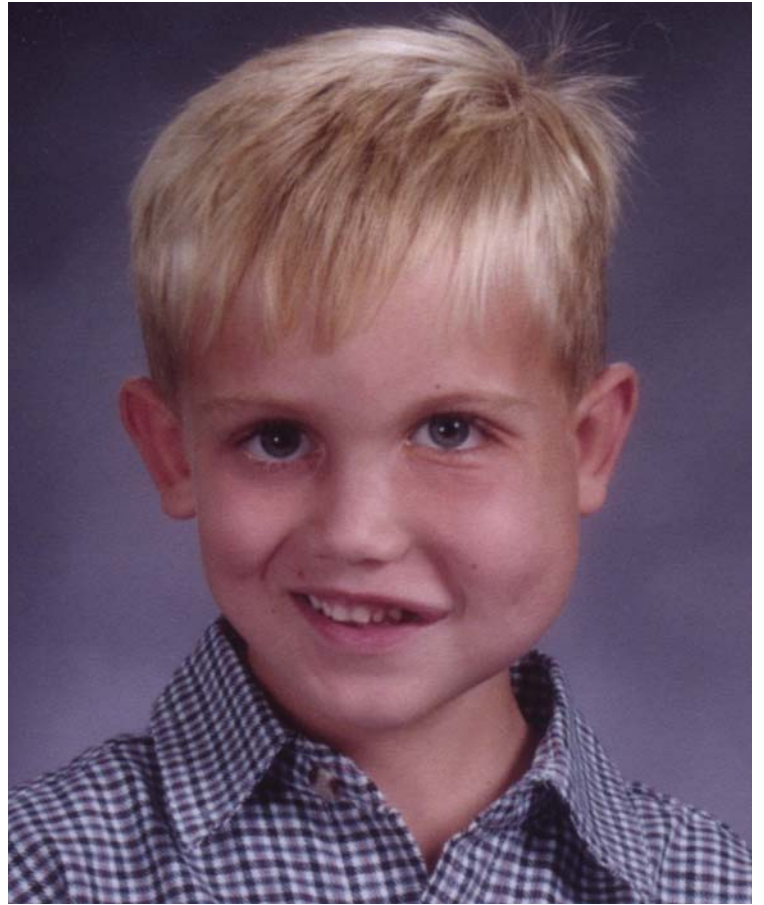
It doesn't stop with basketball, either. He likes soccer and plays golf with his own set of clubs. He's also into football — his favorite team is the Minnesota Vikings, and wide receiver, Randy Moss, and quarterback, Daunte Culpepper, are his favorite players.

When he can, Brevin spends his weekends

fishing with his grandpa at nearby Lake Oahe, where he also loves to jet ski and go boating.

During the week, he attends Stanley County Elementary School. His favorite subject is recess, naturally; when he has to go inside, he likes science the best. "Computers" come in a close second.

At home, Brevin likes to hang out with his dogs, Cassius, an 80-pound boxer, and Josie, a tiny Boston terrier puppy. You can also catch him singing his favorite songs, "Hey Ya" and "The Way You Move," both by the group, OutKast.



brevin klemann

He also spends a lot of time with his best friend, Brandon Hughes. They've known each other for years.

Brevin has fibrous dysplasia, with overgrowth of soft tissue, and has had only one surgery so far. He's had a checkup recently with his doctor in Dallas and is doing great! He doesn't need to see the doctor again for a year or so, and

his next surgery won't be until he's 8 or 9 years old.

Brevin is surrounded by family and friends who love him for who he is, but sometimes he has to handle the stares from other people. He's learned to say to them, "I was born this way."

cca kid

sibling survival!

by Melanie Howington

Little did I realize what an adjustment my first child, **Julie**, would have to make when she became a big sister at the age of four.

Typically, you bring a little brother or sister home from the hospital and life goes on with some adjustments; however, Julie's little sister, **Leigh Ann**, was born with Crouzon's Syndrome and was in the NICU for two weeks. When Julie's friend brought home a little brother after only two days in the hospital, a puzzled Julie said, "They keep them at least two weeks!"

