

ccanetwork



newsletter of the children's craniofacial association Cher—honorary chairperson

winter 2003

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in memorium

this issue of CCA Network is dedicated to the memory of Robbie Dick, who passed away on December 28, 2002. He and his family attended the annual Cher's Family Retreats, and Robbie had many friends among CCA families, staff and volunteers. He lived in Tempe, AZ, and is survived by his mom, Sharon; dad, Robert; and brother, Jonathan. He will be greatly missed by all of us.

13th annual cher's family retreat

have you registered for the 13th Annual Cher's Family Retreat? 2003 promises to be the largest retreat to date. By late February 50 families have already registered, and spaces are filling up fast. So if you want to attend, make your plans now!

The retreat will be held in Washington, DC, June 26 – 29. The major objectives of this annual event are to allow adults affected with craniofacial conditions as well as young craniofacial patients, their siblings and parents an

see **retreat**, page 8



message from the chair

behind the scenes

for this newsletter I wanted to take you behind the scenes and acknowledge and thank the members of the CCA board of directors.

First, I should tell you that none, repeat none of the board positions are paid. In fact, 100% of our board members contribute financially to the charity. But perhaps the biggest contributions are their time and "in-kind" donations. These are contributions that are not tax deductible, but gratify the soul.

see **chair**, page 7

ccakid

meet brielle shea

ask 10-year-old **Brielle Shea** what her favorite school subject is, and she'd say music. The talented fifth grader is a member of an exclusive chorus, a group that includes only the top singing voices in her school.

Music isn't her only passion, though. "She loves animals, all kinds," says her mom, Donna. Bri has three dogs, a cat and three horses: a quarter horse named Charlie, an appaloosa (large riding horse) named Maggie and a miniature horse named Cadillac Man, or Caddy.

In fact, she's been riding horses ever since she was three and goes to many competitions. Even in her very first show, Bri took 1st place out of

about 12 girls competing in the ring! She has collected 25 ribbons as well as plenty of cups and trophies since.

She trains her horses for the upcoming horse shows every spring. "That's when the hard work starts," her mom says. Right now she's training Caddy, the miniature horse, who's only 33 inches tall at the shoulders.

Bri is a member of the 4H Little Hoofbeats, and for competitions they bring the minis into the show ring, where they are shown not only for their beauty, but also their jumping ability. Holding his lead rope, Bri must run alongside Caddy and make him jump over the hurdles.



Bri and her great little horse, Caddy

"Caddy is the best," Mom says. "He knows his job and really looks out for her." Soon Bri will take lessons to teach Caddy to drive, that is pull a cart that Bri will sit in!

Brielle was born with a facial cleft and has had 11 surgeries, each at Boston Children's Hospital. She has gone to about five CCA

retreats so far, with her favorite being Orlando.

Apart from meeting some great friends at the retreats, she also has a great, supportive friend in Cher. Bri has been good friends with Cher for some time. They exchange letters, and Bri has had the opportunity to meet her backstage at her concerts.

look at our web site for a list of our programs and services

meet jennifer evans

growing up, most kids didn't know **Jennifer Evans**, 22, was born with a cleft lip and palate. They also weren't aware that she had about seven or eight corrective operations. "Some were tough, especially the nose job, but I was a tough kid," she said. Jennifer also said she was lucky — by the time she and her peers were old enough to comprehend her situation or notice she looked "different," she was "fixed."

That changed in high school, when she detailed her condition in one of her biology projects. She wanted to let others know that "this is part of who I am." The next summer she underwent an operation, which entailed having her jaw broken and repositioned. This dramatically changed the way she looked. "No one recognized me that fall," she said.

Since she was 11, CCA has always been a part of her life. She has gone to five retreats — the retreats in Orlando were her favorites. She has

met **Cher** on many occasions and had the opportunity to meet her backstage at two of her concerts. For years she did volunteer work for CCA. Now Jennifer works at CCA as the Administrative Assistant.

These days she lives in Royse City, with her parents and her dog **Jake**. Jake was born with a cleft lip too. Jake's original owners didn't know what was "wrong" with him, but Jennifer knew right away. She said she fell in love with him.

"He's perfect, cute and fiesty," she said.

ccagrad



take five

If you weren't able to contribute during our Annual Campaign at 2002 year end because you were putting all your hard-earned dollars toward Christmas and taxes, why not "take five." Watch for our "Take Five" Campaign this spring.

"Take Five" is a way to contribute \$5 monthly. You can donate almost painlessly using a monthly credit card deduction

or just by saving your change in a jar each month. People who like the idea but want to get it over with can send \$20 for three months or make a one-time or annual contribution of \$60. There will be an incentive for when you commit to "Take Five" for the year.

