



inside

cca kid
Rush Allen 2

how to
matching gifts. 2

cca grad
Stephen Wright. 3

what's new?
cca board sets goals . . . 6

new development
director hired 6

new distraction
technology 7

3 cheers
Tony Davis. 8

"meet me in st. louis" provides good time theme for cher's family retreat

By Tim Ayers, Board Member, Tim Ayers and Associates



There were lions and tigers and bears (Oh my!)...and buffalos and elephants and llamas and lots of other furry and feathered creatures for CCA families to enjoy at the St. Louis Zoo and at the famed Grant's Farm just outside the city. The kids (and lots of the adults) had a lot of fun at The Magic House, an interactive children's museum that provided loads of hands-on activities.

The kids, and more than just a few Dads, had an exhausting, but wild time at the pool party. This year's kick-off ice cream social had a special sponsor, **Karen Hartstein**, of St. Louis, who is a great supporter of CCA and particularly of this year's Family Retreat. And, of course, the highlight event is the annual dinner-dance, when everyone gets to let down their hair and strut their stuff.

see **retreat**, page 4



message from the chair

I'm very excited and pleased to tell you about our next big steps as an organization. First, we have enough funding to dramatically increase the programs we offer families! We also have enough funding to create a director of programs position. This new position fits with our strategic plan that envisions CCA as the leader in providing information and support regarding craniofacial syndromes.

So that you realize how significant this is, I'll give you a brief history of how we've arrived at this point. About three years ago, we were struggling

see **chair**, page 7

ccakid

meet rush allen

Rush Allen, a sixth-grader, was born in Neenah, Wisconsin, and now lives on a dairy farm in Oshkosh. Because of his love for the great outdoors, his favorite school subject, naturally, is recess.

As for after-school activities, Rush pitches for the baseball team, Kwik Trip. "I love to play baseball!" he said. He especially likes the Chicago Cubs, and his favorite major-league player is legendary slugger, Sammy Sosa.

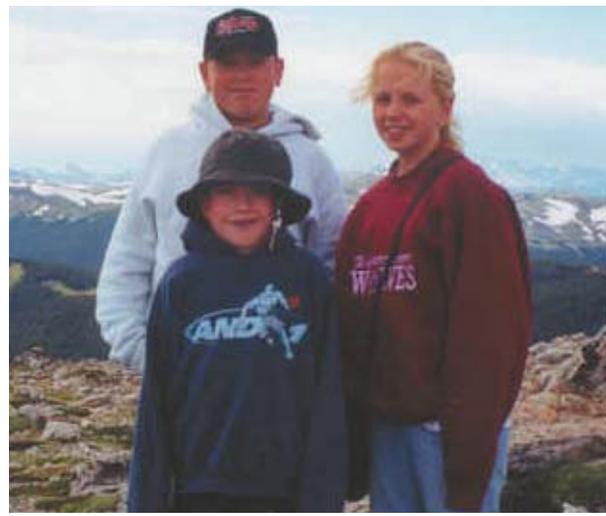
Since he has grown up on a dairy farm—with 80 cows, 100 steers, 20 sheep, 4 donkeys, 2 dogs, lots of cats and his favorite ewe, Bink—Rush has a love for animals, too. In 4-H, he shows steers and sheep and has won six trophies! So guess what he wants to be when he gets older? You got it—a veterinarian!

Rush has Goldenhar Syndrome, excluding eye

involvement. He has undergone 26 surgeries and has more to come. Growing up with a craniofacial condition has taught Rush a lot: "The most important thing I've learned is that people need to not judge others by their outside appearance, but for their personality inside."

Rush has attended four retreats so far. He likes the fact that he's around others that understand, who are not judgmental. The retreats give him a place where he can relax and just be himself.

His favorite retreat by far was in Colorado. Rush and his family also took a side trip to Estes Park, where they did some hiking. "The mountains were awesome!" he said.



Rush with his brother, Cody, and his sister, Kjrstin, in Estes Park, Colorado.

