



Message from the Chair

CCA hit the New Year running. If you have not visited our new Website, log on to <http://www.CCAkids.com>. We have provided help for new parents, booklets, newsletters, product information, and other information about CCA's friends and activities. We will begin Phase II of the Website's development which will allow families and interested parties to register online, offer activities for children and young adults and provide a store from which to order t-shirts, etc. So visit the new site often.

In January we wrapped up the 2x2 campaign. The grand prize winners, by a landslide, were the Cher Convention Trio, **Judy Didelot, Kim Werdman and Jody Cantwell**. You have read about this terrific trio in earlier newsletters. They planned for months to hold the first Cher Convention in Chicago, Illinois. Around \$23,000 was raised for CCA. Judy, Kim and Jody are currently planning the second Cher Convention, which will take place in 2002. Our second place winners were **Dan, Denise, Emily and Danny Paulson**. The Paulson family held a garage sale and solicited funds from Dan's company. Our third place winners were **Fred, Rose and Freddie Seitz** of Poland, Ohio. Honorable mention goes to **Robin Adams** of Bartlesville, Oklahoma and **Troy Lynn Hershman** of Houston, Texas. Thanks to all who participated. It has really been gratifying that so many of you have taken the time and effort to help raise funds for CCA.

In February, CCA moved into new office space and hired a development director.

Thanks to the fundraising efforts of craniofacial surgeon and Chief Advisor of CCA's Medical Advisory Board **Dr. Jeffrey Fearon, The North Texas Hospital for Children** awarded a two-part grant to CCA. First they donated office space for the CCA National Headquarters in Dallas, Texas; and in addition they awarded a matching grant to fund a development director position. Consequently, we hired **Judy White** to that position. Judy comes to CCA with twenty years of fundraising experience for national as well as local organizations. One of Judy's top priorities is building new corporate and foundation relationships for CCA. If you think the corporation or company you work for, or a corporation in your area might be a prospective donor, give Judy a call at **800-535-3643**. She would love to talk with you about funding possibilities. Or, if you have a fundraising idea, please don't hesitate to call.

Look in this issue for details on additional CCA events including the 11th Annual Family Retreat and our 2nd Harley Raffle.

Thanks to the steadfast efforts of CCA families, friends, board, volunteers and staff, CCA is again on its feet and looking toward a bright future of providing much-needed programs and services for our families. However, we still need your continued support. In future newsletter issues, we will be giving you ideas on how you can assist CCA in raising funds. One of the easiest and most common ways to help is to make a planned gift by making a bequest through your will.

Typically, people provide for a charity by making a bequest of a specific amount of money. CCA has developed sample bequest language your attorney may wish to use when drafting a will or codicil, which includes a gift to CCA. For additional information please call Judy White in the CCA office.

Thanks again for your support and we look forward to a productive year.

Terry Carmichael
Chairman of the Board

Family Retreat

The 11th Annual Cher's Family Retreat weekend is scheduled to be held **June 28th - July 1st, 2001** in **Atlanta, Georgia**. The goal of the retreat is to provide opportunities for the entire family to interact, share ideas, discuss problems and their solutions and make lifelong friendships with others having similar experiences. This weekend is for only the immediate families with a member who has a craniofacial condition.

Families are responsible for all travel, food and lodging expenses. For information call the CCA office at **800-535-3643** or email us at <mailto:CSmith@CCAkids.com>. Please give us the affected member's name, condition and the name of the reconstructive surgeon.

To find out more info about the history of the retreat, go to <http://www.ccakids.com/srvret.stm>

Letter to the Editor

I would just like to comment on the use of REDs, from an article in the last newsletter. I believe that parents should know both the pros and cons of this operation. They are not perfect and not for every child. My son had three sets of REDs. Sometimes it takes more than one operation to achieve the desired results. After three operations his mid-face is improved, but not nearly as drastically as the child pictured in the article.