Bringing your second born home is a challenge by itself. Add medical issues and the emotional adjustments for a family with a newborn who has a craniofacial condition, and your challenge seems overwhelming at times. How does life go on as normal, and how can your first child still receive the attention he or she so badly needs?

It seems we spent the first year or so in a fog with all of the medical issues. I went into survival mode and dealt with things as best I could. Still, I truly felt as if I unintentionally lost two years of Julie's life: Did I neglect my first child's needs? Is she going to survive this?

Here are some of our suggestions to make this time more "balanced" for the other brother or sister.

As Christians, we believe that "we can do all things through Christ who strengthens us," and our five-year-old was no exception to God's word. We taught her that "man looks on the outside, but God looks at the heart" and that God had chosen her to be Leigh Ann's big sister.

The first thing we did was to include her in the medical process. When Leigh Ann got her trach, Dr. Dad gave Tom, Julie's doll, a trach. He could be suctioned and trach changed by Julie as Leigh Ann was having her trach needs met. Tom is still in Julie's closet and serves as our "training doll" for our family and friends.

We had lots of "hospital" things around. As a result Julie would often play "doctor" with Leigh Ann as well as her doll. Julie became familiar with all the medical items and got to play "dress up" at the same time. She was very proficient at tube feeding her doll (taping a tube and a syringe to his stomach) as well as taking care of his trach.



Julie (L) visiting Leigh Ann in the hospital.

Visiting in the NICU enabled Julie to get used to medical equipment. She could explain every machine that Leigh Ann used in the NICU. My husband, the nurses or I would explain their functions in very simple terms. She once was asked to draw a picture of her family. She drew a picture of Leigh Ann hooked up to a feeding tube. She had to explain it to her friends and the class. She did a very good job for a five-year-old!

Dealing with surgeries was always essential. We would explain to her in very simple terms why Leigh Ann was having surgery — to breathe better, make more room for her brain, etc. We showed Julie a box with stuff inside. Once the stuff overflowed, we explained, you needed to get a bigger box.

We always told her how Leigh Ann was doing so she wouldn't worry. As Julie got older, she wanted to stay in school with her

friends. We would call the school, and they would tell her when surgery was over and that Leigh Ann was resting and doing okay.

When Leigh Ann had an appearance-changing surgery (i.e., RED, frontal advancement, etc.), we had to prepare Julie. We illustrated this by using toothpicks and tissue. When the toothpicks moved around, the whole look of the tissue changed. The doctors had "moved the toothpicks" to help move her bones for various purposes (breathe better, etc.).

Medical issues aside, it was truly essential that Julie have "her time." Even though we would wrestle and have family playtime together, it was important for each child to have time alone as well with us. Granddaddy would come and take her to get pancakes with smiley faces or for ice cream. We'd have

see **siblings**, page 5

chase, from page 1



conferring with a geneticist, concluded that Chase had some sort of craniofacial syndrome, probably Crouzon. We

Chase before the RED Device. had a blood test done to determine if it was in fact Crouzon syndrome; it wasn't. We haven't pursued it further since it really doesn't impact the protocol of treatments.

During this time, we scoured the Internet for anything we could find on kids with trachs, craniosynostosis, craniofacial syndromes — you name it, we read it. The Internet was an enormous tool in developing an expectation of possible future challenges and associated remedies. We also quickly realized that our family would not be a stranger to the hospital.

In June 2000, when Chase was six months old, he had surgery to detach and reshape the fused skull bones; which by that time had grown into kind of a "cone head." That surgery lasted more than eight hours and was not without risk and difficulty — a severe infection ensued while recovering in the hospital. The infection ultimately took most of the

bone in his forehead (he now has none) and possibly contributed to the onset of hydrocephalus (brain swelling), which required a ventricular shunt to be placed about a month later.

In 2001, we noticed central sleep apnea symptoms (caused by the brain, not an obstruction), which were confirmed by a sleep study at the hospital. A common treatment for central sleep apnea is to ensure that there is no pressure on the sleep center at the base of the brain. So, in both 2001 and 2002, Chase had fossa decompression surgeries to remove slivers of bone from the base of his skull that may have been putting pressure on the cerebellum. Unfortunately to date, we have not seen any major improvements. In the meantime, he sleeps with a bi-pap machine that assists with his respirations.