Rush with one of his 80 cows.



double, triple or even quadruple your gift with corporate matching

Just to remind you, your gift to CCA can be doubled, tripled or quadrupled if you are employed by one of the many companies and their divisions, subsidiaries or affiliates that participate in Corporate Matching. All you need do is obtain a matching gift form from your company's matching gift administrator—usually located in your Human Resources department—and follow directions

based on whether your gift is a payroll deduction or a contribution that you send in yourself.

Speaking of payroll deductions, did you know that if you give to your local United Way Campaign you can have your contribution directed to CCA? This is a great way to not only help your company meet its fundraising goal but also help your favorite charity!

stephen wright



When I was four years old, one of my best friends was an enormous tree, which was in the center of our front yard. I can still hear the sounds of the wind blowing through the branches and rustling the leaves. The tree was a strong fixture in my life and never made fun of me for being different.

I lived with my family next to an elementary school, and a lot of children would pass by the yard on their way to school or other activities. I had not started school yet, so I would often play outside in an imaginary world where I was in control.

I developed a keen ear for impending danger. Whenever I would hear the sound of children approaching, I would run behind the tree and stand quietly until the children had passed. I was different from the other children and was often

teased about how I looked.

One day I was caught off guard and didn't hear when some children approached. I ran to get behind the tree, and a boy saw me running through the yard. He jumped the fence and yelled that I could not hide from him. When I saw him jump the fence, I immediately left the tree and tried to get into my house. I made it up three of the steps before he pulled me from behind and punched me in the stomach. My mother heard my cries and helped me up the steps into the house, where she held me until I stopped crying. I remember her telling me that life isn't always fair but that I was safe.

Now, 29 years later, I still often visit that child under the tree. I tell him not to worry because his life will work out and although the road may be rocky at times, there are

people who will always be there to help. Most important—I will never let him down or let him be left alone.

In my opinion a child should be allowed to hide behind trees as needed, but a strong sense of independence should be fostered in the child so that he/she can eventually stand independently of the tree and interact with other people. A balance is needed between the relief of "crutches" and the pain that is necessary to move through for growth.

Stephen Wright is 33 years old and works in San Francisco at Bank of America. He is currently finishing up graduate school with an MBA at San Francisco State University. Stephen is a published writer with two articles published in *PARADE* magazine. He has also been featured in a Canadian magazine about craniofacial issues.

Stephen has Crouzon's Syndrome and has had 23 surgeries which includes complete reconstruction of the face as well as skull restructuring.



ccagrad

twelfth annual cher's family retreat

june 27 – 30, 2002
hilton st. louis frontenac
st. louis, missouri

It seemed that every adult had a camera, so there will be a lot of memories to share with the folks back home about the great time in St. Louis. In fact, photo albums from previous years' retreats were a big hit.

It was the 12th Annual CCA Cher's Family Retreat, and it just seems to get better every year as CCA families renew old friendships and have a chance to start new ones. One participant said, "I wish my life was like our Family Retreat. I'm working on it. It is just like in the movie 'Mask.' Rocky knew who were the important people in his life were and everyone knew what was

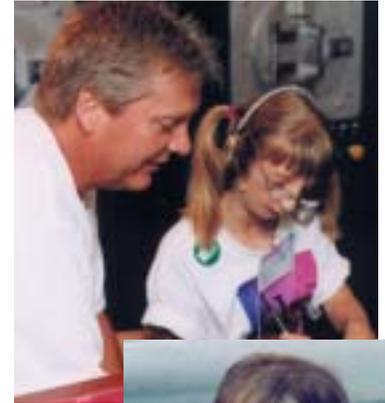
important: family, friends and having a good time."

CCA Honorary Chair, Cher, began the tradition a dozen years ago and has attended as her schedule allowed. This year, however, Cher was on her world tour, which is also a fundraising event for CCA. She was missed but appreciated for her great work on behalf of CCA.

