

Family Faces

A Newsletter for Families of the Craniofacial Center



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Camp Killoqua August 27-31

Children's Hospital is pleased to announce that Camp Killoqua is offering a camp for children with facial differences. The camp is designed for kids entering grades 4-8 in the fall. Campers will participate in a variety of activities that offer the opportunity to work and play with others in small cabin groups. Activity choices include canoeing, swimming, biking, noncompetitive sports, arts and crafts, archery, ropes courses, a climbing wall and many other activities that promote self esteem, confidence and social awareness.

The camp experience gives children an opportunity to build friendships and create special memories with other campers who have craniofacial conditions. As part of the registration process, a conversation will take place to make certain that the camp is a good fit and that each child will benefit from participating.

If you would like more information on the Camp and how your child might participate, please contact Monica Andrews at (206) 987-3191 or visit the camp website; <http://www.campfireusasnohomish.org> (See session descriptions link. The Craniofacial Camp is session 10.)

IN THIS ISSUE:

- Poem by Dana Jensen pg. 2
- Family Liaison Position pg. 2
- College Scholarships pg. 2
- A CHARGEd Up Gathering pg. 3
- Help! I'm Being Bullied pg. 4
- New Faces In Craniofacial pg. 5
- Sibshops pg. 6
- 2007 Connections Conference pg. 6

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What's The 'Scoop' On the Craniofacial Family Liaison Position?

Many thanks to the dedicated parents who contacted us in response to the Craniofacial Family Liaison position advertised in the last issue of *Family Faces*. We were fortunate to receive a number of applications and resumes from highly talented individuals committed to helping Children's Hospital and the Craniofacial Team foster strong community ties with our family partners.

In the coming weeks we will complete the interview process, select a finalist and fill this important position. Stay tuned for a feature on the new Craniofacial Family Liaison in the next issue of *Family Faces*!

Craniofacial Family Picnic

The annual picnic was enjoyed by all who attended. Thanks for sharing the day together. The kids took great pleasure in the door prizes, running around at Matthew's Beach and the magician. A big round of applause to Nancy and James Schoeggl for all their support in making this event such a great success!

Look for details for the next picnic this coming September.

Live by These Words

by Dana Jensen

**You must depart from the world to see my perspective.
Free yourself from the twisted chains
Holding you back to harden the fragile feeling.
Swivel in and out of dreams;
shut the laughter out of your mind.
Do not run away from reality;
Simply walk away from it to protect the jewel inside you.
You are unique, do not let words hurt you;
Let them wash over like a river.
Thoughts can not penetrate clear water.
You are surrounded with a bubble of hope,
compassion and love.
Ignore the passing sharks that try to penetrate your bubble.
Pass through the world with the power of happiness.
Scoot through gaps and passage ways that lay forgotten.
Live by these words and life will bloom before you.**

Dana is a 12 year-old patient in the Craniofacial Center who enjoys writing, drawing, and singing in her free time.

College Scholarships for Students with Craniofacial Anomalies

The Cleft Palate Foundation is pleased to offer undergraduate scholarships for students with craniofacial anomalies. Complete application packages should be postmarked on or before March 01, 2007.

Application packets may be requested via email, info@cleftline.org or by phone, 1.800.242.5388 or download an application from ACPA's website: www.cleftline.org.

A CHARGE^d-up Gathering

In early October, five Western Washington families who have children with CHARGE Syndrome met for support and friendship. The purpose of the meeting was simple – connect with other CHARGE families.

The children ranged in age from 15 months to almost five years old. Families came from Ellensburg, Tacoma, Bellingham, Lynnwood and Edmonds. Mighty Max's mom, Amy, posted this about the gathering:

"... we all absolutely loved getting to spend time with each other's children and admire their tremendous progress. Each of them has something very special and unique!"



From left to right: Dean and Marty Kelly (daughter Maya), Nick and Renae Bogner (daughter Cassidy), Sarah and Jeremy Storrs (son Evan), Amy Sprouse (son Max McKinley), Linden and Rebecca Anderson (son Cameron)

And it is also so interesting how common some of their CHARGE "traits" or "quirks" are...the shape of the ear, the famous happy dance, or the floppiness when they sit. In many ways, they are family as they are genetically linked with CHARGE syndrome.

At one point, three kiddos were being fed via their G-tube...and it was completely normal to have the suctioning machine being used throughout the afternoon. And no one even blinks about any of it because this is the norm for all of us! :) "

Formally identified in 1981, CHARGE Syndrome is fairly complex and can affect many systems including – vision, hearing, respiratory, heart, growth, development, digestive, sensory, and balance. Caring for a child with CHARGE can be extremely overwhelming, especially when they are young and require so much medical attention. However, these children also tend to have an incredible drive (determination and tenacity) to overcome their challenges and witnessing this is so inspiring.

The group plans to meet again in the spring – after the cold and flu season. Several of the families are planning on traveling to Southern California in July 2007 for the national CHARGE conference. If you are interested in attending the next gathering or have any questions, please contact Rebecca Anderson at (425) 776-5069, or visit one of the websites below:

CHARGE Foundation (<http://www.chargesyndrome.org/>)

Cameron (<http://cameronwoweandrew.blogspot.com/>)

Cassidy (www.bognerfamily.blogspot.com)

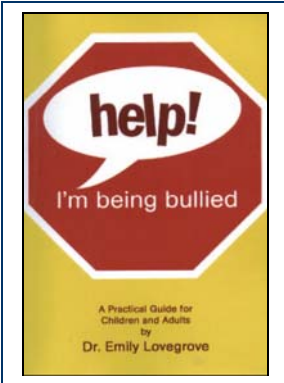
Evan (www.babysites.com/sites/skeybunny)

Maya (www.babysites.com/sites/kellykids)

Mighty Max (<http://maxupdate.blogspot.com/>)

Article submitted by Rebecca Anderson.