When Chase was almost 4 years old, he developed an infection in his ventricular shunt that ultimately required that it be replaced surgically. This was a particularly difficult ordeal as it was originally misdiagnosed and, in recovering from the surgery to replace the shunt, he contracted RSV, resulting in about a month's stay in the hospital. It was during this time that Chase developed his apprehension of nurses

and white coats, as their frequent visits resulted in "owies" (needles). As predictable as Trump's "Your Fired!" Chase would tell the nurses to "Go Out!"

In 2004, we did the "biggie" — Rigid External Distraction (RED) — to advance his mid-face. Our previous surgical team recommended that we wait until Chase was at least 8 or 9 years old before we actively pursued any sort of mid-face advancement. As this would be the surgery that would correct his airway blockage and hopefully result in removal of the trach, we didn't want to wait that long. Based on cases we read on the Internet, such surgeries were being done at much younger ages.

We expressed our concerns with the team, and they recommended we consult with Dr. Fearon in Dallas, Texas. Our initial visit to Dallas was in October 2002, where Dr. Fearon assessed Chase's craniofacial issues and Dr. Swift assessed his central sleep apnea. We stayed in touch with Dr. Fearon by phone and email over the next year.

In April 2004, we drove to Dallas from Richmond, Virginia, and stayed at the



Chase and Jana at a Frisco Roughriders baseball game.

Ronald McDonald House (RMH). We opted to stay in Dallas during the eight-week recovery period as opposed to recovering in Richmond and traveling back to Dallas to have the RED device removed.

What a blessing the RMH was! We made some great friends there, also a blessing during Chase's recovery and inspired by their own experiences and stories. If you have a RMH in your home town, please offer a visit or meal; it means the world to the families staying there.

We moved Chase's mid-face approximately 35mm, which is definitely an appearance-altering change. Dr. Fearon was clear from the outset that "overdoing it" was preferable, as that would reduce subsequent regression and give more time before a repeat procedure was necessary. So, going into the surgery, we understood that his appearance may be as "unusual" in its corrected state as it was prior to the surgery.

The recovery took closer to 11 weeks. We had some setbacks associated with placement of the device because Chase fell and hit the device on the floor. Dr. Fearon expressed that Chase's case was a challenge, primarily due to the missing bone in his head (where the RED anchors to the skull). All in all, we view the surgery as a success in that Chase's airway is now open and cannot wait to see his appearance change as he continues to grow into his new face.

As for 2005, we're exploring another fossa decompression for his central sleep apnea and surgery to fill in the missing bone in his head. We have not decided if those surgeries will take place in Richmond or Dallas.

Given all of these past hurdles, we feel Chase is doing remarkably well. He loves Thomas the Tank Engine (and all related merchandise), TV and movies, playing games and typing words on computer,

and giving hugs — especially to babies.

Developmentally, he has some difficulty with his speech (because of the trach and mouth structure) and motor skills, and he receives weekly therapies for those issues.

Cognitively, he is doing wonderfully. He's in a Head Start preschool program this year to get him ready for kindergarten next year.

Emotionally, he's a happy extravert, which is a relief for us. We worried that, given his challenges thus far, he could have turned out overly shy or withdrawn. He's happy and outgoing, and as noted above, loves babies so much that, if left unattended, will chase the nearest stroller to give hugs and rub little feet.

For the future, we view the major medical challenges to be present but diminishing. We know that guiding Chase through his formative years of self-awareness (e.g., understanding his physical differences and coping with teasing) may not be easy or smooth. Knowing that God has provided us a network of family and friends through church, CCA and RMH that will love and support Chase gives us great optimism about what lies ahead.



Chase after removal of the RED Device.

siblings, from page 3

Mom and Julie dates or Dad and Julie dates; sometimes we'd all go out together.

