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2003 cher's family retreat



this June, CCA came full circle as 70 families gathered in our nation's capitol for the Cher Family Retreat weekend. Back in 1990 while in Washington, D.C., Cher, CCA's National Spokesperson, conceived the idea of a yearly retreat for families. Now, in 2003, seven of the original 10 families were present at the 13th Annual Retreat.

The Retreat is a weekend of relaxed activities, where families gather to share experiences, resources and support.

After registration Thursday afternoon, the Retreat began with the annual ice cream party. Long-time CCA volunteer and mom, Carolyn Johnson, lead the group in some fun icebreakers.

Friday was filled with a day of sightseeing at the Smithsonian. Among many

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message about the chair

terry Carmichael, who served on CCA's Board of Directors since 1996 and as Chairman of the Board since 1999, has stepped down. Although she originally intended to resign in December, she decided to make the transition a couple months earlier than planned.

CCA grew tremendously under Terry's leadership. Now retired from a successful career as an efficiency consultant to well-known corporations, Terry turned her undivided attention to CCA. Terry's goal as Chairman was to create a board that was hardworking and

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Maria (on right) with her older sister, Christina.

meet maria petrulli

ask Miss **Maria Petrulli** a question, and she's bound to know the answer. This girl is smart, full of life and is definitely going places.

Maria is in the Fifth Grade this fall. She loves to read and write. In particular, she has been reading the *Series of Unfortunate Events*, a collection of about a dozen mystery books. She even likes Math, well some things about it.

When she's not reading or writing, Maria likes to bike ride, climb trees, train animals and collect unusual, marbled rocks. And she

loves the store, Staples, confessing that she's a "Staples Freak." That makes sense, considering her love for writing — imagine all the pens and paper she has to choose from! Maria definitely will keep them in business.

This summer Maria, her dad and older sister went to the Cher Retreat in Washington, DC. She'd never been before, so she had the chance to see lots of national monuments and visit museums.

The highlight of the trip, her "favorite part," was the dinner dance. She danced

the hula and the Macarena and left with a goody bag filled with CDs, T-shirts and lots more. After the Retreat, she and her dad and older sister spent some time in Ocean City, in near-by Maryland.

Maria also had a chance to meet Cher in person backstage at one of her concerts. It couldn't have come at a better time, her mom said. Maria's granddad recently passed away; she was very close to him and even wanted to donate a kidney to help him stay healthy. It was a very busy time for her family.

Meeting Cher really meant a lot to her. She listened to Maria, and was thoughtful and approachable. Maria even had a chance to sing for Cher.

Maria also has some advise for other kids. She said, "It doesn't matter what other people think. You're your own person." She also says to "keep praying."

your fair share

did you know?...

When the **United Way Campaign**

at your work asks you to contribute your fair share or any amount, you can designate that the funds go to Children's Craniofacial Association. That way you'll be helping your workplace as well as this important cause! Thank you!

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 at **1-800-535-3643**. All we ask is that you apply at least four to six weeks prior to your next trip.

meet jeannelle rivera

my name is **Jeannelle Rivera.**

I was born in Ceiba, Puerto Rico on April 21, 1978. I moved to Texas when I was three for medical reasons and have been here since.

I was born with Pfeiffer's Syndrome and had my first operation when I was just 17 days old. I've had reconstructive surgeries every year until I turned 18.

Life has been very tough, but through it all I've been blessed with the love and support of my close family and friends. My parents, older sister and three younger brothers have given me tremendous love and support. Most important, I've been blessed with the love of God, who each day continues to give me faith.

I am currently a senior at the University of Texas at Arlington. My major is Communication Technology, and I hope to be a Web page designer after I graduate in 2004.

In my free time, I enjoy drawing and photography. (If you'd like to see my artwork, visit my web page at <http://students.uta.edu/jx/jxr9579/>.)