Help! I'm being bullied



Being bullied at school or on the school bus is a child's worst nightmare. Parents often say, "Ignore the bully and he or she will leave you alone." Most often this doesn't work and the bullying gets worse.

Dr. Emily Lovegrove, an international expert on bullying, does away with myths about bullying and offers parents and children concrete, practical advice on how to stop being bullied. She notes that kids want to be able to deal with bullies themselves, but lack the skills to do so.

Lovegrove offers ways to deal with bullies. These methods have been proven to work based on her extensive research with school-age children who have been bullied. Some of her advice for kids dealing with bullies includes:

1. If it feels like bullying, it is. It's important to decide this for yourself; bullying can be physical, emotional or psychological.
2. Stop and think: What do I want the outcome to be? After this is over, do I want to be able to get along with the person who is bullying me?
3. Create a "self motto." This helps increase self confidence and create positive messages in your head. For example, "I am really brave." Or, "I always try my best."
4. Change the way you think about the bully and come up with new ways to deal with him or her.
5. Use distraction. Don't ignore the bully but distract the bully with a change of subject. Distraction works very well, according to research. For example, "Did you see that ball game last night?"
6. Use humor to poke fun at yourself. For example, if someone says "You have such dorky shoes," try saying, "If you think these are dorky, you should see the ones my mom wanted to buy me." But, be careful not to use sarcasm — that could make the bully mad.
7. Learn how to use your friends when dealing with a bully.
8. Appearance matters. Try to look and act sure of yourself. Your body language can help.
9. Try flattery. People who bully feel insecure in some way. Try giving a compliment to the bully.
10. Reward yourself for success in dealing with bullies.

Lovegrove connects with kids who are being bullied by confirming how they feel. She writes, "The bad news is that right now you probably feel pretty fed-up about it. You feel you're at the mercy of some horrible other kids or grown-up who makes your life miserable. You probably feel there's not much you can do about it. The WORST thing about being bullied is that you feel powerless."

Lovegrove recently spent a week at Children's Hospital in Seattle working with doctors, nurses, staff and parents to help them understand why bullying happens and to teach adults what they can do to help children deal with it. Her new book for children and their parents, [Help! I'm Being Bullied](#), is available in bookstores. Adults and parents can use her book and its practice exercises to help children learn the skills they need.

TO LEARN MORE > Visit Lovegrove's Web site at www.bullyingdoctor.com or www.stopbullyingnow.hrsa.gov

This article reprinted from the Good Growing newsletter

New Faces in Craniofacial

Dr. Jennifer Keagle, MD is a plastic surgeon specializing in craniofacial surgery. She will see patients in the plastics and craniofacial clinics. Her research interests include clinical outcomes in craniofacial surgery as well as the genetic basis for facial disorders. Dr. Keagle's training was at the University of California San Francisco (general and plastic surgery) and University of California Los Angeles (craniofacial surgery fellowship).



Dr. Cynthia Koudela, DDS, MSD specializes in pediatric craniofacial and surgical orthodontics and has special expertise and training in oral appliance treatment for obstructive sleep apnea. Dr. Koudela joins Children's team after leaving the East Coast where she was an attending physician at Providence's Rhode Island Hospital and managed her own private practice.



Sara Kinter, M.A., CCC-SLP is a speech-language pathologist specializing in the diagnosis and treatment of speech disorders related to cleft lip and palate. She brings to the Craniofacial team experience in motor speech disorders, language disorders, and early intervention and is currently completing training in video fluoroscopic swallowing studies. Ms. Kinter comes to us from California where she was the treating speech pathologist for the craniofacial team at Lucile Packard Children's Hospital at Stanford.



Cam Lanier, RD, CD is a clinical dietitian specializing in craniofacial, neuromuscular and neurodevelopmental nutrition. Cam received her training at the University of Washington in Seattle. Prior to coming to Children's, she was a Nutrition Trainee in the LEND program at the Center for Human Development and Disability (University of Washington) and focused on nutrition care for children and youth with special needs.



Sibshops for Siblings of Kids with Special Health Needs and/or Special Developmental and Learning Needs

Children's Sibshops are lively, pedal-to-the-metal, award-winning celebrations of the many contributions made by brothers and sisters of kids with special needs.

Dates for 2007: March 3, April 14, May 5, June 2

Time: 2:00 – 5:00 p.m.

Fee: \$20 (includes snack)

Location: Sound Café, Children's Hospital

Register: (206) 987-3285

2007 Connections Conference

The Cleft Palate Foundation presents the annual **Connections 2007: A Conference for Patients and Families** on Saturday, April 28, in Broomfield, Colorado. Child care and activities will be available throughout the day and registration fees include programming, T-shirt, snacks and lunch. Please mark your calendars and make plans to join us! Registration for the conference will begin in January. The cost is \$30.00 1st adult, \$20.00 each additional adult, and \$10.00 per child. For more information or to be added to our registration and information mailing list for next year, drop us as line at info@cleftline.org.

Children's
Hospital & Regional Medical Center

Craniofacial Center

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