CCA News

Newsletter of the Children's Craniofacial Association

CHER—Honorary Chairperson

Fall 2000

Cher's Family Retreat Marks Ten Years

Children's Craniofacial Association celebrated a milestone June 22-25, 2000 with the tenth anniversary of Cher's Family Retreat. Consensus was that it was the best retreat ever! The fun, yet emotionally intense family retreat was held just outside Denver in Westminster, Colorado. Several families made transcontinental treks as thirty-five families from across the United States assembled to share support and a fun-filled weekend. Friends embraced and caught up with events in each other's lives and new friendships were forged. Many families who attend the retreat each year have made life-long friendships.

The water balloon line-up.

The staff of the **Westin Westminster Hotel** rolled out the red carpet for our group. Conference Services Manager, **Liz Knapp**, was so attentive. She not only took care of every last detail, but also managed to join us for many of the activities. The hotel staff worked steadfastly to ensure a wonderful and meaningful experience for all of us. On Thursday evening, the families were treated to an ice cream bash. Friday night's picnic was held on a second floor veranda with a breathtaking view of the surrounding mountains. Saturday evening included a Mexican feast and a lively night of dancing with kids, grown-ups, and hotel staff dancing about the room in a Conga line. Our sincerest thanks go to the Westin Westminster Hotel! Our thanks as well to **Warner Bros. Records** who surprised the families with bags filled with t-shirts, caps, stuffed animals and an array of other goodies. Thanks to **John Staley** for arranging for this special surprise.

Thursday afternoon brought an unexpected surprise as baseball great **Reggie Jackson**, who was at the hotel for a speaking engagement, took time to sign autographs for many of our kids. He was very interested to hear about the craniofacial conditions. Later that evening he tracked us down so that he could provide photo opportunities for the kids and sign more autographs. What a wonderful commentary on a great guy!

A partial group shot at Heritage Village in Golden, Colorado.

Cher spends time with her kidlets.

On Friday morning, the bright-eyed, bushy-tailed group boarded buses and made a trip into the foothills of the Rocky Mountains to Heritage Square, a Victorian village, near Golden, Colorado. We shopped in quaint artisan shops, maneuvered flying bobsleds down the mountain, and lazily floated in paddleboats. Chassen's on the Square hosted a barbecue picnic lunch with old fashion games such as tug-of-war and balloon toss complete with prizes. Children and "grown-ups" (and we use that term loosely) let their hair down and enthusiastically competed. (Yes, **Don**, **Kevin**, and **David**, we are talking about you!) The **Critchlaws**

see **Cher's Family Retreat**, page 2

The water balloon toss was really heating up.

Cher's Family Retreat, cont'd from page1

and **Shainholtzs** battled to the finish in the hoola hoop contest! Congratulations to all of our champions!

The fun continued on Saturday with a trip to downtown Denver and Colorado's Ocean Journey. It was a remarkable journey over, under, around and through rivers, coral reef, and deep oceanscapes. Endangered Sumatran tigers, playful river otters, curious sea otters and other wildlife amazed us. We were told that the tigers usually sleep in the afternoon so we should not expect an appearance. Well, they must have known we were coming. Not only did they make an appearance, they swam playfully and treated spectators to a frolicking game of ball!

The dinner and dance brought the best surprise of all. To the disco beat of *Believe* in came our best friend, **Cher**! She danced the night away with her special "kidlets." Cher even donned a hard hat and danced with the kids to "YMCA." After taking a breather, she took photos and chatted with each family. It was truly the highlight of the weekend! Her love, friendship and support are always so evident and she never lets us down. Thank you from everyone.

Capping off the evening, a plaque was presented to Cher expressing our deep appreciation for her dedication to CCA and her "kidlets". She has touched all the lives of the kids. Cher, you're the best!

Plan on getting in on the action next year by joining us in Atlanta, Georgia for the 2001 Cher's Family Retreat.

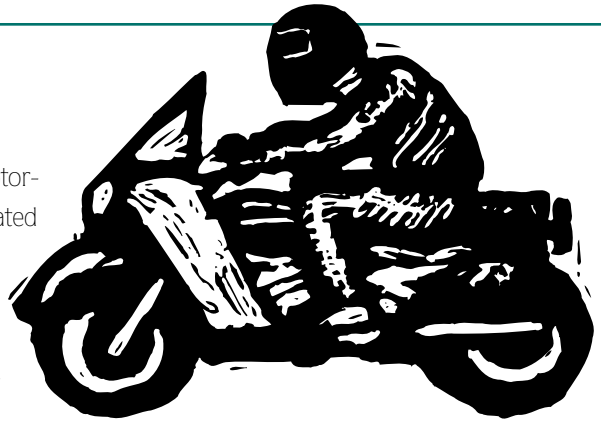
As a postscript, we certainly hope **Vicki Price** is not still wandering around trying to find her way to the train station.

