

# ccanetwork



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

spring 2003

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## legislation introduced in congress to guarantee reconstructive surgery

### CCA families can help pass the law

Legislation has been introduced in Congress that can be of great benefit to craniofacial patients and their families. **Representative Mike Ross** of Arkansas introduced legislation at the end of March to guarantee insurance coverage for craniofacial patients.

As many families know, insurance companies will sometimes label needed reconstructive surgery as "cosmetic" and deny coverage. **The Reconstructive Surgery Act of 2003** seeks to guarantee that insurance companies cover medically necessary surgery.

CCA families can do a great deal to help pass this legislation. The first and most important action is to contact U.S. Senators and Representatives as soon as possible and urge them to co-sponsor the Reconstructive Surgery Act of 2003. The Senators and Representatives can do this simply by contacting the office of Congressman Ross and say they want to sign on to House Resolution 1499. Notifying friends and families about the legislation and urging them to do the same will also be extremely helpful.

What's most effective is a letter or email that describes the need for insurance coverage. The letter does not have to be long or detailed. Just emphasize how important it is for patients to be treated fairly.

**Do not forget to urge your elected officials to co-sponsor HR 1499.**



## message from the chair

Have you ever seen one of those old movies where they show a jump in time by flipping the pages of a calendar? Well, that's kind of the way it has felt around CCA for the past year. We have accomplished so much in a year. It seems like just yesterday that we were in St. Louis for the family retreat! And now the 13th Annual Cher's Family Retreat is just around the corner.

In a way, we have come full circle. While in Washington 13 years ago, Cher came up with the idea of an annual

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## meet jaci samhammer

Sixteen-year-old **Jaci Samhammer** is one busy girl. Besides school, the sophomore from the Fallsington area of Pennsylvania takes dance lessons and works part time for a catering company. She also works at a local elementary school with kindergartners as part of a vocational training program. Monday is her only free day.

Jaci likes school, with Global Studies being her favorite class. The class includes African and European history, taught by **Mr. Ritter**, an instructor that "makes history come alive."

Jaci's big love, however, is dancing. "Once the music starts, watch out because I'll be on the floor in a second," she said, recalling a cousin's wedding she went to,

where she danced the night away. She's been taking dance lessons for seven years, and right now she takes two dance classes a week, jazz and tap. Her recital is coming up in June.

When she's not busy with everything else, Jaci likes listening to country and pop music — never rap. She enjoys playing basketball and baseball, and fishes in her backyard pond. A self-described "NASCAR freak," Jaci keeps up with racing and her favorite driver, Dale Earnhardt, Jr.

Jaci has Apert's Syndrome and has had 24 operations so far, with the first being when she was four days old. She says she has



one more to go. CCA has been a big part of her life for about 10 years. She's been to almost all of the retreats: "They're great. I got to meet people and, of course, dance at the dinner dance." She's also had the chance to meet **Cher** and thinks she's "nothing but great."

And with Jaci's busy schedule, she doesn't have time to worry about what other people think. When asked what her advice would be for other kids, she said, "Look at them and laugh. If people make fun of you, just walk. You're the smart one, not them."

## Last chance to register... for the 2003 Cher's Family Retreat

June is just around the corner and time is running out to register for the 2003 Cher's Family Retreat. CCA is planning a range of activities that will be fun for everyone in the family. Retreat favorites such as the ice cream social, and dinner-dance will still be on the agenda. 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 [jbutera@ccakids.com](mailto:jbutera@ccakids.com)) Don't miss out. Make your plans today!

## 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. All we ask is that you apply at least four to six weeks prior to your next trip.

## meet jennifer johnson, artist

I was born with a unilateral cleft lip and palate and diagnosed with a skull deformity when I was two. I have had 24 operations since I was four months old. I've been involved with CCA since I was 10, and my family are charter members. I even testified during Craniofacial Public Awareness Week in congressional hearings and before the Senate Health Appropriations Committee on behalf of CCA, in hopes of getting legislation passed to fund research on craniofacial deformities.

While growing up, I had to cope with being teased by other children for not being "normal." I learned that if I was teased by other children and I reacted to it, then they would enjoy the reaction and seek to

push my buttons even more. But if there was no reaction, they sought out someone else to tease, because in elementary school, everyone was teased about something. As a child, I used my passion for drawing as an escape.