Most of all, I enjoy "Salsa on Two" dancing (Mambo) and other Latin dances. I'm in a dance group called Sandunga, located in the Dallas area. We've performed all across the metroplex, Houston, San Antonio and Austin. We also performed in Puerto Rico for the Bacardi Salsa Congress in 2001 as the first dance group to represent Texas.

My first CCA family retreat was in 1991, when we went to Disney World, Universal Studios and Sea World in Florida. My family and I also went to the family retreat in Phoenix, Arizona, the following year. We had an incredible time in both retreats. We met and spent time with many families. I am very happy with CCA and what they have done for so many patients and their families, including mine.

I've never met anyone with Pfeiffer's until this year in May. I had the privilege of meeting baby



Macey Atkins and her father, Steve Atkins. Meeting Macey brought back many memories of my childhood. It was nice to be able to share with Steve about Pfeiffer's and compare what Macey and I have experienced. We will continue to keep in touch.



the genetic evaluation: what is it?

Elsa Reich, MS, CGC

a genetic evaluation is usually carried out by a medical geneticist, a physician with Board certification in medical genetics, and by a genetic counselor, a Master's level professional who has Board certification in genetic counseling. It usually helps if, before the appointment, you provide:

- Medical records
- Blood test results
- Specialized evaluations such as CT or MRI scans and X-rays
- Diagnostic reports or letters, etc.
- Photos of your child or other affected family member(s)
- Photos of family members, siblings, grandparents etc., Affected or unaffected

You may need to furnish release forms to your physicians.

It will help you to make a list of questions before you go for the consultation. Never feel that there are things you shouldn't ask. Your geneticist and genetic counselor know that you may be worried about a lot of things and would rather

cca grad

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what is play therapy?

Laura Parsons, M.Ed., L.P.C.I., N.C.C.C.

Our children face a number of problems and encounter various difficult situations. It could be a medical problem, or they feel different or are teased at school. Perhaps their parents are separated or divorced. They may be depressed, have phobias or have difficulty adjusting to new situations. They may experience social problems with their peers, have sibling relationship issues, suffer from grief or the loss of a loved one. And the list goes on.

As adults, we're able to verbalize our problems to others. Unfortunately, children's cognitive development is faster than their emotional development. They take in so much from their surroundings and people they interact with, but how they feel and express those emotions is not as simple. Play therapy is a well-documented and researched area that has been very successful in helping children work through their problems.

Play is children's way of expressing how they feel about events in their lives as well as important people in their lives — all at a level of their cognition and understanding. Children's play, whether it is in terms

of fantasy or reality, is usually in correlation with emotional issues the child is experiencing. Play therapy's main concern is to be sensitive and aware of the child's emotions and understanding of the world.

Nonverbal activities such as play enable the child to address issues that they may not be able to address (or may be scared to address) with regular talk therapy. Through play therapy the child is able to relinquish some of the power of the emotions and symbols at a vital time in life. Play therapy allows the child to use creative expression to work through the emotions they are experiencing. Play therapy provides children with the materials to play and fully explore and express their thoughts, feelings and emotions. In addition, play therapy can help children to learn a variety of coping skills in a safe and relaxed atmosphere.

Play therapy allows children to govern their issues and to advance at their own pace, all within a safe environment. This gives children the ability to process their pain in their own time frame. Themes such as loneliness, sadness, and fear can be expressed through children's play in

the experiences of the play characters and the actual children. Toys are viewed by play therapists as the child's words and expressions of language, which gives children the medium to work through a wide array of feelings.

Play therapists regard the relationship as the key to growth and change within the child. They view the purpose of play as a way for a child to remove him or herself from a traumatic experience by projecting his or her feelings and reactions onto objects in the playroom. Play assists children in gaining an intrinsic resolution, which helps them in dealing with and adjusting to problems.

Play helps children to better familiarize themselves with unclear situations or traumatic experiences and gain a fuller, more tangible understanding of problematic events.