We taught her to tell us if she was feeling lonely or left out and not to get mad or throw tantrums to get attention. All she had to say was, "I need some time with you," and we were there. We explained that sometimes we get busy but she was very important to us and we would never neglect her intentionally. She would take us up on it if she felt the need; however, we always made a point not to wait for her to let us know if she needed "her time." We were always quick to ask her teachers if she acted out in class or seemed to want excessive attention. It takes a village to raise a child!

Julie knew that her sister was different somehow. She could tell you the name of the syndrome and what it meant. She knew and loved Leigh Ann for her true self — all appearances aside.

Still, Julie was not prepared for rude stares and comments from people outside of our circle. You know what I mean by the "circle" — the ones close to you, the ones who spend time with you, the ones who see you as you are and it's not a big deal. We've all been there.

"It's just a matter of balancing time as much as you can — and realizing it's never going to be in perfect balance 100 percent of the time."

Julie was not really embarrassed, but she'd be angry with others when they would stare or make comments about Leigh Ann. We had to teach her to politely say, "It's not nice to stare." She had to be taught that some people only look at the outside of a person, but the true beauty and value is what lies within the individual. We used a Coke as an example. The good stuff is in the can. There are people who only see the can and don't really know just how wonderful the Coke inside can be!

Throughout their lives, they've been typical sisters: Julie is now 18, Leigh Ann 14. I still want back my two years I felt I missed, but I've been blessed to see both my girls grow up into incredible young ladies. Because of the impact Leigh Ann has had in Julie's life, Julie wants to be a doctor.

Siblings do survive this transition, as do the parents. It's just a matter of balancing time as much as you can — and realizing it's never going to be in perfect balance 100 percent of the time.

donors, April 1 through September 30, 2004*

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

Cher Convention Foundation

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

year-end contributions

did you know...

Cash donations to CCA can be made by credit card anytime through December 31st. The IRS considers the date the donation was charged to your card as the contribution date even though the bill won't come due until January.

give a gift...

in honor of a loved one this holiday season

You can give a gift to CCA in honor of a loved one. What a great way to make a person feel good, and make a difference, this holiday season. Maybe the kids can give up one gift for themselves and donate in honor of someone else – get creative! We will acknowledge your donation and note "in memory of" or "in honor of" on a card to the gift "recipient."

ccabikernews

special insert to the newsletter of the children's craniofacial association

Fall 2004

Cher—Honorary Chairperson

ambassador's report

hello from the 2004 Black Hills Bike Rally in Sturgis, SD! This year our raffle bike was a lava-red Harley Heritage Softail, again autographed on the gas tank by **Cher. Rod "Woody" Woodruff**, his wife **Carol**, daughter **Toni** and their entire "crew" were our hosts at the **Buffalo Chip Campground**, and like always, they made us feel right at home. **Jeff Ice** and **Bonnie** helped us park the RV and haul our tent, tickets and banners to our "booth" each day. We were greeted by **Jim Burgess** from Black Hills Harley, where we got our raffle bike. **Dave Vice** and his "**Vice Squad**" had built a Harley store on the grounds, where he displayed our bike each



The Pagsta tank autographed by many of the event headliners

day; then he had **Mike** from the store bring the bike back to our tent each afternoon for ticket sales.

This year, in addition to our Harley, my good friend (and CCA's good friend too!) **Johnny Pag** donated a special USA-style Pagsta Choppa bike to be raffled. (It's just like the one he gave us to raffle at the Cher Convention.) This one was autographed by all the bands who played throughout the week at the Chip.

see **ambassador**, page 8



we have a winner!

Our Harley winner is **Thomas L. Woltkamp** of Topeka, KS. Tom was surfing the net for car raffles and saw a few for Harleys. He searched "Win a Harley" and found our fundraiser and decided to support our efforts. He purchased 30 tickets for \$100 online back in the beginning of June. Tom's charitable generosity paid off big time! Congratulations to Thomas, and thanks to everyone that made this year's raffle a success.



L to R: Tammy Van Ness, Annie Reeves and Jana Butera.



Kevin Braden



ambassador, from pg 7



L to R: Pagsta winners Kristin Grimlie and Randall Okker celebrate with their spouses, Steve Mulder, Jill Gorecki and Duane Tyler.

