At CCA, we are beginning to really sink our teeth into our new fiscal year plan. As we look at what we want to accomplish, I realize how many talented and generous people have helped us get to this point and how important our volunteers are.

Coming from a corporate background where professional people are very well compensated for their talent and time, I know that you often pay for what you get. So I am very pleased and appreciative when highly talented and generous people volunteer their time and resources toward the cause I believe in. I know that a lot of you volunteer many hours in your every day lives and for that I am very grateful.

The children's Craniofacial Association has become a phenomenon. I believe that Cher's passion and determination combined with our skilled volunteers have been key to our success. With the help of all of you, we have made a difference in the lives of so many children and their families.

We appreciate and need you. With your continued support, we will make a difference in the lives of many more children and their families.

Thank you for your volunteer dedication.

Cher
Honorary Chairperson
Children's Craniofacial Association

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Las Vegas was the site of Cher Convention 2002. Cher fans from all over the United States and several foreign countries convened at the Riviera Hotel for a weekend of celebrating Cher's career and benefiting her special charity. Cher became Children's Craniofacial Association's spokesperson after playing the role of the mother of a child with a Craniofacial condition in the movie, Mask.

On July 12, 2002, conventioneers kicked the weekend off with a seated dinner and auction. Entertainment was provided by some of the most talented Cher impersonators in the world, including Wayne Smith, Chad Michaels, Jeffrey Thomas, Amy Hohimer and England's version of Sonny and Cher, Mark Parry and Catherine Carter.

Saturday's events included Ward Lamb's Cher Seminar, Cher Trivia, hosted by Mary Ladd, and BostonQ's Cher's Career Seminar. Interspersed were performances by the five most talented Cher impersonators in the world and many, many more. The entertainment was provided by some of the most talented Cher impersonators in the world, including Wayne Smith, Chad Michaels, Jeffrey Thomas, Amy Hohimer and England's version of Sonny and Cher, Mark Parry and Catherine Carter.

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Late June may seem like a long way off, but it will be here before you know it. Next year CCA will travel to **Washington DC** for the 2003 Cher Family Retreat, where we will be staying not far from the White House, the monuments, museums and many other attractions. Because Washington has so much to offer, CCA is planning a range of activities that will be fun for everyone in the family. Transportation is being planned to make seeing the sites easy, safe and affordable while families are attending the Retreat. And Retreat favorites such as the ice cream social, pool party and dinner-dance will still be on the agenda.

Families may want to do some early planning or possibly extend their stay in Washington. It will be summertime, and there’s a lot to see and do in the Washington DC area and the mountains and beaches nearby.

Here are some great Web sites to get you started:
- [www.washington.org](http://www.washington.org)

What you don’t want to do is miss out. The Family Retreat will be **June 26 – 29**. To reserve your hotel room and register, call or email the CCA office for a retreat registration form. (800-535-3643 or csmith@ccaKids.com) Don’t miss out. Start making your plans now for next year’s Retreat!

CCA is pleased to congratulate **Dan Freeman** from Tucson, AZ, on his high raffle ticket sales and we have presented him with the autographed Cher doll. Dan sold 400 tickets and is also sending us a check for what he thinks the collector’s item might be worth. Wow! Thanks, Dan, for helping sell tickets and for making a difference for our families.

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**Meet Elizabeth Hubbard**

Elizabeth Hubbard, an outgoing 11-year-old from Fairfax, VT, is an avid reader. “I just finished *Maniac Magee*, and now I’m reading *Stargirl*,” she said. She’s a sixth-grader at Bellows Free Academy, where her favorite subject is, naturally, Language Arts. And out of all of the teachers, she likes Mrs. Nelson the best.

When she’s not busy reading, Elizabeth loves collecting. Her collections include marbles, porcelain dolls and figures, and Beanie Babies. “I had about 420 marbles the last time I counted,” she said.

Elizabeth has gone to two Cher concerts, where both times she got to meet Cher back-stage. “She’s really nice. I also got to meet her cat, Mr. Big,” she said.