As with many artists, my career began early. I began drawing at the age of two, and although primarily a self-taught artist, I never visualized myself as anything other than an artist. I was born with this creative urge, and I

use my talent for art to express who I am. Each day I find enjoyment and satisfaction in sharing my skills and my soul with

others through my art. My favorite compliment once came from an unlikely critic — a four-year-old girl. She said, "you sure stay in your lines good."

I recently snagged a full-time job as the Webmaster and graphic artist for A-1 Sign Engravers, Inc., a large, family-owned sign/engraving business. They produce custom signs and banners, plaques

and trophies, window graphics, caps and T-shirts, decals, embroidery, laser engraving, business cards, etc. They are thrilled to have me as they

want me to bring in new business through their Web site, and I am their only freehand artist. They have nice incentives for snagging new customers or big projects, they pay me well and they have a very positive work environment. The company is the biggest



one in town and have been in business for 27 years. They hope I'll stay with them long-term. And that's a true blessing.

If I had the opportunity to be born "normal," I don't think I would want it. That might sound strange, but my birth defect is a part of me. Without it I'd be a different person and wouldn't have the same outlook on life. It's taught me to be strong, less fearful and more confident. I've finally realized that if people don't understand me then that's their problem. I've learned how to read people and see people clearly for who they are. I am who I am and I wouldn't change it for the world.



# ccagrad

# 3 cheers for volunteers!

## klubhousekids

**W**e would like to introduce our newest volunteers, the **KlubHouseKids**.

These kids have been hard at work helping with our CCA Harley Raffle, selling tickets and making clear their good intentions as kids helping kids.

They have already sold almost \$500 worth of tickets for CCA, and the KlubHouseKids will be volunteering with CCA for other fundraisers as well. The following speech was given at a recent Rotary Club meeting. Read more about these great kids in their own words:

### Start-up

At the beginning of KlubHouseKids, my brother and I were sitting on our bunk beds and Matthew asked me if I wanted to start a club. Then, I decided that it would be a good idea to start the club and have something to do over the summer. June 2002 was our beginning.

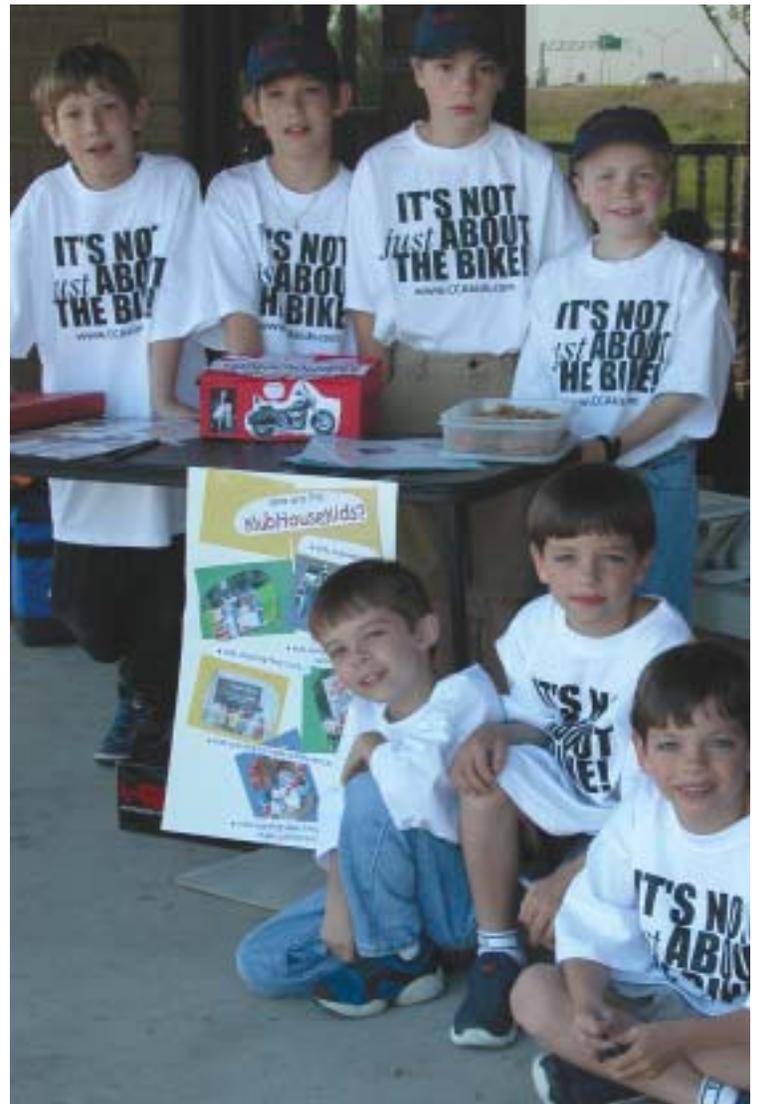
We had a plan, now we needed a name and other members. KlubHouseKids name was created based on having a club and making a clubhouse during our meetings, and then we were focusing on doing stuff for kids. So, KlubHouseKids was born.

