

2003-2005
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www.costellokids.org.uk

~Join the List serve...

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~New Families...

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~Fundraising...

Lori Crossley, lcrossley@onlinefusion.net

~Donations & Tax ID info...

Ray Gardiner, raygard@netzero.net

~Newsletter; submissions/ideas...

Lori Gerhardt & Debbie Krause
lori@gerhardt.org, dkrause1@excite.com

Message from the President

By: Lisa Schoyer

Hello and Welcome to our first United States Costello Syndrome Family Network (USCSFN) Newsletter!

I am so pleased that we are able to launch this! MANY thanks to Lori Gerhardt (mom of Bret), and Debbie Krause (mom of Victor), for taking this on. Without their energies, this would still be on our wish-we-could-do list. We recognize how important it is to reach people who are not able to communicate with us through our usual means, the internet.

I would like take this opportunity to share how rewarding it is to attend a conference. It's like finally coming home: meeting family members you didn't know you had, being around people who understand intimately what you are going through. You don't have to explain yourself. Having such dedicated and devoted professionals and researchers as collaborators also builds on the pleasure of the gathering. The opportunity to learn about the most current information, to participate in generating the next level of information, truly cutting edge, is important for our children, past, present and future. It is immensely gratifying. **PLEASE CONSIDER COMING TO THE NEXT CONFERENCE**, June 23-25, 2005 in St. Louis, Missouri. Dr. Mary Dasovich, PhD, has offered her services and college, St. Louis University. She will assist Ray Gardiner and me, the co-chairs of the Conference Planning Committee. Please contact Ray or me with suggestions or ideas. (Ray can be reached at raygard@sbcglobal.net) If you have financial hardship, please contact Tammy Moore, Vice President, to help brainstorm about resources in your area! We have 16 months to plan - plenty of time!

Sincerely,
Lisa Schoyer (mom of Quin)

244 Taos Road, Altadena, CA 91001
626-569-6086, 626-794-7343
lschoyer@dhs.co.la.ca.us

Stories from Siblings

Winter, big sister to Bret Gerhardt, age 21, Illinois:

Hi! I'm Winter, Bret's sister. That is how most people know me. When I was younger I used to wonder what it would be like if Bret was "normal". What would he look like? What would he act like or be involved in? As I have grown up, I have stopped asking those questions altogether. I wouldn't want Bret any other way. He is a great brother! Bret has taught me more than any college course, seminar, or workshop ever could. Bret has brought challenges into my life, sadness, happiness, awareness, acceptance, inspiration, patience, and most of all laughter. When I was asked to write something about my brother I felt so honored to write about someone I love so much. However, when I sat down in front of the computer I suddenly didn't know what to say. I was searching for that one really great story that would make everyone laugh, because, well, that is what Bret would want. He is always looking to put a smile on everyone's face. Make a joke, play a prank, and get a laugh. The more I thought about it Bret isn't a story man; he is a one-liner man, or what we like to call in our family

"Bret-isms". Some are originals and others you may have heard, I hope they will bring a smile to your face if not a few laughs....

10. As Curly from the Three Stooges would say, "Whoop, whoop, whoop!"

9. Bret answers the phone, "Hello, (raised intonation) hello, (raised intonation) hello, HELLO."

8. Bret answers the phone, "Mickey Mouse's residence."

7. Out of nowhere,

www.Americasmostwanted.com - [You Can Run But You Cannot Hide.](http://www.Can Run But You Cannot Hide.com)

6. "Hot Mama!" (a perfect dog whistle).

5. Any siren that makes you feel like pulling your car over, sweating bullets, and pulling out your registration.

4. "Ohhhh you said the /A/ word!" In response to any word that may seem even remotely bad.