Some seem to be working harder than others at the tug-o-war contest.

Cher rocks the night away with the kids.

Zach shows off his own personal style during the limbo contest.

Get Your Motor Runnin'



On August 11, 2000, CCA's National Spokesperson, Entertainer **Cher** took the stage at Buffalochip campgrounds during the famous Annual Harley Motorcycle Rally in Sturgis, South Dakota. Flanked by **Robbie Gorecki**, Cher drew the winning ticket for a brand new Harley Davidson motorcycle that was presented to a lucky winner from Souix City, IA.

Robbie and his mom, CCA Board Member **Jill Gorecki**, CCA Board member and event organizer, **Tony Davis**, CCA Executive Director **Charlene Smith** and six-hundred fifty-thousand bikers converged on the little town of Sturgis for a rally of riding motorcycles, talking about motorcycles, comparing motorcycles, and buying motorcycle-related merchandise. Acting as CCA's ambassador, Harley enthusiast Robbie, spent time riding and sharing CCA's mission with motorcycle daredevil, **Robbie Knievel** and Jazz/Blues singer and guitar player, **Jonny Lang** and many raffle-ticket-buying bikers.

In addition to the raffle, Harley bikers from Wyoming, Idaho, Nebraska, South Dakota, New Mexico and Missouri organized the *Believe* ride honoring Cher and benefiting CCA.

Our heartfelt thanks goes to Tony who gave freely of his time to organize this event and to **Rod Woodruff**, **Mike Sanborn**, and **Brad Coombs** for their support. A big "Thank you" also goes to **Glade Jones** and his organization, Wester Resources for dis-Abled Independence who helped us sell the raffle tickets and to the *Believe* ride "survivors," as they dubbed themselves after braving the rain on Mt. Rushmore. These efforts raised $19,000 for CCA in just a few days!

Meet 8-year-old Zachary Joseph Muller

Zach leading the conga line at the 2000 Retreat with Cher close behind.

Q. Where were you born?
A. I was born in Secaucus, New Jersey.

Q. Where do you live now?
A. I live in Bayonne, New Jersey.

Q. What grade are you in?
A. I am in 3rd grade.

Q. What are your hobbies?
A. I like to collect Pokemon cards and coins.

Q. What other activities do you enjoy?
A. I love music. My two favorite CDs are *Millennium* by Backstreet Boys and Cher's *Believe*. I play them so much and so loud, mom yells at me sometimes to lower them. I know all the words to every song. I also like to play Nintendo and Gameboy. Basketball is my favorite activity, but I like the New York Yankees too. I like to go to the library and get books to read, but I lost my library card. I have to get a new one.

Q. What do you want to be when you grow up?
A. I don't know what I want to be when I grow up because I'm only 8. But I want to do something with computers.

Q. What kind of craniofacial condition do you have?
A. I'm not sure what kind of craniofacial condition I have, but I had 3 big operations on my head to fix my forehead. My nose still has to be fixed and I have a glass eye in my left socket. I've had about 19 surgeries so far to fix my face. (Dr, Bartlett's office informs us that Zach has frontonasal dysplasia.)

Q. How many family retreats have you been attended.
A. I've been on three retreats.

Q. Which was your favorite retreat?
A. I liked all the retreats. I can't pick a favorite one, but Planet Hollywood in Texas was cool, Disney World was nice, but hot. And, dancing with Cher in Colorado was the best! She is so pretty. I think I liked meeting her best of all.

Q. What has growing up with a craniofacial condition taught you?
A. I'm not all grown up, but I think kids that look different are not so different because we're all beautiful inside. That's what Mom and Dad say all the time, but it's true. We are all the same no matter what we look like. We're just kids.

Q. What is your favorite joke?
A. "How do you make a tissue dance? You put a little boogie in it!"

Cher Convention 2000

On July 14-15, 2000 exuberant Cher fans gathered at the Congress Hotel in Chicago to celebrate the spectacular career of actress and entertainer CHER. The noble cause for this event was to raise funds for Cher's pet charity, Children's Craniofacial Association of Dallas, Texas.