References

- Barile, L., Clark, E., de Jong, A., Zambelli, G., (1988). An interdisciplinary approach to clinical intervention for childhood bereavement. *Death Studies*, 12, 41-50.
- Glazer, H. R. (1998). Expressions of children's grief: A qualitative study. *International Journal of Play Therapy*, 7 (2), 51-65.
- Herzog, J. (1985). Suffering perceptions and adaptations in three pre-school siblings. *International Journal of Family Psychiatry*, 6 (3), 273-282.

Landreth, G.L. (1991). *Play therapy: The art of the relationship*. Munice, IN: Accelerated Developmental Press.

Landreth, G.L. (1993). Child-Centered play therapy. *Elementary School Guidance & Counseling Journal*, 28, 17-29.

Landreth, G.L., Homeyer, L. E., Glover, G., & Sweeney, D. S. (1996). *Play Therapy Interventions with Children's Problems*. Norvale, NJ: Aronson.

Levick, M. (1983). *They could not talk and so they drew: Children's styles of coping and thinking*. New York: Thomas.

O' Connor, K. & Braverman, L. (Eds). (1997). *Play therapy and practice: A comparative presentation*. New York: John Wiley & Sons.

Seager, K. M. & Spencer, S. C. (1996). Meeting the bereavement needs of kids in parent/families-not just playing around. *Hospice Journal*, 11 (4), 41-66.

2003 retreat photos



2003 retreat, from page 1

things, the group saw space suits and capsules at the National Air and Space Museum, a diamond exhibit at the Natural History Museum and a very emotional 9-11 exhibit at the American History Museum.

Friday night's activity was a big surprise for the group. Knowing that our hotel didn't have a pool, Cher treated everyone to a pool party and picnic feast at another hotel nearby. Thanks, Cher, for making this fantastic party possible!

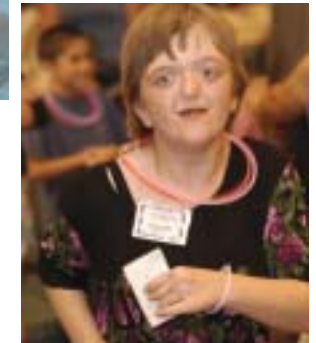
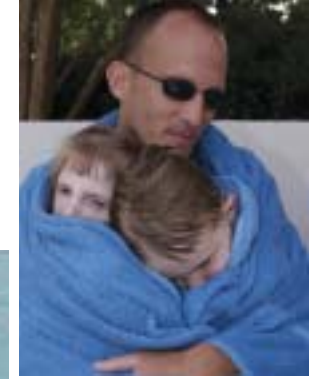
Saturday was a beautiful day, the perfect backdrop for another day of sight-seeing. The group enjoyed a tour of national monuments, including the Franklin Delano Roosevelt Monument, Vietnam Wall, Lincoln Memorial, Korean War Memorial, Jefferson Memorial and Washington Monument.

Of course, the highlight of the retreat was the dinner dance Saturday evening. The night began with a surprise magic show provided by well-known magician, Turley, who heard of the retreat from

our tour guide, Patrick Knowlton. Many of the kids participated in the show and all enjoyed it. After the show, we had a wonderful dinner and danced the night away, donning glow-in-the-dark necklaces and stick-on clothing decorations that Cher sent. At the end of the evening, each child left with a bag full of goodies, courtesy of Cher.

Sunday morning breakfast was spent saying goodbye, exchanging addresses and phone numbers, and promising to stay in touch until next summer's retreat.

The 2004 Annual Cher Family Retreat will be held in Tempe, Arizona, June 24-27.



genetics, from page 3

you ask all of your questions instead of stewing about them at home.

At the time of the appointment, your counselor or geneticist will obtain a complete health and medical history of your child (or other affected family member), a developmental history (if applicable), a detailed pregnancy and a complete family history. Ask your parents, siblings and grandparents about their health histories. Get as much information as you can. Don't worry if you don't know too much about your family. Many people don't.