### Members

We have a total of eight members. Four of us are in third grade and four in first grade. Matthew and I each picked three friends. Something interesting about the members is that there are two sets of twins. The membership list: **Nathan Abernathy, Matthew Abernathy, Patrick Snell, Dylan** and **Tyler Petersen, Andrew Bramlett, and Ryan and Blake Brown**.

### What is KlubHouseKids?

- Kids wanting to make a difference...
- Kids concerned about their community...



Nathan Abernathy, Matthew Abernathy, Ryan Brown, Blake Brown, Dylan Petersen, Tyler Petersen, Patrick Snell, Andrew Bramlett

- Kids learning about how they can make a difference...
- Kids showing they care...
- Kids helping kids...

### Goals

Our goal is to do community service projects with kids in mind! We want to help kids get what they need like books and toys. We

want to show that kids can make a difference by helping out in their community.

### Projects

- Snacks to firemen, July 2002
- Books to Vogel Alcove, July 2002
- Games to Scottish Rite Hospital, July 2002

see **klubhousekids**, page 7

## legislation, from page 1

To find the postal or email address of your Senators and Representatives, visit **congress.com** on the Internet. Just enter your zip code and you'll get contact information for your elected representatives. There is simply nothing more effective in moving legislation through Congress than hearing from constituents.

**In addition, CCA will be sponsoring a public meeting with Representative Ross and other officials on June 25**—the day before the annual Cher's Family Retreat in Washington. The meeting will take place on Capitol Hill so

that families can actually visit the offices of their Senators and Representatives after the meeting. **The event is scheduled for 10:45 a.m. in the LBJ Room** on the Senate side of the U.S. Capitol. We hope that as many families as possible will be able to attend that meeting. In preparing for the meeting, **CCA needs actual stories from families about denial of insurance coverage.** Individuals or families that have had this experience should contact **Tim Ayers** at **202-857-9734** or email him with your contact information at **tim@ayersassociates.net.**

## chair, from page 1

get together for the families so they could support one another and share ideas, resources and experiences. Now we are back in Washington with the largest group ever registered for a retreat. As of this writing we have 64 families registered.

In addition, we are in the hometown of **Tim Ayers**, long-time board member and father of **Shannon Ayers**, who has hemifacial microsomia. We are so grateful for Tim. He has spent countless hours planning the upcoming retreat, which we know will be a fun, educational and

overall great experience for everyone attending.

Alongside the usual retreat activities, Tim has made it possible for CCA families to attend a meeting on Capitol Hill in support of a bill to improve insurance coverage for individuals with facial disfiguring conditions. To find out how you can participate, see page 1 (continued on 5).

So, if you haven't registered for the retreat yet, call the office and we will email or fax the registration details. See you in Washington!

**Terry Carmichael**  
*Chairman of the Board*

## donors, january thru march 2003\*

### Gifts from Individuals

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#### CCA Benefactor (\$5,000 +)

Cher

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

### Memorial Gifts

John or Arleen Heirty  
Kathy J. Hubbard  
James & Kathryn Kemp  
Doris & Norbert Lustine  
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### Corporate and/or Foundation Gifts

#### CCA Corporate Friends (up to \$1,000)

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Mother's Club

#### CCA Corporate Sponsors (\$1,000-\$5,000)

Dorian Sanchez Productions

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

Chatlos Foundation

Also, while many concert venues donated prior to this publication, the following are corporations donating a portion of the ticket proceeds for Cher's farewell tour since January, 2003.

