

7th INTERNATIONAL COSTELLO SYNDROME FAMILY FORUM



July 27-31, 2011
Chicago, Illinois USA

WELCOME!

Welcome to the 7th International Costello Syndrome Family Forum. The CSFN Board of Directors and Steering Committee have planned a conference program that will be educational, insightful, and fun. Be sure to attend as many sessions as possible, take notes and ask questions. Take time to mingle and get to know other families. You'll be putting faces with the names that we see on the ListServe and Facebook, which makes it so much more personal. During our time together, we will learn important skills, inspire each other, gain support from each other, and return home better empowered to face our day-to-day challenges.

CSFN is committed to working together with ICSSG (International Costello Syndrome Support Group) and the RASopathies Network USA to educate and support the families who live daily with the challenges of Costello Syndrome. We will also continue to support research so vital to that education and support. The support of our Professional Advisory Committee and other presenters is vital and we greatly appreciate all those who have generously given their time to be here. Thank you to each of you for caring and supporting our families and children with Costello Syndrome.

*Tammy Moore, President
Costello Syndrome Family Network*

CSFN Board of Directors

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Lori Gerhardt, Vice-President
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Cherie Takemoto
Sharon Harvey

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FUNDRAISERS & SPONSORS

The Family Forum is substantially dependent on fundraising by its families. A special thanks to each of these families who have generously donated and fundraised to make the Forum possible.

\$250 Level

The Holcomb Family
The Moore Family
The Harvey Family
The SanGiovanni Family
The Lanik Family

\$1,000 Level

The Slawitschek Family
Valentina Cuperman

\$500 Level

The Kazakoff Family
The Bushee Family
The Crossley Family
The Shannon Family
The Deckman Family

\$2,500 Level

The DiMaria Family
The Driessen Family
The Gerhardt Family (in memory of Bret)
The Hefner Family
The Johnson/Schoyer Family (in memory of Quin)
The Morrison Family
The Taylor Family

\$5,000 Level

The Bahnsen Family
The Hunt Family (in memory of Willa)

Thank you to each of these sponsors for the following contributions:

The Morrison Family
ICSSG (Colin Stone, Founder)
The Sullivan Family

\$1,000 donation for child care
\$500 donation for meals
\$250 donation for child care

Bag Makers (Scott Noe)
Brian Nash, Nashtech Inc.
Dee and Terry Sellke
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Lisa Schoyer

Forum Tote Bags
CSFN website design and tech support
Audiovisual Equipment and Support; Forum Program Printing
Transportation to/from Forum
Conference Folders; Friday Night DJ (PM Mobile Entertainment)
Printing – Brochures, Trifolds and Registry Handout
Forum Neck Wallets, Printing Comment Cards
Printing Parents Booklets

VOLUNTEERS

It takes many helping hands for the Family Forum to operate. Thanks to each of you for volunteering your time during the conference so that others may benefit. This list is current at the time of printing but I am sure there are others who have helped as well. A big heartfelt THANK YOU to each of you.

Wednesday, July 27, 2011

Kara Bahnsen
Doreen Crofts
Gail Deckman
Mary Ernst
Lori Gerhardt
Steve Gerhardt

Bob Hefner
Erin Hefner
Kathy Hefner
Tammy Moore
Katie Slawitschek
Pete Scampavia

Lisa Schoyer
Diane Shoemaker
Joe Shoemaker
Cherie Takemoto
Jill Taylor
Larry Taylor
Sandra Taylor

Friday, July 29, 2011

Arlis Bahnsen
Becky Winn
Heather Hamblin
Jenny Coates
Bruce Deckman
Anjuli DeMaria
Mary Ernst

Colleen Farnham
Amelia Gardiner
Cathy Gardiner
Ray Gardiner
Lori Gerhardt
Tammy Moore

Sue Schaeffer
Kari Shemansky
Katie Slawitschek
Larry Taylor
Sandra Taylor
Christine Waldvogel
Kim Woodard

Saturday, July 30, 2011

Mary Ernst
Amelia Gardiner
Ray Gardiner

Lori Gerhardt
Tammy Moore
Sue Schaeffer

Katie Slawitschek
Sandra Taylor
Christine Waldvogel
Kim Woodard

Special thanks to Becky Winn (sister to Chris Coates), our volunteer Forum Photographer!