On Friday evening guests gathered for dinner and a Cher impersonator contest. Saturday's daytime activities included "Name that Cher Tune," "Cher Bingo," and "Cher Trivia." Fans enjoyed seminars on topics such as Cher fashion, music and movies. The grand finale of the evening was a dinner, dance, and auction in the beautiful Gold Room. Families of **Leslie Upton** and **Scott Guzzo**, CCA "kidlets" (as Cher affectionately calls them) joined the festivities and danced into the wee hours of the evening. Cher fans generously bid on auction items posters and albums to a wide range of Cher memorabilia.

Our sincerest thanks to our new CCA friends—**Jody Cantwell**, **Judy Didelot** and **Kim Werdman** for giving countless hours for an entire year so that Children's Craniofacial Association could be the grateful recipient of proceeds of the Convention.

The organizers of the convention will continue to raise funds until the end of the year through convention sponsors and from the sale of souvenirs. For additional information go to **www.cherconventionmerchandise.com**.

Cher Convention 2000 raised in excess of $21,000 on behalf of CCA!

Commemorative programs will soon be available for $25 each. Profit on the sale of these programs will benefit CCA. Keep checking the convention Website for details.

(Back row) Jody Cantwell, Kim Werdman and Judy Didelot of the Cher Convention 2000 present the $21,000 check to CCA kids (front row) Leslie Upton and Scott Guzzo.

A Special Thanks to the Following:

Wayne Smith, **Jeffrey Thomas** and **Amy Hohimer**, impersonators, and their assistants, **Sonny Smith**, **Ellis Swanson**, and **Mark Hussman**; **James Heath**, printer; **Michael Werdman**, graphics artist; **Sharon Deutscher**, Chicago liaison; **Mary Ladd**, Games; **Ward Lamb**, Boston Q, and **Wayne Smith**, Seminars; **Sally Johnson** and **Kids**, Museum; the **Fisher Family**, Framing Posters; **Kim Ritz**, Donation of the Millennium Chip to the auction (sold for $2,500.00), **Stan Kotecki** the photographer, **Kevin Bernal** the DJ, **Kelly Frank** the Auctioneer;and finally, the wonderful volunteers: **Bill McMullan**, Boston Q, **Brad Wright**, **Carolyn Hall**, **Dave Didelot**, **Diana Fields**, **Jolene Little**, **Linda Alamprese**, **Mark Burdine**, **Mary Carlson**, **Rob Ward**, and **Wendy Carlson** for their non-stop work and support.

Three Cheers for Volunteers

Volunteers are essential to an effectively run charity. We are always looking for good volunteers; and on occasion volunteers are looking for us. So was the case with three volunteers who contacted CCA early in 1999. We received a call from one of them telling us the trio planned to put on an event to raise money for CCA's programs and services. These volunteers admitted they had actually never put on such an event before, but were willing to do whatever it took to pull it off. Well, they not only pulled it off, they pulled it off in great fashion. So were the beginnings of Cher Convention 2000. **Jody Cantwell** from Dundee, Michigan, **Judy Didelot** from Valparaiso, Indiana and **Kim Werdman**, from Arlington, Texas spent the better part of a year organizing the event, which met and exceeded all of our expectations. And they are in the process of planning for Cher convention 2001! So, three cheers for super volunteers, Jody, Judy and Kim.

Ways to help CCA

Our goal is to raise $2,000,000 by the end of the year 2,000. And there is still time to help us do it by joining the 2x2 Challenge. You see, rather than raising these funds in one impersonal, anonymous, wall-to-wall effort (which requires much more time and stamp money than we have), were soliciting your help. Become one of 2,000 individuals/families/groups/corporations nationwide to commit to raising $1,000 or more for CCA. Your focused efforts to raise $1,000 will make it possible for us to attain our collective goal of $2 million. But that's not all the family or group that raises the most money wins a trip for four to Disney World in Orlando, Florida. Call 800-535-3643 today to get your 2x2 information packet.

Our Gift

You can help CCA every time you send flowers. Just call Our Gift Florists at **800-OUR GIFT** and CCA will receive a portion of the sale. It's simple, and fast. Call Our Gift and help CCA fund important programs and services. Visit www.ourgift.com to view sample floral arrangements.

Corporate Partnerships

Did you know many corporations will match your charitable gift. Inquire with your human resources department about your company's policy and maximize your giving. If your company participates in the United Way, you may designate CCA to receive your contribution.