You also have to be very, very careful with the device. My son's first RED broke and had to be replaced in another painful operation. He could not sleep in any position other than flat on his back and he was in a lot of pain from the RED. The weight of the device puts a lot of pressure on a child's small neck muscles. The weight of it pushing against the skin at the pin sites often causes tears in the skin, as well scarring. Luckily, one of my son's scars is heart shaped (3/4 the size of a dime), so he's decided that if it had to scar, at least it's a kind-of-cool shape.

You also have to be careful so that infection does not set in. His (site) became infected several times. We live a

clean life and we followed the doctor's directions for care, but it still happened. Then there is the turning of the screws. There was so much pain involved in this process that after each time I would go to my room and cry. My son would scream, cry, and beg me not to turn the screws because it hurt him so terribly. Occasionally, if I didn't have the correct pressure on both turning wands, the device would slip and slam all the way back to the place it had been in the beginning. That is extremely dangerous as not only does it feel like being hit with a sledgehammer to a child, but it can completely undo every bit of work that the device has done up to that point.

As you can imagine as a result of all this pain and bone manipulation, my son was on a liquid diet for several months. He also lost a couple of teeth during the operation, which did not help matters. The doctor said that he could go on a solid diet after the surgery as soon as he felt like it. He tried solid food a few times, and it hurt so badly that he gave up. We had to give him PediaSure for about two and a half months.

All in all, I would have to say that this operation is very good for some children,

but very bad for others. Every parent considering it needs to sit down with their child's doctor and discuss ALL of the pros & cons of this surgery. It is a big undertaking, and may have to be repeated one or more times. Our doctor thought once would be enough, but it was not. So sometimes the doctors do not even know for positive. You need to weigh the amount of pain involved and the potential problems. Factors to be considered are the following:

- Is it medically necessary for my child or is it just for cosmetic reasons?
- Is my child fully aware of what this operation entails and willing to go through with it and any subsequent complications?
- How beneficial will it be in changing the things that need to be changed?
- Is there a less painful or easier way?
- Last, but not least, will our insurance pay for this operation and any other procedures of this type that may be needed in the future?

This is a big decision. Please think about all of the aspects before making your decision.

Sincerely,
Melissa Hooper

Mitch and his baby brother, Max.



Q. Where were you born?
A. Columbus, Indiana, but I live in Seymour now.

Meet Mitch Cobble Vonderwell

Q. What grade are you in?

A. I'm in Mrs. Chase's fourth grade class at M. R. Brown School.

Q. What are your hobbies?

A. I love to roller blade and ride my bike. I also love music. I play the drums, guitar, harmonica, but in my own style.

Q. What other activities do you enjoy?

A. I'm on a basketball team at the Boys and Girls Club.

Q. What do you want to be when you grow up?

A. I want to work at Riley Hospital for Children in Indianapolis. But working at McDonald's or being a policeman would also be fun.

Q. What kind of craniofacial condition do you have?

A. I have Amniotic Band Syndrome.

Q. How many of Cher Family Retreats have you attended?

A. I have been to five.

Q. Which retreat was your favorite?

A. I had a blast at the one last year, but have had fun at all of them.

Q. What has growing up with a craniofacial condition taught you?

A. I try to just show people I'm the same as they are, but I just look different.

Tips for Behavior Management at Home

By: Kristen E. Bolomey, Psy.D.

It is possible for any child to experience behavior problems. However, a child with attention deficit disorder (ADD), a chronic illness, increased anxiety, or numerous medications are at a much greater risk for problems in both home and school environments. Although there are medical reasons for a child to have a behavior problem such as ADHD or epilepsy, the source of the troublesome behavior can be the result of frustration or learning difficulties. A child who acts out generally craves attention, but does not know how to ask for it appropriately. Learning to ignore minor rule infractions while praising positive behavior is often the most effective.