Forum Schedule at a Glance

Tuesday, July 26

6:00 pm – 7:30 pm	Conference Registration	Hotel Lobby
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Wednesday, July 27

8:00 am – 12:00 pm	Conference Registration	2 nd Floor
8:00 am – 5:00 pm	Meet the Researchers & Experts *Please arrive at your assigned time.	2 nd Floor
7:00pm – 9:00 pm	CSFN, ICSSG, PAC, RAG Meeting	O'Hare Room, 12 th Floor

Thursday, July 28

8:30 am – 9:00 am	Conference Registration	Hotel Lobby
9:00 am – 10:00	Yoga for Families	3 rd Floor
10:00 am – 12:00	Mingling and Swim Time	Pool
12:30 – 2:00	Chicago Dawgs Lunch	LaSalle A, Lobby Level
7:00 pm – 9:00 pm	CS, CFC and Noonan Dessert Welcome Reception	Grand B Ballroom Lobby Level

Friday, July 29

8:30 am – 9:00 am	Conference Registration	Hotel Lobby
8:30 am – 5:30 pm	Camp RAS	Lower Level
8:30 am – 5:30 pm	CS Lounge	O'Hare Room, 12 th Floor
9:00 am – 5:30 pm	Medical Topics	LaSalle B/C, Lobby Level
6:15 pm (please be prompt)	Group Conference Photo	Hotel Lobby
6:30 pm – 11:00 pm	Family Dinner & Dance Announcements, Awards, Special Recognition Craft Sale & Raffle, Conference T-shirts	Grand Ballroom B/C Lobby Level
8:00 pm	Symposium Dessert Reception & Poster Session	Grand Ballroom A Lobby Level

Saturday, July 30

8:30 am – 3:45 pm	Camp RAS	Lower Level
8:30 am – 3:45 pm	CS Lounge	O'Hare 2, 12 th Floor
8:30 am – 11:15 am 1:00 pm – 3:45 pm	Sibshop – Session 1 Sibshop – Session 2	Rosemont, 3 rd Floor
8:30 am – 3:45 pm	Non-Medical Topics	Lobby Level
5:30 pm – 6:30 pm	CSFN Board Meeting Everyone welcome!	O'Hare 2, 12 th Floor

Sunday, July 31

12:30 pm – 2:30 pm	Post Symposium Panel	Madison, Lobby Level
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WEDNESDAY - JULY 27, 2011

Meet the Researchers and Experts

8:00am – 12:00am - Registration

Important! Please arrive at the time assigned in your registration package.

 **Station 1** (*Renewal A, 2nd Level*)

The Gathering Room A place to hang out with other families during Meet the Researchers & Experts!

Longitudinal Assessment of Cognitive, Behavioral, and Adaptive Functioning in Costello Syndrome

Marni Axelrad PhD, ABPP

My research is longitudinal, and has been going on for eight years thus far. I am investigating the developmental profile of individuals with Costello syndrome. This has included the behavioral presentation, intellectual strengths and weaknesses, and adaptive skills. The measures we have used have changed over time, as information we have gotten at each time has informed us about additional information that would be helpful for families, as well as suggesting different measures that would be more helpful in gaining the information. As our goal is to gain information about the course of development over time, we have appreciated being able to assess each individual at multiple time points. Assessment involves spending approximately 1.5 hours with the individual, asking them to look at pictures and answer questions. An additional 45 minutes is spent with parents to assess their perceptions of their child's adaptive skills and parents are asked to complete questionnaires on their own time. We then put all of the information together to give us information about the course of Costello Syndrome. This is different from seeing a doctor at home, as your information will be de-identified and entered into the large database, which gives us information important to all families and researchers.