Cellar Door Concerts of Florida, Inc.  
Contemporary Group Acquisition Corp  
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Ford Center  
New Avalon, Inc.  
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Pavillion Partners  
S.M.G. Vanandel Arena  
Salter Enterprises  
Sunshine Concerts  
The Cajundome Commission  
The Entertainment Group Fund  
Von Braun Center

# dental milestones and oral health

Patricia Hall Schiffman, D.M.D. Practice limited to Orthodontics  
Plastic and Reconstructive Surgery a division of Children's Surgical Associates, Ltd.

As a full-time orthodontist on a craniofacial and cleft palate team, I am asked many questions about oral health. Some families know quite a lot about the care of their children's teeth while others do not. Some families need help accessing care, and other families need help clarifying the timing of care. I try to provide a logical approach to managing oral health issues by highlighting "dental milestones" and discussing what to be aware of at different stages of growth. I hope this information is useful.

**Before the birth of any child:** Chew gum with Xylitol. The Scandinavians have shown that it significantly lowers the rate of decay in your child's first two years.

**After birth and before the first tooth:** Discuss fluoride supplementation with your pediatrician. He or she should know the fluoride level in your community, and will decide if your child needs a fluoride

supplement for optimal fluoridation. Fluoride has been shown to significantly lower the rate of decay for many years. Revisit this issue if you move or your child's diet changes significantly.

**After the first tooth:** Clean the tooth/teeth at least twice daily. You may use a soft brush or any soft cloth to do this. Only use toothpaste if your pediatrician advises this. Never allow your child to take a bottle with milk (which rapidly turns to sugar) or juice (which is sugar) to bed overnight. If a bottle must be used at night please use water. Baby bottle use (with anything other than water) overnight will cause rapid decay of the upper four front teeth first, then the others. If your child hates to have his/her teeth brushed, continue to try to desensitize him/her by brushing lightly during the day and brush once when they are asleep to assure that daily plaque is removed.

**When most baby teeth (16 to 20) are present:** Take your child to a pediatric dentist. Pediatric dentists are trained to handle children and have special training in the care of children with cleft lip and palate, craniofacial or other complicating conditions. If you or your child have a bad experience consider trying a different practitioner. Be sure your private dentist communicates with the team dentist before any irreversible non-emergency procedures are done.

**When the first baby tooth loosens and falls out (or around the age of six):** Take your child to an orthodontist. If you have an affiliation with a craniofacial team please ask for your child to have a baseline evaluation by the team orthodontist. If this is not possible please be sure your team orthodontist is contacted by your treating orthodontist. The team orthodontist will be sure your child's orthodontic plan is coordinated with your child's surgical plan.

Your child should be re-evaluated at least once per year until orthodontic treatment begins. Before beginning orthodontic treatment be sure your team orthodontist has reviewed your child's treatment plan.

**When permanent teeth are present:** Be diligent about preventative dental care. Discuss fluoride, sealants and home care regularly with your dentist. Keep regular dental appointments, adhere to the orthodontic re-evaluation schedule and communicate with your craniofacial team members and your child can enjoy good oral health for a lifetime.

## what a great idea!

Special thanks to parent, **Connie Williams** of Baltimore, MD, her co-workers and **Piper Rudnick LLP**, her employer. Children's Craniofacial Association was one of their chosen charities for a monthly "Denim Day" fundraiser the company supports. Employees donate \$5 for each day they wish to wear jeans to work. Participation amassed a donation of over \$500 for CCA.

## cca welcomes two new staff members

When you call the CCA office in the morning, you will be greeted by the cheerful tones of **Annie Reeves**, our new Administrative Assistant. Having experience in a corporate environment, Annie will be maintaining our database of families, donors and volunteers as well as sending out packets of information. And having come from Snyder, Texas,

she brings her friendly southern hospitality to our office. Annie lives in Mesquite, Texas with her husband, **Tommy**, and their Boxer, **Brittany**.

**Jana Butera** was hired to fill the newly created Program Director position. Jana's background is in the for-profit and nonprofit fields, with her experience at the Citizen's Development Center providing a good

foundation for her position with CCA. Jana brings a lot of energy to the office, and she works tirelessly to make sure CCA's programs and services are administered efficiently and effectively. Jana lives in Plano with her equally enthusiastic Dachshund, **Bruno**.