Elizabeth also has gone to four retreats so far — Dallas, Orlando, Atlanta and St. Louis. She really liked the St. Louis retreat the best, where she loved going to the zoo. She has neurofibromatosis and one of the sweetest dispositions. Remembering a beautiful St. Louis sunset during the last retreat, Elizabeth remarked, “The sun looked like it was right on top of the arch.”
CCA lends support for rare diseases legislation

At the beginning of November, President George Bush signed into law the Rare Diseases Act. CCA’s Board of Directors had urged the President to sign this important legislation. The legislation addresses a longstanding, unmet need to develop new treatments and cures for rare disorders.

“Not since the passage of the Orphan Drug Act in 1983 which created financial incentives and research grants, has legislation been enacted that has such a profound and lasting impact on the millions suffering with rare diseases,” said Abbey Meyers, President of the National Organization for Rare Disorders (NORD). “The entire rare disease community has worked so hard for this momentous day.” CCA is now working in conjunction with NORD on important federal legislation such as the Rare Diseases Act.

Originally introduced in August 2001 by Senators Edward Kennedy (D-MA) and Orrin Hatch (R-UT), the Rare Diseases Act of 2001 (S.1379) was later split into two separate bills: H.R. 4013, sponsored by Representative John Shimkus (R-IL), nearly doubles the budget for the Office of Rare Diseases at the National Institute of Health and authorizes the office to enter into cooperative agreements and to award grants for clinical research into rare diseases. H.R. 4014, sponsored by Representative Mark Foley (R-FL), doubles the funding for the Food and Drug Administration’s Orphan Products Research Grant program. Congressman Henry Waxman (D-CA), a long-time supporter of the rare disease community and the chief sponsor of the Orphan Drug Act, co-sponsored both H.R. 4013 and H.R. 4014.

As she did in tours past, our National Spokesperson, Cher, has generously given concert tickets to CCA. Diana Sweeney, CCA board member, helped many families across the country and Canada attend Cher’s shows and visit with her backstage.

The Living Proof Tour is Cher’s farewell tour, but she intends to stay busy with acting in and directing movies. In fact, as this is printed she is extending the tour, with an end date still unknown.

This may be her farewell tour, but it isn’t goodbye as far as CCA is concerned. We are grateful to our favorite star for all she has done, and we send her a huge, heartfelt thanks from all the families and kids!
My child has a craniofacial condition. How can I be sure I am doing everything possible to prepare him for starting school.

If your child is experiencing developmental delays in one or more of the following areas — physical, cognitive, communication, social or emotional or adaptive development — you can contact your local education agency and request a multidisciplinary assessment. This assessment will determine the unique strengths and weaknesses of your child. If the child is eligible to receive special education services, the services would be put into an Individual Education Plan (IEP). The IEP is a written plan that the teacher follows to address your child’s individual needs. This plan would then be delivered by the local school district or special education co-op. The extent of services depends upon the individual needs of the student.

What types of early childhood services are available?

Once your child reaches the age of 2.5 years, federal regulations through the Individual Disabilities Education Act (IDEA) require local school districts, through Child Find, to perform preschool screenings. These are conducted by a multidisciplinary team (i.e. speech pathologist, psychologist, social worker, etc.) and determine if your child is eligible to receive special education services and at what age these services should begin.

How do I get my child screened?

Parents should contact their local special education cooperative or special education district to determine what service might be available. If you are uncertain how to find these agencies, contact your local school. If, upon evaluation your child is eligible for special education services, the services would be put into an Individual Education Plan (IEP). The IEP is a written plan that the teacher follows to address your child’s individual needs. This plan would then be delivered by the local school district or special education co-op. The extent of services depends upon the individual needs of the student.

Once my child is in school what other services are available?