After the history-taking, the physician will examine your child or affected family member thoroughly. He/she will look in detail at aspects of the individual that most specialists don't pay too much attention to. They will tell you what they see in language you can understand. They will tell you if what they see is something to be concerned about or if they are seeing a physical variant that has no medical significance for your child. They will tell you if they recognize a specific condition or if there is uncertainty. It is possible that they will want to do some blood tests, imaging studies or other tests before giving you their opinion. They may refer you and your child to

another specialist for an additional evaluation. They will want to make certain that they have done everything they should to provide you with a specific diagnosis.

Sometimes, after all of the evaluations, they still may not have a definitive diagnosis. They will want to see you again if they have specific test results that require further explanation. If they are unable to make a specific diagnosis, they will ask you to return in a specified length of time. Sometimes a diagnosis may become more apparent as time goes by.

Usually you can expect your counselor or geneticist to send a summary letter to your referring physician as well as to your pediatrician or other primary care physician. When the evaluation has been completed, you should request that they send you a letter for your records.

In addition to the medical part of the genetic evaluation, you will have the opportunity to talk about your situation, to discuss what has happened in the time since you first learned about your child's condition. Sometimes parents have misunderstandings about what has happened and why. The geneticist and genetic counselor want to help you to learn about the condition, what to expect in the

future and what their team can do to help you. They want to assure that all of your child's medical problems and that the emotional issues in the family are addressed.

What will we learn?

Information about the medical aspects of the condition would include:

- Any associated abnormalities
- Available treatment
- The natural history of the condition, i.e. life expectancy, intellectual development, etc.
- Identification of other affected family members
- The chance for the parents or the affected individual(s) to have an/another affected child
- The applicability and availability of prenatal testing
- Resolution of uncertainty

What are the psychological benefits of having a genetic evaluation?

Many parents have concerns about a variety of issues when a child with a craniofacial condition is born. Most of the time, the condition has occurred unexpectedly.

1. "Did I do anything before or during the pregnancy to cause this to happen to my baby?" Although it is possible that something

happening during the pregnancy could have caused the condition, most of the time there is nothing that can be identified that has contributed to its occurrence.

Most medications do not cause craniofacial conditions. Although we recommend that pregnant women not take medicine unnecessarily during pregnancy, there are very few drugs that are known to cause a very significant increase in the frequency of birth defects. It is extremely uncommon to identify a medication that has caused a craniofacial condition. Although we recommend that you not smoke during the pregnancy, smoking is not known to cause craniofacial conditions. Ask the genetics professionals about anything that worries you.

2. What is the chance that this will happen again or what is the chance that our affected child will have an affected child? Your concern about future children will be addressed during the genetics consultation. This is a common worry. It depends on what the condition is and whether it has occurred anew or whether it has been inherited from a parent. The genetics professionals will give you their best estimate of the likelihood of the condition hap-

pening again. It may be a small to modest chance and it may be as high as 50%. It is almost never 100%.

If you are unaffected yourselves, you may feel differently about having another affected child than your affected child may feel when he or she is ready to have children. Allow your child to make up his/her own mind up on the basis of his/her own genetic counseling, personal experience and values.

3. You may feel angry that you have had a child with a craniofacial condition perhaps because you think it should have been identified on a prenatal sonogram.

Sometimes the condition can be identified, and sometimes not. You may feel angry because you are the only one in your family who has had a baby with a problem. It can happen to anyone. You weren't chosen. It just happened.

4. You may be worried because one or both of you used recreational drugs prior to having children and think they may have contributed to the occurrence of the condition.

There have been several studies that have shown that people who have used recreational drugs have no greater number of babies

with abnormalities than other people.

5. You may worry because one of you is adopted and doesn't know his/her biologic background. There may or may not have been someone in the family with this condition. This is very unlikely. In addition, there have been studies that show that individuals who have been adopted have no greater risk of having a baby with a problem than anyone else.