With the addition of Annie and Jana, CCA will be able to improve current programs and services to families as well as identify additional needs. Let's give a great big CCA welcome to Annie and Jana!



Annie Reeves  
Administrative Assistant



Jana Butera  
Program Director

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### klubhousekids, from page 4

- Lemonade Stand for Rainbow Room, July 2002
- Proceeds from Lemonade Stand to Rainbow Room, August 2002
- Adopt-a-Trail, August 2002
- Sandwiches for the homeless, August 2002
- Pledge at City Council, September 2002
- Valentine Sale, February 2003
- Making care packages for the soldiers, March 2003
- Current project: Selling raffle tickets for the Children's Craniofacial Association for chances to win a Harley

Davidson Motorcycle signed by Cher

### Future Projects

- Keep Plano Beautiful, April 5, 2003
- Lemonade Stand
- Creek clean-up at our school

### Plans for KlubHouseKids

- Web site
- Educate kids on how they can start their own klub and make a difference
- Kid's newspaper
- Continue to do community service projects
- Have different chapters of KlubHouseKids around Texas

## CCA to evaluate programs and services

Your opinions and ideas are important to CCA, and that's why we will soon be sending out a program evaluation questionnaire. Your feedback will help in our ongoing effort to provide relevant programs and services that make a difference, and, in turn, you'll help us fulfill our mission to empower and give hope to individuals

with craniofacial conditions and their families. If you receive this form, we encourage you to complete it and mail it back in the stamped envelope that will be provided in the mailing. If you prefer, you can complete the questionnaire at CCAkids.com. We appreciate your input!

# living with a sibling who has a disability

by Kristen E. Bolomey, Psy.D.

**W**hen a child is born with or diagnosed with a disability, the whole family is impacted. Although the parents are the primary caretakers, the siblings are also greatly affected. Although the presence of a brother or sister with a disability is considered stressful, there are many positive effects both the disabled and non-disabled siblings have on one another. However, there are common pitfalls that occur as members of the family grieve, develop an understanding of the disability and its effects, and handle other daily life stressors. This is compounded by the developmental issues that occur as siblings grow up and have to cope with these issues from a new developmental perspective.<sup>1</sup>

**Children who have siblings with a disability are often well behaved, responsible, and have a strong ability to be compassionate.<sup>2</sup>**

They often have to grow up quickly, learning that “life is not fair” before other children their age. They are also faced with the realities of financial hardship, fear, and recognition that parents can’t always “make things better” far earlier than would be expected. Although these characteristics are desirable, understanding that siblings may be behaving this way due to fear and anxiety is very important.

**When children go to school, they begin to see how others are similar and different and their sibling’s differences become more apparent.<sup>3</sup>**

At this time, they may begin to wonder whether they will become disabled themselves or worry that the disability is contagious. As they become adolescents, siblings may be embarrassed by their brother or sister, and then feel guilty about this embarrassment. They may feel burdened

by responsibilities not only to complete increased chores but by the feeling that they must protect their siblings from the teasing and criticism of others.<sup>4</sup>

It is important to realize that even if a child has lived with a disabled sibling for many years and seems to have a strong understanding of the disability, there will still be grieving to be done. For example, a young child who does not have the verbal skills to ask questions or understand the feelings he/she is experiencing may act out their confusion through behavior problems. Some of these problems may include difficulty focusing their attention, listening, following directions, becoming aggressive, and withdrawing.

As they get older they may feel guilty about “causing” the sibling’s disability. It is quite normal for children to have ambivalent feelings about brothers and sisters, even before they are born. They may have wished that the child would never be born or they may have acciden-

tally hit or kicked their mother in the abdomen when she was pregnant. Magical thinking, or the belief that one can cause things to happen because it was imagined is prevalent among school-age children. At this age there is a tendency for behavior to fall on opposite sides of the continuum. They may be overly helpful with their siblings out of guilt or as a way to decrease the stresses on the parents, or they may become non-compliant as a way to gain the parents’ attention. As older children and adults, siblings may learn to hide their feelings to keep from “burdening” others.<sup>5</sup>

The sibling relationship is unique and powerful.

**Unlike the parents, siblings of disabled children don’t usually have a concept of life without living with someone who has a disability.<sup>6</sup>**

The sibling relationship is often the longest lasting because it continues

past the death of the parents. Also, siblings share a history between them that is more similar than they will experience with anyone else. The acceptance of the disabled sibling by the non-disabled sibling is imperative in the overall development and self-esteem of both children.