Behavior issues among children with chronic medical conditions are often exacerbated by parents who mean well and caregivers who "feel sorry" for the child, who may not be able to do everything other children can or who has to endure painful medical interventions on a regular basis. These parents often assign the behavior problems to situational causes. Unfortunately, these children are often acting out their anger and anxiety, as well as frustration and confusion as to what is expected of them.

When "push" comes to "shove"

Giving a child a piece of candy or a doll after he or she kicks the nurse who is trying to draw blood is interpreted by the child as "I will get a reward if I can fight the person who is trying to hurt me." The same situation occurs when a child cries at not getting a cookie. Not until the parent gives in to the child's demand, does the parent enjoy a little peace and quiet. In this situation, the child has learned, "If I cry long enough, I will get a prize."

Being firm and consistent is necessary so that the child knows what is expected of him and what to expect from the caregiver. Attempting to minimize the power struggle can be an effective way to handle the situation. In a power struggle,

between two people, no matter what the age, achievement and intellectual difference or subject, NO ONE WINS!

Be consistent, and always follow through

One of the best ways to handle this type of situation is to decide the appropriate method of discipline before a situation arises. In order to be taken seriously, the parent must always follow through with the stated consequence.

For example, telling your daughter that you will give her \$100 if she will go to bed right now will not provide you any leverage the next time you want her to go to bed. That is unless you are willing to pay the \$100 this time.

In order to keep from setting the expectation for expensive items that may feel more like bribes than the development of behavior expectations, it is best to use natural consequences. For example, "If you do not eat your dinner, you won't get dessert," or "If you take too long getting ready for bed, we won't be able to read together." However, if a natural consequence is not available or reasonable, time out or other loss of privilege can also be used.

Don't make "time out" a reward

Time out only works when handled correctly. My general rule is that the length of the time in minutes should equal the child's age (i.e. 5 years old = 5 minutes).

Time out should also be taken in a location with few distractions and no rewarding stimulation. Sending a child to his or her room where there are a VCR, radio, toys, telephone, and video games is likely to be rewarding rather than punishing.

Also, it is not likely to be effective if the child uses the time out as an escape from an activity that is thought of as boring, such as doing chores or homework. I usually suggest using the kitchen table as the

place to carry out time out. This is typically a part of the house that is uninteresting and an egg timer or microwave timer are readily available. A timer can then be set for the appropriate time where it can be seen and heard when it goes off.

However, it must be understood that time out does not begin until the child is quiet and in control of his or her behavior. During the time out, the caregiver should attempt to avoid conversation and eye contact with the child while remaining in the vicinity to keep an eye on his or her activities.

Once the child has completed the time out, then the caregiver can help the child process the situation by asking what triggered the behavior and how could it have been better handled. These questions should be tailored to the child's age and level of understanding.

Respect for others

The most effective way to teach children how to behave appropriately is to teach them to respect others and to examine the consequences of their actions. This is a tall order, but is not out of the realm of possibility.

Parents are usually the first "others" that a child encounters with friends, siblings, teachers, and employers in close succession. By teaching them to respond appropriately to requests and rules, the foundation is being laid for the development of stronger social skills to enhance school and employment abilities.

It is important to let children see you express your feelings through appropriate tears, anger, excitement, and affection. However, the child's best interest must be considered and the parents' role as the grown-up be maintained. It is okay to let your child see that you are sad because you lost your job or because somebody hurt your feelings, but it is not alright to become violent or destructive. It is alright for you to let your 5-year-old help fix a bowl of soup for you when you are ill,

see **Tips**, page 4

Tips. cont'd from page 3

but it is not all right for you to expect that child to listen to your problems.

Apologizing for mistakes and admitting that you do not know all of the answers or have the solutions for all problems are also ways of teaching children respect and compassion for others.

1-2-3

In the book, *1-2-3, Magic*, (1996), Thomas Phelan, Ph.D. suggests giving children warnings regarding their behavior. This is accomplished by asking the child to follow through with a request, such as taking out the trash. If the child follows through, thank him or somehow acknowledge the response. If the child does not respond, then tell the child "I asked you to take out the trash. This is the second time I have had to ask. If I have to ask you again, you will go to time out."