Jennifer Katzenstein PhD, assessment

David Schwartz PhD, research

 **Station 2** (*Sheffield, 2nd Level*)

Costello Syndrome: Clinical and Molecular Investigations

Karen Gripp MD – Lead Researcher

Our research focuses on the clinical problems seen in individuals with Costello syndrome, and how the different Costello syndrome causing mutations present. We will ask you questions about how the individual with Costello syndrome grows and develops, and what medical problems the person has. We will ask about the specific change in HRAS. We may ask for a cheek swab DNA sample. Dr. Doyle will measure the Costello individual and ask questions about growth and use of growth hormone. Dr Thacker will ask about orthopedic problems and about x-rays that were done previously. The total time will be 30 minutes to 1 hour. In addition, Dr. Axelrad may ask you to participate in a study about learning and behavior. This research encounter is different from a regular clinical visit, because we have a limited amount of time and we do not provide medical care. We share the results of our ongoing research study by presenting it at the Costello Syndrome family meetings. We provide the published papers through the Costellokids website, so that you can make copies for yourself and your doctors.

Beth Hopkins, genetic counselor

Elizabeth McCormack MS, genetic counselor

Mihir Thacker MD, orthopedics

Stacey Rickard, genetic counselor student/assistant

Angela Lin MD, Blood pressures and cardiac history

Dan Doyle MD, Endocrine, Growth Hormone. **Natural History of Pubertal Development in Costello Syndrome.** Will be taking height, weight and head circumference.

 **Station 3** (*Graham, 2nd Level*)

Musculoskeletal Problems in Syndromes of the Ras/MAPK Pathway

David Stevenson MD

Sue White MD

Some individuals with Costello syndrome have orthopedic problems including osteoporosis. Our goal is to investigate the musculoskeletal problems in Costello syndrome. We plan to do this through the following after informed consent:

1. A brief physical examination and medical history will be performed to document any orthopedic problems. This will include assessing the strength of individuals with Costello syndrome.
2. We will potentially obtain blood and/or urine samples to look at bone cells and markers of bone resorption to see if bone resorption is increased potentially leading to osteoporosis.
3. We will potentially obtain DNA from blood or cheek swab to identify the HRAS mutation and correlate it to the above bone findings.

Individuals can participate in some or all of the above aspects of the study. The visit takes approximately 30-45 minutes.

Heather Hansen BS, research coordinator

Austin Stevens, research assistant

 **Station 4** (Franklin, 2nd Level)

Molecular Analysis of Costello Syndrome , UCSF Gene Study

Kate Rauén MD, PhD - Lead Researcher

The gene team will collect your spit! We will be able to look at differences in the genome that influence behavior, muscles, cancer risk and other traits that make each person unique.

UCSF Muscle Study

The muscle team will examine the families muscle strength. We will use very simple muscle measuring devices to check the muscle strength of all the kids and their siblings. Simple history questions will be asked and we may take pictures of your child's arm and leg muscles.

Megie Okumura MD, assistant


Lauren Weiss PhD, assistant

Keren Messing-Guy PhD, assistant

UCSF Dental Project

Alice Goodwin DDS, research

The dental team will be taking a close look at your teeth! We will ask you a few questions about your dental history, take pictures of your teeth and perform a quick dental exam. We will be happy to answer any oral health questions as well!

 **Station 5** (Fulton, 2nd Level)

The Skin Study

Dawn Siegel MD

The skin team will once again be doing examinations! If your child was examined at the Berkeley, CA meeting in 2009, we will be able to compare how your child's skin is doing. (CS Derm Issues)

Amy Paller MD assisting

 **Station 6** – (Waveland A, 2nd Level)

Consultation – **Bronwyn Kerr MBBS FRACP FRCPCH**

CS Expert, will be available to families for consultation

 **Station 7** – (Waveland B, 2nd Level)

The Eye Study

Suma Shankar MD (Ophthalmology) with Deborah Orel-Bixler PhD, OD (Optometry)

We will obtain consent for the eye exams from parents. We request copies of eye exam results from your ophthalmologists if available. Your child will be seen first by an optometrist and have visual function and strabismus assessed. They will then have eye drops put in to dilate their pupils for refraction and dilated fundus exam.