3. Out of nowhere. "You fight like a woman!"

2. After just marrying the one you love. "The next time you get married...."

#1 "Brettism" - Out of nowhere. "Do you know what Simone said?" or "I love Simone!" (Simone would be our dog)

Fundraising

By: Lori Crossley

Hi Everyone! We have established an eager fundraising committee and projects will soon begin. We have decided to get started by creating a fundraising packet which parents can use in their local/state community. This will be available on the web or by mail (for those who do not have internet access). Included in the fundraising packets will be a list of ideas (golf tournaments, spaghetti dinners, bake sales, etc.), preprinted forms (brochures, donation forms, etc) and thank you notes. There are a great deal more ideas we have to work on, but the packets are our top priority at this point. Hopefully we will have packets ready sometime in the spring. You can still collect donations and send to: Lisa Schoyer, 244 Taos Road, Altadena, CA 91001.

NACSFN 2003 Financial Report

Beginning Balance	\$7015.78
Contributions	5878.96
Expenses: Board Conference Call	95.00
Conference	<u>(6350.40)</u>
Ending Balance 12/31/03	\$6433.83
Conference Breakdown	
DJ at family dinner +tip	325.00
Children's Entertainment	569.00
Family Dinner	3581.40

Total Conference Costs \$6350.40

2005 FAMILY CONFERENCE
JUNE 22-25
St. Louis, Missouri
Free Clinics: swallowing, speech,
academics, family topics,
professional presenters,
fun family events & more!

~~ Thank you! ~~
We extend our deepest thanks to
the contributors listed below
whom have donated recently...
In memory Thomas Wotherspoon,
And in honor of AJ Silvestre
_CE and JR Brousseau
Rosalie Fain
Ruth and Jonathan Fain
Lorraine & Letha Kappmeyer
Lillian Messak
Lillian Ryan
Manuel and Virginia Teixeira
Your generous kind-hearted gifts
help us help families raising children
with Costello syndrome by providing
parent-to-parent support,
encouraging and facilitating
research on our children's syndrome
and organizing conferences for
parents and researchers from
around the world.

Please help us help others!
~~~~~  
**United States Costello Syndrome  
Family Network**

Name:  
Address:  
Home Phone:  
Email:

Enclosed please find my donation

of \$\_\_\_\_\_. Payable to USCSFN  
Make a donation in honor of someone.  
*In honor of:* \_\_\_\_\_.

**Send Checks to USCSFN President:**  
**Lisa Schoyer, 244 Taos Road, Altadena,**  
**CA 91001. 626-794-7343**  
**Make payable to USCSFN**  
**(United States Costello Syndrome Family**  
**Network)**

We are an exempt organization under  
501(c) (3).  
Our EIN number is 02-0622876.

**PROFESSIONAL ADVISORY BOARD**

Angela Lin, MD, Co-Chair  
Karen Gripp, MD, Co-Chair  
John Carey, MD  
Paul Grossfeld, MD  
Marie Ines Kavamura, MD  
Rosanna Weksberg, MD  
Sue White, MD

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Dr. Karen Gripp is doing research on
**"The Natural History of Costello
Syndrome"** and is looking for more
families to participate. If you are
interested, please contact her at:
Karen Gripp, MD
Division of Medical Genetics
Al DuPont Hospital for Children
1600 Rockland Road
Wilmington, DE 19803
302-651-5916/302-651-5033 fax
You will receive more information, a
consent form, and instructions. Dr. Gripp
would encourage those who have not
supplied the following, to please do so:
Parents' names, Child w/CS name and
birth date, sibling's name and birth year,
address, phone number, email address,
who diagnosed your child & at what
age. Also, information is needed
regarding seizures, heart, lung, bone,
puberty & sleep issues, and skin issues
(sweaty/smelly/itchy etc.), cancer, false-
positive tests. This information will be kept
confidential among a select, small
group of parents and doctors, to

develop as complete a roster as possible. We will contact you for permission before using it for any other purposes. Please forward to Lisa Schoyer at 244 Taos Road, Altadena, CA 91001 or lschoyer@dhs.co.la.ca.us

If you have an Adult with CS, and have not already been contacted by Dr. White, please contact:

Dr. Sue White

Genetic Health Services

Victoria Royal Children's Hospital

Flemington Road, Parkville

3052

Australia ph 020 7905 2393

fax 020 7813 8141

email sue.white@ghsv.org.au