While disabled siblings may feel anger about their differences and frustrated because they can't do everything their non-disabled sibling does, they also need to develop a sense of independence and confidence that they can have control of parts of their lives.<sup>7</sup> Many parents feel guilty about the disability and may blame themselves. As a result, they may let the disabled child get away with behavior that they would otherwise find unacceptable. There is often conflict as the non-disabled siblings feel that they are being treated unfairly. This can lead to beliefs that the disabled child is the parents' favorite because of the time spent helping the disabled child and excusing the negative behaviors. This should be addressed early; setting reasonable expectations of the dis-

abled child and having them complete appropriate chores.

Although they may not be able to do the chores expected of the non-disabled child, they should be held accountable for their responsibilities and disciplined in a developmentally appropriate manner. In this way non-disabled children see that they are not solely responsible for chores about the home and don't experience feelings of rejection as the "less favored" child. It also helps the disabled child learn what is expected of them so that they are prepared to accept responsibilities as they begin school or participate in social groups.

**It is also important to regularly (and often) praise the non-handicapped child for the efforts that they make and the help that they provide.**

Siblings are also the first people that we learn to fight with, compromise and make up with. It is very important that all members of the family be open and honest in

expressing their feelings.<sup>8</sup> Often non-disabled siblings are fearful of adding to the family stress level and hold their feelings inside to avoid conflict. They may feel guilty for their feelings of anger and embarrassment and be reluctant to express these for fear of being scolded or thought to be "bad." Openly discussing the feelings helps these children keep from holding in these feelings until they spill out in explosive anger, depression, or show up in physical complaints such as headaches and stomach aches.

Children are wonderful barometers of family tension. If they are not told what is causing this tension, they often believe that they have caused it.<sup>9</sup> By having parents that model their own feelings openly and honestly, the children learn to manage their feelings more effectively and avoid many of the costly mental and physical symptoms that affect both themselves and the whole family.<sup>10</sup> In this way these feelings are likely to be addressed gently on a day-to-day basis rather than through more painful confrontations.

Siblings will often ask questions that will become more detailed as they grow older.<sup>11</sup> They may have a strong need to have as much information as they can about the disability and that need may endure their whole lifetime. Frequently these siblings become advocates for individuals with special needs.<sup>12</sup> Again, it is important for families and professionals to answer these questions as openly and honestly as possible, while taking into consideration the child's developmental level. Just because a child can explain his brother or sister's condition to others does not mean that he/she understands how the disability will impact his/her own life.<sup>13</sup> He/she may not realize that his/her sibling is handicapped until school begins. Just because a child lives with a brother or sister with a disability does not mean that they understand it.

**Siblings have to be told specifically about the limitations (and strengths) that having a disability can cause.**

Having information puts fears into perspective. In most cases, the fear of the “unknown” is worse than the reality of the truth. Without this knowledge, non-disabled children may feel that their parents are not protecting their disabled sibling or that others are hurting him/her.<sup>14</sup> This may lead to fearfulness of medical professionals and difficulty trusting others.

Although fear, embarrassment, and anger still occur, knowledge helps the individual to cope. Even though the provision of information and communication is very important, it is also important to let each child determine how much information he or she wants to hear.<sup>15</sup> Resistance is a good indicator of an individual’s coping style and readiness to cope with more information. Some children prefer to know as much as possible, while others don’t want to know any more information than they have to. Both methods are normal and healthy as long as they do not cause increased stress for the child or disruptions in the family.

As the non-disabled siblings get older, they may have fears about the future.<sup>16</sup> Parents also experience these fears, but may be reluctant to express them to their children. Teenagers begin to wonder what will happen to the disabled child when their parents die or are too old to care for them. They may assume that it will be their responsibility to take care of the adult disabled sibling and fear how potential mates and friends will react. Although, many siblings choose to help in the care of their disabled brothers and sisters, this should not be an assumption. Research suggests that older sisters most often bear the brunt of the responsibility and often feel resentful of this expectation.<sup>17</sup>

**Having a financial plan and will that specifically states how this child is to be cared for will help to reduce the stress a sibling experiences, particularly in the case of a sudden death of one or both parents.**

Setting up this plan when the disabled child is still a young child is also important as there are often waiting lists for services and housing, particularly as the individual becomes an adult. Speaking openly about these plans as the non-disabled child becomes old enough is strongly suggested. Having both the non-disabled and the disabled siblings participate in this decision-making is imperative in setting up an effective plan with a transition that is as smooth as it can be.