Once the child is in school, and an evaluation determines that he or she is not eligible for special education services, he or she may still be able to receive accommodations under Federal legislation Section 504. To determine if a 504 plan would be appropriate, it will need to be determined if there is an impairment, that affects a major life function (i.e. caring for ones self, performing manual activity, walking, seeing, hearing, speaking, breathing, learning and/or working). If the answer is yes, a 504 plan will be written for your child by school personnel and you, identifying the accommodations needed.

My child will require many surgeries. How can I make sure he doesn’t fall behind in his schoolwork?

Once your child is absent 10 consecutive days, his or her physician can request that the school district provide homebound tutoring. In the state of Illinois for instance, the students would be eligible for a minimum of five clock hours of homebound tutoring per week.

If you have additional questions on this subject, please contact the CCA office at 800-535-3643. This article is intended for information only.
This year’s Harley Davidson Raffle was a success. And the winner of the 2002 Heritage Softail signed by Cher, Bryan Stahl, from Oneida, SD, agrees wholeheartedly. “When I got the voice message saying I won, I couldn’t believe it,” he said.

Before his raffle win, he was actually in the market for a new bike. Bryan had owned street bikes since he was 18, but about five years ago, he had to give his Honda up when he bought a house. Coincidentally, he visited the Buffalo Chip site on the Internet and noticed an ad for the CCA Raffle. He thought it would be a good idea to support CCA, so he bought five tickets for $20 online—money well spent.

Bryan loves his new bike and has already clocked 2,000 miles. About half of those miles he spent riding with his family. “My wife and two girls go riding with me a lot,” he said. He has even ordered personalized plates that read “IBLIEV.”

And he believes in CCA: “You come across a lot of giveaways, and you wonder what’s behind them. It’s just good to see people, especially high-profile people like Cher, take the time to make a difference in other people’s lives.”

On more than a few occasions, he has had offers to buy the bike, but he turned them down. “It’s got a good home here,” he said.
We are extremely grateful that Pace American donated a Pace motorcycle trailer for us to use during the 2002 CCA Harley Raffle. We hauled our bike from San Diego to Las Vegas to Denver to Sturgis and all points in between. Having the bike on display while selling tickets spurred more sales, and hauling it saved us from having to ride the bike in the dusty Black Hills, which makes for a happier winner. The exposure was great for Pace, too, as we were permitted to sell the trailer while in Sturgis, making it a great deal for everyone involved. Thanks Pace American!

Cher’s autograph on the gas tank. The people there were so nice to me and all of our CCA crew. I am even staying in touch with Marilyn by email because she was a lot of fun. The managers, Brad, Kim, and Derick, were all cool. We also sold tickets at the Back Porch bar and grill in Spearfish, courtesy of Leland and Teri Ruzicka. I got to take a ride in the sidecar of Leland’s motorcycle, driven by my new friend, Fred Sala.

While we were in other locations, our fearless leader, Dr. Tony Davis, headed up ticket sales in Rapid City with our friend Karim Merali, General Manager of the Radisson Hotel there. We were able to sell in so many places this year because we had more volunteers, including Greg Patterson, Mike and Mary Parsons, Lisa Sharp, Tammy Van Ness and Kevin Braden, and a mom from the area, Jody Klemann, who also brought her mom and sis to help.

Woody lead our ride, now dubbed, “Rod’s Ride for Cher’s Kids” and this year we went up through a scenic canyon to Reptile Gardens where we got a behind-the-scenes tour with John Brockelsby, Robbie Knievel and I held a giant python.

Everyone at the “Chip” was so helpful again this year. I got to help Dave Vice and his grounds crew. His wife De helped a lot. Tom, Brad and Steve and everyone backstage made sure the bikers and bands knew about our charity.

We got some good media coverage thanks to Mike Sanborn and especially to my buddy, Gregg “The Goat Boy” Cook from the local radio station, K-Sky. He had me on his show, and we talked about our raffle and our charity ride.

In closing, thank you to all who sold tickets leading up to the rally—this was by far the best year yet! And for all of you who bought tickets, your money will help CCA help a lot of other kids besides me. I am excited to go back again next year, and I will let you know all about in my next report.