These are just a few of the concerns and worries that people have. You should feel free to ask your geneticist or genetic counselor any question that is bothering you, about the cause of the condition in your child or family, its natural history (what to expect), how to talk with other people about it, how to help your child adjust and how to deal with it yourself. They can make referrals for you to support groups, knowledgeable therapists or others familiar with the condition.

Don't be afraid to go for a genetic consultation. You may feel a lot better afterwards.

chair, from page 1

dedicated to the cause, fiscally responsible, and one that took an active role supporting the charity using their business expertise and/or fundraising abilities. She wanted to make the struggling organization financially secure in order to sustain programs and services that would make a positive impact on the lives of children and adults with craniofacial conditions and their families. Terry accomplished all of her goals.

During her tenure, CCA developed a strategic plan that serves as a map to ensure we stay on course. In 2002 the plan was revisited and revised to better reflect the state of the organization and the needs of craniofacial patients.

In her dedication to making sure all areas of governance were scrutinized, Terry oversaw the updating of bylaws and developed thorough budgeting and auditing strategies. Financially speaking, when Terry joined the board CCA was working on a deficit and today CCA is financially secure.

Terry was not a leader who stood on the side-

lines and coached. She was always right in the game playing alongside the other board members and staff. Terry used her unique ability to seek out talents and knowledge in people she knew or met to help CCA. She was a hands-on fundraiser and encouraged that in others.

Terry led by example. After a fellow board member initiated the annual Harley raffle in Sturgis, South Dakota, Terry and her family members dedicated weeks each year to help make the event successful. For example, last year Terry picked up the prize motorcycle in San Diego and drove it across the country to a bike rally in Daytona, Florida and then back to Texas for an Austin rally, before she was to transport it to Sturgis for the raffle, logging thousands of miles on behalf of CCA.

CCA grew and flourished under Terry's leadership. CCA Directors, Staff and the families we serve thank her for her hard work and dedication. Terry raised the bar for Children's Craniofacial Association and we will all work hard to meet the standards she set.

3 cheers

for volunteers!

When we say our volunteers are in it for the “long haul,” we’re not kidding.

Terry Carmichael has traveled across the country for CCA — from her home in Colorado to pick up our borrowed motorcycle trailer in Utah from the **Pace American** plant, to the **San Diego Harley-Davidson** to pick up the special 100th anniversary edition Heritage Softail Classic motorcycle for our summer raffle, to Tucson, Arizona, to the home of Cher Convention friends, **Robyn, Marina, Edna** and **Fred Fisher**. (Fred designed, built and donated the Plexiglas boxes for displaying Cher-signed

Harley gas tanks and holding the raffle tickets.)

In Texas, **Phil** (Terry’s husband) and **Greg Patterson** joined Terry as she continued her travels to CCA Dallas headquarters to collect more raffle gear then on to the East coast to sell raffle tickets during Daytona Florida’s bike week. As a matter of fact, the winner of our raffle purchased 5 tickets for \$20 when he noticed our web link while checking out the Daytona events online.

And our friends at **The Harley Shop of Longview TX — Keith Calhoun, Jeff Brown, Randy Burkhalter** and **Wayne Hotaling** — removed the motorcycle’s

gas tank to ship out to **Cher** on tour so she could autograph it for us, and then they replaced the tank after she signed it — no small undertaking.

With the bike ready again for display, Terry, Phil and Greg then hauled it around Texas to various venues for raffle ticket sales — the Lone Star Corvette Club festivities at Texas Motor Speedway outside of Dallas in Justin, Texas; the ROT (Republic of Texas) Rally in Austin; and at Pier 121 in Lake Lewisville with the unwavering support of our new friend **Jim Butera** (CCA Program Director, Jana Butera’s father).

So you see, this is how our volunteers spent their summer vacation — helping with the CCA summer raffle fundraiser. 3 CHEERS!

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Cher

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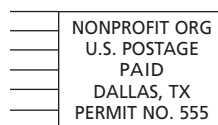
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