Handicapped siblings may want to experience independence at the level that they are capable and should be encouraged to make plans for their life beyond the family home. In this way they feel encouraged and trusted by others to do as much for themselves as possible, while feeling secure in the understanding that someone will be there to help them if they make a mistake.

How the family is likely to react to the stress of having a child with a disability depends on many factors, including family and community resources, current stres-

sors, financial resources, the number of children in the family, the severity of the disability, acceptance of the disabled child, communication between family members, family coping skills, and child-rearing practices.<sup>18</sup> Siblings of these children have a unique relationship with their brother/sister and can play a major role in helping to maintain family cohesiveness, but they need help.

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## references:

1,8 Rubin, Sandra, 2002. *What about the rest of us?* The Pull-Through Network, Children’s Hospital, National Medical Center.

2, 4, 7, 9, 13, 16, 18 NICHCY, 1994. *Children with disabilities: Understanding sibling issues.* NICHCY News Digest, #ND11, 1988 (Updated, 1994).

3, 4 Schubert, D., 2003. *Sibling Needs – Helpful information for parents.* Sibling Information Network.

4, 12, 17 ARCH, 1993. *Siblings of children with special health and developmental needs: Programs, services and considerations*. ARCH Factsheet Number 23. National Resource Center for Respite and Crisis Care Services.

5, 14 Rainbow Babies & Children's Hospital, 2001. *Suggestions for Parents: Helping siblings cope with a brother or sister's hospitalization*.

6 Meyer, D. & Vadasy, P., 1994. *Sibshops: Workshops for siblings of children with special needs*. Paul H. Brook Publishing Company.

8 Baylor College of Medicine, 1999. *Suggestions help children cope with sibling's illness*.

10 Janes-Hodder, H. & Keene, N., 1999. *Childhood Cancer; A parent's guide to solid tumor cancers*, Chapter 23. O'Reilly & Associates, Inc.

11, 15 SIOP, 1999. *Guidelines for assistance to siblings of children with cancer*. Medical Pediatric Oncology, 33: 395-398.

## here are some ways parents can help children live with a sibling who has a disability

- Discuss feelings and emotions openly and honestly and let them know that all feelings are okay.
- Be truthful in each situation.
- Allow siblings to become actively involved in the care of the ill child.
- Work to recognize the sibling's concerns (they may not be obvious).
- Provide jobs or tasks for the sibling and the disabled child to feel a part of the family.
- Make time for each child as well as the family as a whole.
- Allow all children time to be on their own.
- Inform others including teachers, relatives, parents of the children's friends about the situation.
- Continue usual family activities and encourage participation in activities outside the home.
- Understand the grief process (denial, bargaining, anger, sadness, and acceptance).
- Keep schedules as routine as possible.
- Encourage children to visit their siblings in the hospital, however, if they are hesitant, allow them to choose whether they will go or not.
- Keep communication open even during hospital visits or separations through telephone calls, email, and letters.
- Allow the sibling to determine whether or not to participate in discussions regarding the disability and how much information that he/she wants to know.
- Seek family and sibling support groups.
- Plan in advance, some events for each child to bring a sense of normalcy, hope and excitement for the future.
- Make financial plans and set up a will early, to ensure the care of the disabled sibling and choices for the non-disabled sibling.
- Include both the non-disabled and disabled child in family decisions and plans for the future.
- As much as possible, minimize expectations of older siblings to care for the handicapped child.
- Attempt to emphasize the positive abilities of the handicapped child rather than the disabilities.

# harley dealers back cca raffle

CCA, with the kind assistance of our friend **New York Myke** of **San Diego Harley**, asked the Harley-Davidson dealerships across the country to support our annual Harley raffle by purchasing 30 raffle tickets for \$100 and hanging our poster in their stores. The following are participating dealerships as of this printing.

We thank you from the bottom of our hearts. If your local dealership is not listed, please encourage their participation!

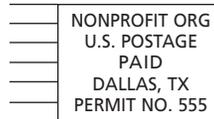
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