Robbie Gorecki, CCA Ambassador to Sturgis
when friends become family

It's a good feeling when friends continue to selflessly extend their help and generosity. Such is the case with some of the participants of “Rod's Ride for Cher's Kids.” When returning home to Milwaukee, John “Bud” Curtis and others, including Nicole Pappas and John “Papa Hog” Curtis, got together and held a bike wash for CCA. Hal’s Harley-Davidson hosted the event and raised $400 in just a couple of hours on a Saturday. This just goes to show how an idea can turn into something big! Thanks Nicole and Bud and all who helped!

Other friends, now family, who met us in Sturgis include David Curtis, Kaptain Robbie Knievel and Tiny McLarge, who, with the help of lodge brother, Doc Remer and the entire Century Lodge #492 Independent Order of Odd Fellows along with Dave Plote from Ideal Rides all in Illinois, put on a weekend event that netted a $3,500 donation to CCA. Activities included a Pig Roast on Saturday, Kaptain Knievel's appearance and autograph session (and a promise to do a jump at the event next year), a Sunday morning breakfast at the lodge followed by a Shriner-escorted motorcycle ride, a “bike” drop (no mercy for foreign-made bikes) and an auction. A big thank you to everyone!

If you would like to hold an event, please call CCA for more information and guidelines.
is your philanthropy showing?

We’re always talking about people getting involved with fundraisers and volunteering. Sometimes, even though you’d like to give your time, you’re just too tied up. Well, if you’ve the means to do so, there are other ways you can “be there” with us.

We are in need of sponsors/underwriters for our yearly summer fundraiser, our Cher-Autographed Harley Raffle. You or your business will receive great exposure at all levels of sponsorship. See all of the different opportunities below.

This is not just embracing your charity and displaying your altruism. It can be a wise business decision, given the extent of exposure and enhanced PR. If you can’t be every place, get the recognition as if you are.

Interested? Contact JGorecki@ccakids.com

help wanted for summer fundraiser

We raffle off a new Harley-Davidson motorcycle, autographed by our national spokesperson, Cher, in August during the biker rally in Sturgis, SD. We’re always looking for people to help us sell raffle tickets, and because of the Harley-Davidson 100th anniversary events already underway, we’re starting 2003 ticket sales right away. If you would like to sell 150 tickets in your area, please contact Jill Gorecki at JGorecki@ccakids.com.

As an extra incentive, we’ll have a special prize again this year for the person who sells the most tickets.

If you think you will be at the 2003 rally in Sturgis, SD, we would love to have you join us. We’ll have volunteers selling raffle tickets at locations in Rapid City, the Buffalo Chip campground, The First Gold Casino in Deadwood and The Back Porch bar and grill in Spearfish. Please call or email us as soon as you know if you have some time available and would like to help.

sturgis 2003

Next year’s CCA Harley Raffle should be a big one as 2003 marks the 100th anniversary for Harley-Davidson. We will be raffling off a 100th Anniversary Edition Harley Heritage Softail® Classic Autographed by Cher! Because the anniversary festivities are well underway, we plan to begin selling tickets soon. Raffle tickets will still be $5 each, 5 for $20 (1 Free) or 30 for $100 (10 FREE!). Of course tickets will also be available on our Web site. (By the way, did you know our 2002 winner bought his tickets online?)

The raffle will be held once again at the Buffalo Chip Campground in Sturgis, SD. Our host, Rod “Woody” Woodruff will also hold “Rod’s Ride for Cher’s Kids” again in 2003. And there’s talk about having our friend, Kaptain Robbie Knievel, come out and do a jump for CCA.

Keep checking www.ccakids.com for all of the latest developments!
It's incredible how many great people stepped up to help make our fundraising efforts successful this year. In 2002 CCA conducted its third annual Harley Davidson motorcycle raffle. The first two years, CCA got its feet wet, learning about the Black Hills Motorcycle Rally and ticket sales opportunities. This year, with the help of fabulous volunteers, CCA raised more than $22,000 and, with the continued support of our valuable volunteers, plans to expand this fundraiser significantly in the years to come.