It's about the cost of five cups of coffee, each month (unless you go to the gourmet place), but

when all of us do it together, the funds will add up quickly. If just four people commit to the "Take Five" plan, we can pay for airfare for one CCA kid to get to our family retreat. Multiply that by 10 (40 participants) and we can pay for 6 months of our 800# helpline. When your information arrives, please consider participating.

ccachristmasparties

cca dallas

On Saturday, December 14, 2002, CCA once again joined forces with **Medical City Hospital Dallas, Dr. Jeffrey Fearon, Dr. Kenneth Salyer and Dr. David Genecov** to hold the 13th Annual Holiday Party in Dallas, Texas. Some 400 kids, moms, dads, doctors and other craniofacial team members gathered at Medical City Hospital Dallas for a morning of holiday fun.

Radio Disney DJs enthusiastically emceed the event and led party goers through a morning

of fun and games. Families went home with door prizes, including tickets to the **Dallas Stars** hockey games, and a hockey puck autographed by **Richard Mitivichuk**, a **Texas Rangers** baseball cap autographed by **Jeff Zimmerman**, tickets to the **Mesquite Championship Rodeo**, many coupon packages to **Celebration Station**, coupons to local restaurants and movie theaters, and much more. CCA also presented each child with a little



teddy bear and our book, *Fearless*.

Clowns were on hand to make balloon animals and paint little faces. In addition, the children made a variety of holiday crafts. Of course the highlight of the party was a visit from **Santa**

Claus, Mike Lorfing. Each child had a picture taken with Jolly Old St. Nick and went home with a special gift.

Our special thanks to **Mattel, Inc.** for their generosity!



cca midwest



There was also a small gathering of the newly resurrected group in the Midwest. (The Smiling Faces support group from a few years back is once again serving Midwest families.) Held at the Brat Stop in Kenosha, Wisconsin, a number of families met and visited while waiting for **Santa (Oddfellow lodge member, Tiny McLarge)** to arrive.

Everyone enjoyed refreshments while they made glitter ornaments as well as photo ornaments. The children were treated to candy canes and grab bags of stocking stuffers and toys donated by **Mattel, Inc.** With the help of **Marla Verdone** and friends, next year's party promises an even better turnout and another fun craft project for the kids. And a special thanks to "Tiny" Claus. We look forward to his reappearance next year, too!

talking with children about death

Susan Porter-Levy, Psy.D., Licensed Clinical Psychologist

(Excerpted from a prior newsletter)

Question: How do I respond to my child's questions when a friend (and fellow Craniofacial patient) has died? He has expressed a fear that he, too, will die and is having difficulty dealing with the loss.

Answer: Responses to the questions about death and dying vary, depending on the age and experience of the child. A child younger than two years of age very likely does not have a clear-cut idea of death and will probably not profit from a specific discussion of death. He may, however, respond with anxiety to the separation by death of a constant and familiar person and will need comfort and reassurance.

Children begin to develop a basic understanding of the concept of death from three to six years of age. Their primary concerns will continue to be separation, but they will gradually comprehend that death is different from other forms of separa-

tion. They may become focused on fear regarding the threat of loss or being left alone and become more dependent or clinging, or they may have nightmares or difficulty sleeping. Generally, they do not see death as permanent or irreversible and fully expect the deceased to return.

Around the time that children reach seven or eight years of age, they begin to see death as an event which is inevitable and which happens to all living creatures. It is at this point that they are just beginning to realize that death is something that can happen to them. It is not uncommon that a child will be worried about dying himself, especially if a brother, sister or other child has died. These worries are sometimes referred to as contagion fears. Those children need to be reassured that what caused the death of another person will not cause them to die. Another potentially harmful belief is survivor guilt. The healthy child may wonder why his

friend has died while he has been spared such a fate. The guilt that can develop from such thoughts can lead to anxiety and self-punishment and take the form of loss of appetite or problems with sleep.

It is particularly difficult to talk with children about death, fearing that sooner or later the child will say, "Will I die?" or "Will you die?" We are all somewhat frightened of the answers that we would rather not give. However, the next step in children's understanding death is that of relating it to themselves and to those they love and need. In those cases, the child can best understand when the parent says, "No, I do not expect to die for a long, long time," and adding that he or she expects to enjoy the child as a grownup and have many years of being a grandparent.

Discussions with your child about death need to be honest and, particularly with younger children, as simple and concrete as possible. For

example, "Your friend Bobby got very sick and he died." With very young children it may be appropriate to help them label their feelings or to tell them how you feel. "I am very sad that Bobby died, I will remember him and I will miss him." Parents can assist their children in the process of working through and understanding death by carefully listening to and observing their reactions. It is best to display an accepting attitude toward whatever way the child chooses to express himself. Children may display many emotions in the grief process such as denial, panic, anxiety, anger, and/or desire for replacement. Children who feel somehow responsible or guilty for a death should be quickly assured that they have no cause for those feelings.