When Pagsta's Midwest Distributors, **Steve Mulder** and **Duane Tyler**, heard about Johnny's donation, they arranged to give one away each of the other nights as well. We had those bikes signed nightly by the headliners, including **Montgomery Gentry; Styx; Blue Oyster Cult; ZZ Top; The Beach Boys**, who also signed some beach balls for us to use as incentive gifts for those who bought 30 tickets for \$100 that night; **Classic Rock Allstars; Heart; REO Speedwagon;**

Nickelback, who also donated ticket sales incentives; and **George "Bad to the Bone" Thorogood!**

Brad Coombs rounded up some great talent for Woody this year, and I got to take our giveaway Pagsta bikes backstage for their autographs!

Mike Sanborn got **Erin Pelton**, this year's poster model, to draw people to our booth by signing posters when they bought a ticket, and she and her husband, **RJ**, also escorted me onstage for the Pagsta drawings.



Shari Green & Kim Morris from First Gold Casino, Rob Gorecki and Dave Perewitz pose with Dave's custom Gibson Bike

Steve Owen, the stage crew and the security people both backstage and on the grounds not only helped us with getting our bikes onstage and with the

tumblers for our raffle drawings, but they also bought a lot of raffle tickets from us! **Hank Rotten** made announcements onstage about CCA, and **Tom Kingsbury's team** put a CCA commercial on the big screen to get everyone to buy tickets. **New York Myke** had us on his radio broadcast out there too!



Tom Nelson of Erie, PA, Friday night's Pagsta winner.

our ride. Thanks to him, we had well-known custom bike builders, **Dave**

Perewitz, Donnie Smith and **Kendall Johnson** all leading our ride. It looked awesome with lots of **Hamster's bike club** custom bikes pulling up in front of the **First Gold Casino** in Deadwood, where we staged the ride. My friends there treated our people to a buffet and some casino cash while they registered. (I was sorry to hear the gambling age is 21 not 18... shoot!)

The ride went to Mt. Rushmore, where security gave us special entrance so we didn't have to wait in line. We had drinks and



Tom Kingsbury with his "friend."



L to R: Donnie Smith, Dave Perewitz and Kendall Johnson, all well-known custom bike builders, led the CCA Ride.

Our ride was scheduled for Tuesday, and my buddy **Harry Bostard** helped us by getting stuff for our goodie bags and asking some of his friends to join

snacks before heading back to the Chip for a Buffalo Pitchfork Fondue dinner, door prize drawings and that night's Beach Boys

continued next page ⇨

concert. Everyone had a great time.

Since I had my motorcycle, thanks to **Greg Patterson** who hauled it for me, I rode into town later in the week and met with **Debbie Martin**, a custom bike builder who's donating a special *Mask*-themed bike to CCA for 2005.



Kenneth Goodman and Robbie Gorecki

Jana and **Annie** also sold more tickets in town during the day at the **Knuckle Saloon**. The weather held out and was perfect all week long. Before we got to Sturgis, our sales were enough to pay for our expenses (buying the bike, etc.). By the end of the Sturgis rally, we had raffled eight Pagstas and our Harley and raised more than \$20,000 for CCA! I'll be back there again next year to report all the happenings.

Robbie Gorecki, CCA Ambassador to Sturgis



Jeremy, Kristine and George Dale

high on sales

The CCA family/friends winner for Harley raffle ticket sales is the **Dale family** of Horsehead, NY. Kristine and George Dale whose eldest son, Jeremy 5, was born with Goldenhar's syndrome, had just moved to a new city and still managed to sell 480 tickets. The Dales raised \$2,030 and were presented a Franklin Mint replica of our raffle bike, with a happy surprise — the display case was autographed by Cher! Congratulations go to **Kristine, George, Jeremy** and **Tommy Dale**. And, a big thanks to all of our families and friends who helped sell!

thank you!