At the dinner-dance, CCA Board Chair Terry Carmichael reminded



everyone about the great progress that the Association made during the past year. She thanked all of the families for their support and for their



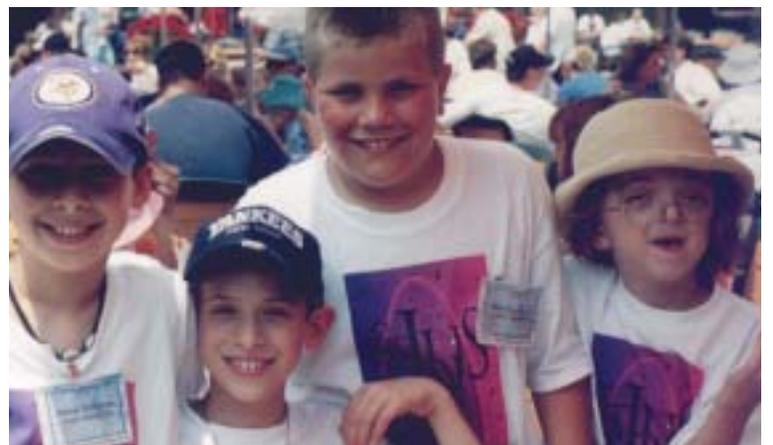
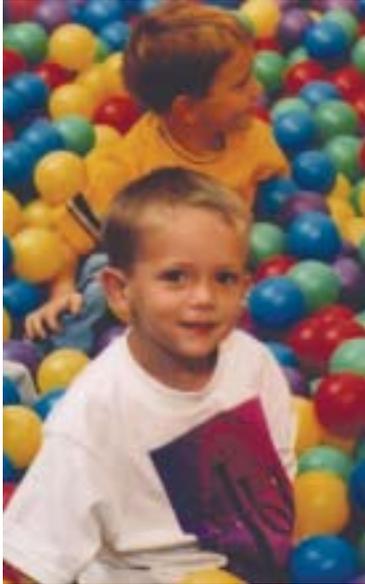
volunteer efforts and urged all to keep up the effort. Then she advised them to "Parteeeee."

Planning has already begun for next year's Cher's Family Retreat in Washington, DC. In an effort to share the fun



among more families, there will be a heightened effort to reach out to a greater number of people through the Association's network. CCA will also identify more sources of support for the families wishing to attend the event.





cca board sets goals for next 3 years



doubling the number of families served by CCA and increasing fundraising to more than a million dollars are just two of the ambitious goals set by the CCA Board of Directors at a two-day strategic planning session, May 4 – 5. At the meeting, the Board developed a strategic plan designed to set the course for the Association through 2005.

The value of these sessions was underscored by the progress of the past two years. In 2000, the Board met for the first strategic planning session. At that time, CCA was operating in the red financially. The Board established a plan for developing a firm financial foundation so that CCA would have the money to

continue and eventually expand services to families. This initial plan ultimately led to a major increase in funding, and the Association now finds itself in a more financially secure position.



Facilitators John Paul and Sheryl Paul with Charlene Smith.

With more resources available, the Board is now turning its attention to expanding programs. The new strategic plan revolves around three major themes: 1) family support, 2) education and information, and 3) research. To realize the goals, the Association will seek feedback from CCA families, conduct a new public awareness campaign about CCA among health care professionals,

launch an aggressive recruitment campaign for volunteers and develop more sophisticated fundraising efforts. The Board also enthusiastically agreed to provide more staff to assist in implementing the expanded programs.

As in 2000, John and Cheryl Paul of Association Works conducted the 2002 planning session. The Board truly appreciates the work of the Pauls in providing this service to CCA.

new development

Jill Gorecki has been hired to fill the vacant position of Development Director for CCA. Jill's son, Robbie, was born with a facial cleft resulting from Goldenhar's Syndrome. The family has been involved with CCA since 1990, when they traveled with other families to Washington, DC, to testify on behalf of craniofacial patients everywhere at a congressional hearing of the House Budget committee. Jill has since been active as a parent



Charlene Smith with board members Tony Davis and Di Sweeney focus on the issue at hand.



Board member Robert Vargas at the "Idea Board" with facilitator John Paul.

volunteer and has served as a member of CCA's Board of Directors. A background in sales coupled with her knowledge of issues faced by children and adults with craniofacial conditions and their families makes her an ideal candidate for this position. Welcome, Jill!



Charlene Smith along with board members Di Sweeney, Tim Ayers and Terry Carmichael enjoy a heated game of foosball.

new distraction technology

a new technology for facial bone distraction has been brought to our attention by OsteoMed Corporation of Dallas, Texas.