As you begin to feel more comfortable with this process and your child is better able to understand what is expected of him or her, you can say, "This is two. If I get to three, then... it's up to you." Make sure the child knows that the consequence is directly related to his or her choice of behavior. This helps the child learn to take responsibility for his own behavior rather than blaming it on a parent or teacher.

For younger children, the statements can be shortened to be more understandable. For a toddler who may be playing in the water, you could say, "Please get out of the water." If he responds, you should respond with a thank-you. If the child does not stop, then show the number two with your fingers and say, "That is two. If I get to three, then you will go to time out." If the child still does not stop, then say, "That is three. You need to go to time out."

But what happens if the child refuses to go to time out? You begin by asking the child to go to time out, then if the child does not follow through, usher the child to the chair with gestures (pointing to the

chair). On the third try, you may have to physically guide the child. If the child refuses to go to time out or if his/her behavior has become dangerous to him/herself or others, then stand behind the child and take each hand in your own so that the arms cross in front. Be careful not to allow the elbows to cross (this keeps the child from being hurt and provides a guideline for the parents, particularly when angry or when the adrenaline is pumping). This position may be all that is necessary to help the child become more cooperative and gain control over his/her behavior. In this position, the child's energy is focused inward, rather than outward.

You may then want to sit with the child on your lap if he is a toddler or let the older child sit alone. If the child becomes more agitated, then you may want to sit down on the floor with your back against a wall and the child between your legs. In this position, the caregiver is vulnerable to head butting. To avoid this gently lean into the child with your head turned sideways and your face against the back of his head. Try not to speak with the child or use eye contact until he or she has calmed down. Time out begins after the child has calmed down. Then, after the appropriate amount of time, you may let go.

Okay...so what just happened here?

After the time out, it is important for you and your child to discuss his behavior and the reason you responded as you did. Then try to find out what triggered the behavior. If this type of agitated behavior occurs on a regular basis or if the child's behavior becomes dangerous, behavior modification is necessary to help you and your child maintain safety. This is not normal behavior and it needs to be stopped. Contact a psychotherapist who specializes with pediatric behavior modification or your pediatrician for a referral. The techniques listed above are methods of behavior modification, but a psychotherapist will be able to help make more specific suggestions for your situation.

Reward good behavior

Finally, it is more important to reward a child's good behavior than to punish the negative. Saying thank you or somehow acknowledging that the child is doing well helps him/her develop a sense of success that he/she can draw on during more questionable moments. If a child is having trouble following directions, instituting a reward system in which he gets stickers, stars, or poker chips as rewards for positive behavior allows him/her to see the evidence of behavioral success. The tokens can be given for each activity or time period that the child successfully completes and can be saved and traded for a prize at later time. The prizes do not have to be expensive. Many times being able to set aside time with a parent is enough.

Generally, once the above strategies have been in place for several days, the child will become accustomed to what is being asked and will follow through more quickly. However, don't expect a completely smooth transition. Children do not like change any more than anyone else and with change comes the opportunity to question whether the parents really mean what they say. Persistence and consistency with early efforts in developing these behavioral plans will eventually pay off. Your home may not be perfectly harmonious or quiet, but there should be greater respect and cooperation between family members.