Ticket sales activities increased with the help of New York Myke of San Diego Harley Davidson (www.sandiegharley.com). Besides procuring a Heritage Softail for CCA, NY Myke arranged for CCA to sell tickets for three weeks at the Del Mar Fair in Del Mar, California.

How did a Dallas-based charity manage to pull off such a feat? Enter

Susan Ickes and Jenny Winburn from San Diego. First, a little background. In 1997, CCA held its Annual Family Retreat in San Diego. During the retreat, CCA families were guests of Planet Hollywood, where Jenny Winburn was the Public Relations Director. Family members had photos taken with Cher on a Harley provided by NY Myke. Char Smith, CCA’s Executive Director, asked San Diego local, Susan Ickes, (relative of a relative) to volunteer her services assisting the families at Planet Hollywood.

Fast forward to 2000. CCA Kid Robbie Gorecki, his mom Jill, who is now CCA’s Development Director, and Char Smith run into NY Myke in Rapid City, SD, during the biker rally and reestablish contact with him. Myke then sets up a raffle ticket booth at the Del Mar Fair, where Jenny Winburn is also coordinating public relations for Myke. Meanwhile, Char Smith once again calls upon Susan Ickes, this time to help recruit volunteers to man the CCA ticket booth at the Fair. Susan recruited friends to sell tickets and ended up raising more than $6,000.

All of these people who happened to be in the same place at the same time years ago are back together once again helping CCA. A coincidence? I think not!

Once at the Buffalo Chip in Sturgis, SD, last year’s volunteers rallied to make this year’s raffle successful. Of course our family (too numerous to mention) at the Chip, including Rod and Carol Woodruff and Beth Greene once again took grand care of us. One of CCA’s moms, Jody Kleeman, recruited her mom and sister to help with ticket sales on our busiest night at the Chip. In addition, enthusiastic repeat volunteer Megan Bennett sold tickets plus recruited a local band to sell tickets. She also introduced CCA to Kim Morris, Public Relations Director for First Gold Casino in Deadwood, SD, where CCA sold tickets all week and set up a ticket sales location at The Back Porch in nearby Spearfish.

Whew! Is it any wonder that this fundraiser is becoming so successful? Well, it’s because of the generosity of all of these wonderful people. So three cheers for all of our Harley Raffle Volunteers!
Over the past several months, my son, Andrew, has had several radical procedures to correct some of his craniofacial anomalies. Andrew, who is eight years old, was born with micrognathia (very small jaw), microglossia (almost no tongue), seventh nerve facial palsy and optic nerve hypoplasia. On April 11, Andrew had surgery to place distraction devices in his jaw and was hospitalized for 16 days. On July 16, he had the second part of his jaw distraction surgery and was hospitalized for about seven days. During his hospitalizations, I have been able to stay in touch with our many friends and family through a wonderful Web site called CaringBridge.

CaringBridge offers a free Web site, up to a year, to any person who is undergoing medical treatment of any kind. Through the Web site, you will be given very simple directions to set up your personal Web site and are offered many pre-made sites from which to choose.

Andrew and I designed ours and had it up and running in under an hour. It was simple and very “user friendly.”

With the assistance of CaringBridge, I have been able to keep many people informed of Andrew’s progress. When Andrew is in the hospital, I am emotionally drained, and the thought of making umpteen phone calls is not something I look forward to. This venue made it possible for me to reach many people with the “click of a mouse.” Once Andrew was finished with this round of surgeries I printed the pages I had written so he could read them whenever he wants. The site allows you to choose options like a guest book, pictures, a journal history, and links to other related sites. They also allow for a security password if you wish to keep the site secure. It has been therapeutic for me to journal our progress. It has also been uplifting to read the daily entries in the guest book and know that so many people have read our pages.