Every year, thousands of patients with facial differences are treated under distraction osteogenesis. Traditional distraction

devices are large, cumbersome and metallic devices, resting outside the mouth.

Newer distraction devices are low-profile and rest completely inside the patient's mouth and can easily be adjusted at home by parents. The device remains in place for the duration of treatment

and after distraction as well, acting as a support while the newly formed bone hardens. One such device, the Logic

Mandibular Distraction System, is manufactured by OsteoMed.

retreat, from page 5



chair, from page 1

to survive. I asked the board of directors, our families, the medical advisory board and you, our loyal newsletter readers, for help and a commitment to help save CCA.

Everyone stepped up and helped in too many ways to mention, allowing us to:

- Become financially stable.
- Hire Jill Gorecki as our new fund development director. (By the way, we get her assistant, Robbie, for free. Robbie is 15 years old with Goldenhar's Syndrome and is an enthusiastic fundraiser for CCA)
- Increase participation in the family retreat. We had 42 families from six countries and 20 states attend last year and plan for more in the years ahead.
- Write a children's book of empowering stories/poems.

- Write and develop a new informational brochure.

The CCA board of directors has been very busy validating and ensuring that CCA remains a 501(c)(3) charity, in compliance with all regulatory agencies—we're "squeaky clean" and proud of it!

- All of our financials are audited and certified by an outside CPA.
- Our bylaws have been rewritten.
- All of our state and federal filings have been reviewed and updated.

I'm proud that CCA is in its current situation, and I promise to continue to work hard to raise the money required to fulfill our mission to empower and give hope to facially disfigured individuals and their families.

3 cheers for volunteers!



CCA is very fortunate to have a hardworking Board of Directors. Each has expertise and interests important to CCA's success. One very eager board member is **Dr. Tony Davis**, nicknamed "Relentless" by fellow board members for his persistence in his fundraising efforts.

After meeting CCA's families during his first retreat, Dr. Davis became passionate about helping CCA develop funds to maximize services for these most deserving families. Tony immediately became a major benefactor of the Annual Cher's Family Retreat. Next he created

an annual fundraiser that would help CCA sustain its important programs. After much research and many inquiries, the Harley Raffle fundraiser was born.

This year CCA will raffle off its third Harley Davidson motorcycle at the Blackhills Motorcycle Rally in the shadow of Mt. Rushmore in Sturgis, South Dakota. Each year Tony has increased sales opportunities for the raffle. This year Tony and his committee debuted the Heritage Softail®, autographed by Cher, at the Del Mar Fair in Del Mar, California. They have

recruited families to help sell tickets and increased the number of sales sites at the rally. (Tickets have also been on sale at CCA's web site, www.CCAkids.com.)

When he's not beating the pavement for CCA, Tony practices dentistry in Piedmont, Alabama. He lives with his wife, Laura; his daughters, Bonnie, who is completing her freshman year of college; and Amy, who is a junior in high school; Buddy, the basset hound puppy; and a cat and her nine babies. (By the way, the kittens are available for adoption.)

CCA is lucky to have Tony on the team, with his incredibly kind heart and engaging sense of humor. Three cheers for Tony!

Honorary Chairperson:
Cher

Board of Directors:
Terry Carmichael, Stonewall, CO,
CHAIRPERSON
Tim Ayers, Washington, DC
Tony Davis, Huntsville, AL
Sally Longroy, JD, Dallas, TX
Bill Sims, CPA, Dallas, TX
Diana Sweeney, Maple Glen, PA
Robert Vargas, Dallas, TX
Robin Williamson, Carrollton, TX

Medical Advisory Board:
Jeffrey Fearon, MD, Chief Advisor

CCA Network Editor:
Kelly Liszt

CCA Network Production:
Robin Williamson, Williamson
Creative Services, Inc.

Executive Director:
Charlene Smith

Development Director:
Jill Gorecki

Business Manager:
Cathy Evans

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

VOICE 214-570-9099

FAX 214-570-8811

TOLL-FREE 800-535-3643

URL www.CCAkids.com



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

return service requested

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