Suggestions for further reading:

Lott, Lynn & Intner, Riki (1995). *The family that works together...: Turning family chores from drudgery to fun.*

Phelan, Thomas (1998). *Surviving Adolescents: How to manage and let go of your 13-18 year olds.*

Phelan, Thomas (1996). *1-2-3 Magic: Second Edition.*

Whitham, Cynthia (1994). *The answer is no: Saying it and sticking to it.*

Wychoff, Jerry; Unell, Barbara; & Wychoff, Jerry (1985). *Discipline without shouting, or spanking: Practical solutions to the most common preschool behavior problems.*



**North Texas Hospital for Children
at Medical City Dallas**

A heartfelt thanks to **The North Texas Hospital for Children** for the generous two-part grant that provided CCA new offices and telephones as well as the matching grant that sponsored the hiring of CCA's new Development Director, Judy White. This generous grant will help us to continue meeting the needs of families across the country with members affected by craniofacial conditions. Many thanks to **Britt Berrett**, President and CEO of The North Texas Hospital for Children, **Janet Galaway**, Physician Service Coordinator, and **Lynn Rich**, Communications.

Ways YOU can help CCA

If you **SHOP ON THE WEB** you could help CCA at the same time. Charity Malls including <http://www.4charity.com> and <http://www.iGive.com> will give CCA a percentage of your shopping dollar. So, please keep these sites in mind when you shop online.

Kroger and Albertson's will donate up to 3% of your total grocery bill to CCA each time you present a special card at check-out. Call CCA for your free card and use it each time you shop. To have your **Tom Thumb Reward Card** benefit CCA, link your Reward Card to **charity #2417**.

SENDING FLOWERS FOR EASTER AND MOTHER'S DAY? Order your flowers through Our Gift and CCA will receive a donation for each order you place. Call **1-800-Our Gift**.

WIN a Harley Fat Boy® Autographed by Cher!

Ever since making the movie, *Mask*, Cher has been a fan of both motorcycles and The Children's Craniofacial Association (CCA).

Register to win

by visiting <http://www.CCAkids.com> or calling **800-535-3643** or buying tickets in downtown Sturgis or at the Buffalo Chip Campground during the Rally. Also available before the Rally at selected dealers. Visit our Website for a list of participating dealers.

On August 10, 2001, a motorcycle autographed by Cher will be raffled off at The 60th Annual Black Hills Motorcycle Classic Rally in Sturgis, South Dakota to benefit CCA.



Cher and CCA's Robbie Gorecki last year at the Sturgis Rally

3 Cheers for Volunteers



CCA is fortunate to have many skilled professionals who generously donate their time and talents. In an effort to achieve its goal of patient and family outreach and to disseminate up-to-date information to the public and healthcare providers, CCA realized that a comprehensive Website was a necessity. We also recognized that this meant a sizeable financial commitment. However, as we set about obtaining quotes from Web designers, we were shocked to discover what this actually meant in dollars and cents.

We are committed to keep pace with the Age of Technology, so we formed a committee and asked **Fred and Rose**



Fat Tuesday Party Benefits CCA

Razzoo's Cajun Restaurant celebrated Fat Tuesday with 5,000 of their closest friends. Revelers dined on delicious Cajun food, partied and danced the night away. Razzoo's then generously donated \$1 from each cover charge to Children's Craniofacial Association. Thank you Razzoo's for your donation and community spirit!

Seitz to be a part of our group, as we knew of their reputation and expertise regarding Websites. We were surprised to learn that the Seitzs owned **Directed Technologies Inc** (<http://www.directed-tech.com>), a company dedicated to professional consulting, application development, information outsourcing, and network design and implementation. We also discovered that they enjoyed client relationships in the corporate world and in legal and business arenas, as well as in the insurance and medical sectors.

In cooperation with CCA's board member, **Robin Williamson** of **Williamson Creative Services Inc** and **George Beaver**, Fred's and Rose's coworker, they created (pro bono) a site for CCA. We are extremely proud of our new site, <http://www.CCAkids.com>. The new Website offers a wealth of up-to-date information regarding craniofacial conditions and gives us the opportunity to showcase the programs of Children's Craniofacial Association. Through the commitment of this fabulous foursome, CCA has saved thousands of dollars, which have been earmarked for other programs to serve our kids and their families.

We tip our hats and say, "Three cheers for **Fred, Rose, George, and Robin**, four incredible volunteers!"

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Cher

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

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