I was thrilled when I was asked to share this information with other parents and caregivers through the CCA newsletter. I hope many of you will take advantage of this wonderful way to keep your family and friends up to date with your children.

To read more about Andrew go to: www.caringbridge.com/ma/andrew.

Visit www.caringbridge.com and start your site today!

Karin Perry, Andrew’s Mom
Brockton, MA
people volunteer to make a difference in our world.

I continue to be amazed by the number of dedicated, talented volunteers we have recruited or who have stepped forward over the past couple years. Some were recruited by staff and board members for specific professional needs. Others came to us wanting to be a part of making a difference for kids and adults with craniofacial conditions. These people are all willing to work without compensation to make a difference. Some are only able to dedicate a couple hours a year to help, and others spend days, months and even years to accomplish their volunteer tasks. Nevertheless, all are volunteering out of a desire to help children and adults with craniofacial conditions. The levels at which volunteers help vary, but all are important. Some like the Critchlaws go to the corporation for which they are employed and check into their matching gift plan or United Way campaign. Others, like Donna Shea, take an opportunity to contact a local businessperson to procure a donation. Or others, like Stephen Wright, place an article in his company’s national newsletter. The Cher Convention people plan and conduct their own weekend event. And the Sturgis volunteers plan several fundraising activities during an existing event.

Some of our families, like the Mullers and the Freemans, help by selling our Harley Raffle tickets. And others, like the Paulson and the Evans families, organize garage sales.

We appreciate ALL of our volunteers. There is nothing you can do that is too little. Every volunteer act helps CCA move closer to our vision of a world where all people are accepted for who they are, not how they look.

Terry Carmichael
Chairman of the Board

P.S. If you have any ideas or would like us to give you some, just call Jill Gorecki, CCA’s development director at 800-535-3643.

Can’t decide what to give those special people on your list who have everything? Consider a gift of $25 or more to CCA in honor of a relative, friend or business associate. We’ll then send them a card that will acknowledge your generous gift on their behalf. What a wonderful way to honor someone, help your charity and teach your children the true meaning of the season.

teach your children well — give a meaningful gift this holiday season
impersonators and lively karaoke performances. We were especially surprised to receive a generous donation from Las Vegas-area Walmart Stores. On Saturday, Walmart manager, Charlene Weakley presented CCA’s Executive Director with a check for $3,000. Kathy and Cherie DeWilde are the Cher fans and the Walmart employees who initiated the idea among the area stores.

The highlight came Saturday evening during a seated dinner dance, which included a live band performance by Dallas based “Girl,” when the talented cast of impersonators performed a live Sonny and Cher Show! And Elvis himself (Or was it?) made a guest appearance. Wayne Smith stole the show with a behind-the-scenes, ad-libbed skit with a fellow cast member whispering that he was sick of CCA’s Char Smith always wanting to come to his room and try on his Cher clothing! It was an evening of hilarity intermixed with the emotion of Cher fans emptying their pocketbooks during a live auction to support the charity with their generous bids on auction items.

We wish to thank from the bottom of our hearts the convention creator, Judy Didelot and her partners, Kim Werdman and Jody Cantwell. This awesome threesome dedicated years of tireless work to make this convention happen. They not only performed their jobs diligently but even added an online auction to raise additional funds for CCA.

You are our heroes and we love you!

We wish also to thank the impersonators and seminar leaders mentioned above, as well as the many volunteers who also gave of their time to help coordinate the convention including James Heath, Brad Wright, Linda Alamprese, Robyn Fisher and her entire family, and videographer, Michael Werdman. (Mike also did ALL the graphics, which were used for the Website, all the merchandise, the convention signs, etc.)

We are so proud to be associated with a group of fun, passionate and compassionate Cher fans! Cher’s fans are the Best!!!

If you no longer wish to receive this newsletter, please email your wishes to CSmith@CCAKids.com or mail the label to the CCA office and ask that it be removed from the mailing list.

If you know of someone who would like to be placed on the mailing list please forward to us their name and address.