Children from seven to 11 years, in particular, may be very reassured when they are told that the deceased is not suffering. Typically, these children ask many questions like, "Does it hurt

to die?" Because, with children this age, there is often some uncertainty about the cessation of bodily functions upon death, they may also ask questions about how the deceased will breathe underground, or what they will do for food.

It may be more useful to speak in terms of what not to say to children about death. Do not describe the death as going to sleep or as a journey. The child may fear sleep as a consequence or expect the deceased to wake or return. If a death is explained in terms like, "We lost Bobby yesterday," the child may likewise expect him to be found. It is usually not wise to associate death with goodness or badness. It may be confusing for a child to hear that "God took Bobby to live with Him because he loved him so much," or "...because he was so good." Again, a simple, honest, straightforward response without metaphor or euphemism is always best.

chair, from page 1

One of our board members is a Certified Public Accountant and a partner in his firm, Salmon, Beach & Co. **Bill Sims** has served as a board member since 1997, oversees our accounting/bookkeeping, and is the treasurer. To attest to his good work, CCA's (independent) financial audit has consistently been very good.

Dr. Tony Davis joined the board in 2000 and has proven to be a prolific fundraiser. He initiated and is currently leading the 4th Annual Harley fundraiser. Tony has several other big fundraising projects in the works and really enjoys attending the annual family retreats.

The immediate past-president of CCA is **Robin Williamson** who has been graciously serving CCA since 1995. Robin owns a graphic design firm in Carrollton, Texas, Williamson Creative Services Inc. She is the creative force behind ccakids.com and the wonderful new look of all CCA's printed materials. Not a week goes by that Char Smith doesn't call Robin to do something for CCA. This

newsletter is probably the example you will most recognize. And as a bonus, with Robin we get a package deal that includes the artistic expertise of her husband **Bruce Williamson**.

Our newest board member is **Robert Vargas**, the Executive Director of the Epilepsy Foundation of Greater North Texas. Robert has 25 years of experience with nonprofits and is past president and board member of the Dallas chapter of the Association of Fundraising Professionals. Robert has brought a much-appreciated perspective to the board that he readily and willingly shares.

Sally Longroy brought her legal expertise (and that of her Dallas law firm, Carrington, Coleman, Sloman & Blumenthal) to our board in 2000. Sally has worked tirelessly to assure that every legal aspect of the charity has been reviewed, updated and polished. We are very proud to be "squeaky clean," thanks to Sally.

Diana Sweeney, our longest seated board member, has been involved with CCA since 1991. Diana works at the

Facial Reconstructive Center at Children's Hospital of Philadelphia as a parent liaison. Diana provides the board perspective as a mother of a craniofacial child — her son, **Dan**, was born with a Craniofacial condition. Diana's primary passion is with the families and CCA's annual family retreat.

We are extremely fortunate to have **Tim Ayers** as a board member since 1994. Tim's daughter, **Shannon**, is a young adult with a craniofacial condition. Tim is President of Ayers & Associates, a public relations firm in Washington, DC, and generously contributes his professional expertise to promote CCA. He is currently spending untold hours organizing and planning the 2003 family retreat to be held this June in Washington, DC.

Each board member brings their knowledge and experience to CCA, which we shamelessly utilize to its fullest. While they are not paid, their service is greatly appreciated.

Terry Carmichael
Chairman of the Board



You may have noticed **Kelly Liszt** has been editing the *CCA Network*. Kelly was introduced to CCA by way of coworker and long-time CCA volunteer, **Bruce Williamson**. Kelly is a copywriter for Rapp Collins Worldwide, a marketing agency in the Dallas area. She and her husband Craig will soon be moving into their first home in Richardson, Texas. (Kelly and Craig eloped. They drove to Vegas and were married by Elvis.)

Kelly lived in London, England, on and off for most of the 1990s, where she enjoyed acting in a theatre group. In 1998 she moved back to the US

and pursued her Master's degree in journalism.

Kelly aspires to write the great American novel and get more involved in acting. In fact she has recently done some voice-over work, which she thoroughly enjoyed.

In addition to acting, Kelly enjoys skiing and traveling. Most recently she and Craig spent 2002 Valentine's Day in Paris, France where they enjoyed a kiss under the Eiffel Tower.

Kelly plays a very important volunteer role for CCA. She gives selflessly of her precious personal time. So, "Three Cheers for Kelly Liszt" a super CCA volunteer!

retreat, from page 1

opportunity to interact with one another, share ideas, problems and solutions, and make long-lasting relationships. Families will enjoy a welcoming ice cream party, visit the Smithsonian Institute and the national monuments, and dance the night away at the annual Saturday night dinner dance.

The retreat is a casual format that allows plenty of time to build new relationships and bonds of understanding and caring among children and adults alike.

For more information and/or registration forms call the CCA office at 800-535-3643.

(The retreat is for Craniofacial patients and their immediate family members only.)

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Cher

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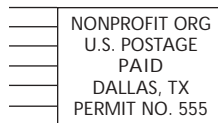
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