Tom Thumb/Kroger/Albertson donation cards

Tom Thumb (link your Reward card to charity #2417), Kroger, and Albertson grocery stores have donor cards available. When you use your card at a participating store, a portion of your purchase goes to your favorite charity. Call CCA at 800-535-3643 for a card.

T-shirts

CCA has a fresh supply of newly redesigned t-shirts. To order a shirt, please call 800-535-3643.

We need volunteers

If you live in the Dallas area we need your help. CCA participates in Our Children's Store at Northpark shopping center. Our Children's Store carries gifts for every person of every age. It prides itself on offering unique gifts that you wouldn't find in most stores. Another unique feature about the store is that it benefits 50 children's charities. The charities receive all of the proceeds from sales. Each charity runs the store one day a month. That means CCA needs 3 volunteers for each of three shifts, one day each month. We need your help. If you would like to work a 4-hour shift, while you meet new people and do a little shopping at a fun store, call 800-535-3643. (It really is fun and the shift seems to really race by!)

CCA Has Its Own Chatroom

We now have a chatroom for our patients and families! **Jennifer Johnson**, one of our young adults from Midland, Texas, has set this up for our use. We have plans to schedule organized chats with surgeons, psychologists, social workers, and other healthcare professionals on a variety of topics. Some of the chats will be designed with specific age groups in mind, such as children, teens, young adults, and adults. In addition, children and adults can chat at their leisure with each other as is the case at most chat sites. The address is the following:

clubs.yahoo.com/clubs/childrens-craniofacialassoc

This site is also linked to our Website. In order to chat, one must register with Yahoo. There is no cost for this registration. **Sue Smith**, a mental health worker, is volunteering to be a host in the chat room. Her goal is to make this a place where people of all ages can chat in a "PG environment."

A Caution to Parents: Although there are people who are volunteering to monitor the site as much as they can, this chatroom is not moderated. Therefore, there is no way for CCA to have control over who joins in a chat. It is for this reason that we ask you to supervise your children and their use of the computer and this Website.

Financial Assistance Program Reinstated

Thanks to a generous donation from New York based **Smile Train**, CCA has reinstated its financial assistance program. This program is designed to help needy families with funds for food, travel and/or lodging when it is necessary to travel to receive quality medical care. There is an application process that must be completed four to six weeks in advance of the date of travel. For an application, call 800-535-3643.

What's New

Many craniofacial patients, both children and adults, require procedures such as distraction and the wiring of jaws. These procedures require restrictions in one's diet and eating habits. Many patients with post-surgical swelling, pain and sutures have experienced discomfort from sucking liquids and pureed foods through a straw. In other cases, doctors prohibit the use of a straw altogether. Yet using a cup is often an inconvenient, clumsy task. Parents often face a formidable challenge when trying to ensure proper nutrition for their children on liquid or soft diets.

Doctors, nurses, and parents are often called upon to be creative in coming up with ways to dispense these foods and liquids. Syringes and catheter tubing are often used. However, many of these makeshift devises are not only inconvenient, but awkward. The contents often leak making eating a frustrating and messy experience for both parents and children.

Children's Craniofacial Association has recently been made aware of a new product that can take the worry out of post-surgical eating and drinking. A nurse working in an acute care facility has developed a product called **Zip-N-Squeeze®**. It is similar to juice bags, which are very popular with the kids. However, this bag features a leak-proof zipper and flexible tubing which inserts easily into the mouth. The tubing includes a clamp to prevent spills. Dispensing the contents only requires a gentle squeeze from the patient. **Claudia Nouhan**, a clinical dietitian in Michigan, states, "I have had the incredible luck of finding out about the awesome feeding bag called Zip-N-Squeeze®. This is the most exceptional tool that I have ever encountered that replaces the standard rigged syringe that is nothing but cumbersome and limits nutrition."

The squeeze bag has multiple uses. Besides dispensing food and beverages, this bag can be used to irrigate difficult to reach areas of the mouth. The Zip-N-Squeeze® bag is disposable and can be rinsed with soap and water.

For more information on Zip-N-Squeeze® visit their Internet site at **www.zip-n-squeeze.com** or call 714-997-7146.

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Cher

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Website: www.childrenscraniofacial.com

Children's Craniofacial Association
P.O. Box 571097 • Dallas, TX 75357
972.240.7730 • 800.535.3643
972.240.7607 Fax
www.childrenscraniofacial.com

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