Our raffle was supported (with a ticket purchase) by the following Harley dealerships:

Black Hills Harley-Davidson

San Diego Harley-Davidson

Hal's Harley-Davidson New Berlin, WI

High Harley Davidson Frederick, CO

Graves Harley-Davidson Lubbock, TX

Milwaukee Harley-Davidson

Mike's Famous Harley-Davidson Groton, CT

McGuire Harley-Davidson Walnut Creek, CA

Fletcher's Harley-Davidson Clearwater, FL

Carolina Coast Harley-Davidson

Wilmington, NC

Dudley Perkins Harley-Davidson

San Francisco, CA

Harley-Davidson of Cincinnati, Inc.

Schaeffer's Harley-Davidson Orwigsburg, PA

Gulf Coast Harley-Davidson

New Port Richey, FL

Grove's Harley-Davidson Winchester, VA

Laugerman's Harley-Davidson York, PA

Gary Bang Harley-Davidson Atascadero, CA

Harley-Davidson/Buell Ukiah, CA

Barnett Harley-Davidson El Paso, CA

Red River Harley-Davidson Iowa Park, TX

M&S Harley-Davidson Chambersburg, PA

Harley-Davidson of Baltimore

River City Harley-Davidson Fort Wayne, IN

Chattahoochee Harley-Davidson

Columbus, GA

Zepka Harley-Davidson Johnstown, PA

Kersting's Cycle Center, Inc. Winamac, IN

Visalia Harley-Davidson/Buell Visalia, CA

Walker's Harley-Davidson Sales, Salem, OR

investments

Children's Craniofacial Association has selected **SIG Fiduciary Management** to provide investment management services and assistance with charitable giving. SIG has the ability to assist with any charitable giving method, including outright gifts of cash or property, bargain sales, charitable remainder trusts, charitable lead trusts, remainder interests in a personal residence, life insurance and testamentary gifts. Gift development services available to our donors include: (1) technical assistance in the development of the gift, (2) guidance in the transfer of assets, (3) initial asset valuation, (4) computation of donor's charitable tax deduction and (5) design of investment strategies customized to meet the specific desires and needs of the donors and beneficiaries.

This new relationship with SIG provides a unique opportunity for CCA donors to significantly help build our resources. If you are considering a deferred gift to benefit CCA, please give us a call for more information.

3 cheers for volunteers!

We'd like to say "THANK YOU!" to our terrific group of volunteers! All spring and up until we leave for bike week in Sturgis, our families and friends help us sell our Harley raffle tickets. Once we're out there, we have a week-long push to raise funds. This year we were especially busy each day of the rally.

We are truly grateful to **Jodi Klemann** (Her son, Brevin is this issue's CCA Kid.); her sister **Nicole Saylor**; her sister-in-law, **Laura Klemann**; her mother and dad, **Walt and Colleen Reinert**; and her parents' good friends, **Dave and Jean Meher**. These folks are veteran volunteers, traveling for hours each way to help us out.



L to R: Laura Klemann, a ticket buyer and Nicole Saylor.



Jodi Klemann poses with a ticket buyer on the Harley.

Saturday and planned our ride.

Tammy Van Ness and **Kevin Braden** have been with us every year we've been out in Sturgis, and they contribute an enormous amount of time and money to CCA. They also sell tickets at various venues at home in Idaho and are "agents at large" for the charity, gathering donations — both monetary and in-kind (door prizes etc.) — to help make our efforts a success and spread awareness of craniofacial conditions. Kevin helped plan our ride and lead our celebrity grand marshals on the route.

Robbie's uncle, **Al Gorecki**, used his vacation to help at our charity tent throughout the week and helped Kevin on our ride by acting as road captain at the rear, making sure

nobody got left behind. He also beat the pavement back home in Wisconsin, selling more than \$500 in raffle tickets before leaving for Sturgis.

Speaking of our ride, it was staged at **First Gold Casino** in Deadwood, and our good friends including **Brad Hemmah, Kim Morris** and **Marilyn Harrison** hosted a buffet and provided casino coupons for our ride participants during registration. They also sold our raffle tickets at the casino.



Al Gorecki (L) with two ticket buyers.



First Gold Casino...L to R: Robbie Gorecki, Jill Gorecki, Brad Hemmah, Marilyn Harrison, Kim Morris, Annie Reeves and Greg Patterson.

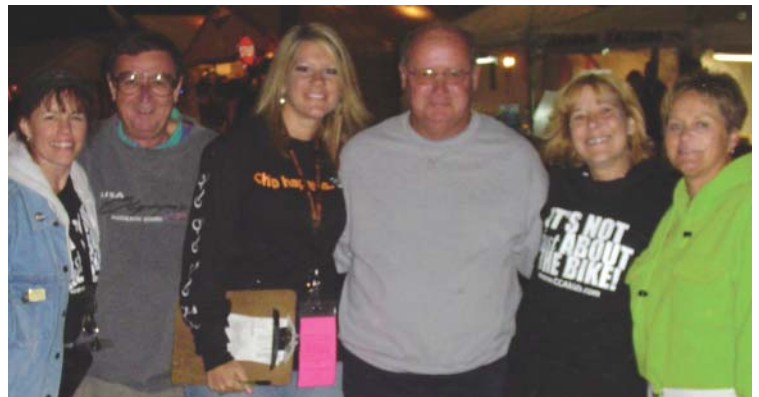


Rhonda Hilliard

Our favorite lady biker from Oregon, **Rhonda Hilliard**, was camping at the Buffalo Chip and helped out at the CCA tent during the week. She's also helping to plan our women's ride.

And, of course, our South Dakota "extended-family" member, **Megan Bennett**, was with us as always.

Thanks to all who helped and to all who bought tickets. **Three cheers for Team Sturgis!**



L to R: Jill Gorecki, Dave Meher, Annie Reeves, Walt Reinert, Megan Bennett and Colleen Reinert.

new board members, from page 1



Donna Gossett lives in Cullman, Alabama, where she is a substitute teacher, PTA Secretary, mother of two great kids and will soon be celebrating her 20th wedding anniversary. Donna has Fibrous Dysplasia. Because her insurance company labeled any reconstructive surgery as “cosmetic,” she has never had an operation to correct her condition. Donna is at ease with her face, but is now a determined advocate to make insurance companies do the right thing. She lobbies senators and congressmen and has received sensitive coverage of her campaign by both newspapers and television in Alabama.



Heather Lermont-Pape is also a craniofacial patient, born with a cleft lip and palate. The “old timers” among us remember her dedication and commitment to CCA in past years. Heather was absolutely critical in helping to get our annual retreat program off the ground. Her understanding and empathy was a real inspiration for the kids. Heather had to reduce her involvement in CCA for a while, but now she is back and ready to go to work! Heather lives in Indianapolis, where she is a trainer with Monster.com



Dan Paulson lives in Moorehead, Minnesota,

and represents the Far North wing of the country for CCA. Dan is a partner and vice president of Imaging Solutions, a medical imaging firm in Fargo, North Dakota. We’re looking to him to bring his business acumen to CCA. Dan is the proud father of Emily and Danny and became involved in CCA because of Emily’s Treacher Collins condition.



Rose Seitz is well known within the CCA community. She and her husband Fred have been extraordinarily generous with their time and talent in helping us to create and continuously improve CCA’s Web site through their company, Directed Technologies, Inc. — now one of the most important tools we have for helping craniofacial patients. If you’ve been to recent annual retreats, you have doubtlessly met Rose, Fred and their three sons, particularly Freddie, who has Goldenhar Syndrome.



Stephen Wright is also a retreat regular. Stephen has had 23 surgeries to deal with the results of Crouzon’s Syndrome, but that hasn’t prevented him from earning his MBA from San Francisco State University and working for Wells Fargo. Stephen says that living in liberal California and growing up in conservative Utah gives him a balanced perspective on the world. I know that CCA will certainly benefit from his positive view of life.

As you can see, we have great new recruits joining myself and fellow board members Dr. Tony Davis, Bill Sims, Robert Vargas, Robin Williamson and, of course, ex-officio member Char Smith. It’s a great team!

Tim Ayers
Board Chair

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

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!

children's craniofacial association

13140 Coit Road, Suite 307 • Dallas, TX 75240

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.



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Cher

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