THURSDAY - JULY 27, 2011



FAMILY FUN DAY

- 8:30 am – 9:00 am Conference Registration desk is open
Hotel Lobby
- 9:00 am – 10:00 am Yoga for Families
Rosemont 4, 3rd Floor
- 10:00 am – 12:00 pm Gather at the Hotel Pool for Swim Time and
Mingling with the other Costello Families
- 12:30 pm – 2:00 pm Come & Get your CHICAGO DAWGS
Chicago Style Hot Dogs & Chicken Fingers with
all the trimmings
LaSalle A, Lobby Level
- 2:00 pm – 7:00 pm Personal Time, dinner on your own
*Individual photos will be taken as scheduled.
Location to be determined.
- 7:00 pm – 9:00 pm CS, CFC and Noonan Dessert Welcome Reception
Grand B Ballroom, Lobby Level

FRIDAY - JULY 28, 2011

7:30am – 9:00am	Breakfast Buffet – Grand B (Lobby Level)	
8:30am – 9:00am	<i>Drop-off to Camp RAS (Hotel Lower Level) & CS Lounge (O'Hare Room 12th floor). Both open promptly at 8:30</i>	
9:00am – 9:30am	Costello Syndrome: Traveling Down the Road of the Ras Pathway <i>Kate Rauen, MD – LaSalle B & C</i>	
9:30am – 10:15am Choose One	The Natural History of Costello Syndrome <i>Elizabeth Hopkins, PhD</i> LaSalle B (Lobby Level)	Cancer Risks in Costello Syndrome <i>Bronwyn Kerr MD</i> LaSalle C (Lobby Level)
10:15am – 11:00am Choose One	The Heart of Costello - Research Advances <i>Angela Lin MD</i> LaSalle B (Lobby Level)	The Eye and Vision in Costello Syndrome <i>Suma Shankar MD</i> LaSalle C (Lobby Level)
11:00am – 11:45am Choose One	Development of Normative Growth Curves in Costello Syndrome <i>Dan Doyle MD</i> LaSalle B (Lobby Level)	CS Oral Manifestations <i>Alice Goodwin DDS</i> LaSalle C (Lobby Level)
11:45am – 12:00pm	Pick-up from Camp RAS (Hotel Lower Level) & CS Lounge (O'Hare Room 12th floor). Both close promptly at 12:00pm.	
11:45am – 1:00pm	Lunch Grand B (Lobby Level)	
12:45pm – 1:00pm	<i>Drop off to Camp RAS (Hotel Lower Level) & CS Lounge (O'Hare Room 12th floor). Both open promptly at 1:00pm.</i>	
1:00pm – 1:55pm Choose One	Genotype-Phenotype Correlation in Costello Syndrome <i>Elizabeth McCormick MS</i> LaSalle B (Lobby Level)	The Skin in Costello Syndrome-What to Expect <i>Dawn Siegel MD</i> LaSalle C (Lobby Level)
1:55pm – 2:50pm Choose One	Brain abnormalities, Rare Mutations and Clinical Management <i>Karen Gripp MD</i> LaSalle B (Lobby Level)	Joint Interactive Workshop on Healthcare Transitions <i>Kate Rauen MD</i> <i>Megie Okumura MD</i> LaSalle C (Lobby Level)
2:50pm – 3:45pm Choose One	The Cognitive Profile in Costello Syndrome: What We Have Learned <i>Marni Axelrad PhD</i> LaSalle B (Lobby Level)	The Musculoskeleton in Costello Syndrome/Walking in Costello Syndrome <i>David Stevenson MD</i> <i>Sue White MD</i> LaSalle C (Lobby Level)
3:45pm – 4:00pm	Break	
4:00pm – 5:30pm	Best Practice – Ask the Docs	

DESCRIPTIONS OF FRIDAY TALKS

Keynote: Costello Syndrome: Traveling Down the Road of the Ras Pathway – Dr. Kate Rauen

Costello syndrome is a developmental disorder caused by activating mutations in the oncogene HRAS. HRAS is a key regulator of the mitogen-activated protein kinase (MAPK) pathway --- a critical pathway for cell cycle regulation, cellular differentiation, and growth. Increased activity of the Ras/MAPK pathway has long been implicated in cancer, and has more recently been recognized to cause the "RASopathies", a group of syndromes that include CS, cardio-facio-cutaneous syndrome, neurofibromatosis 1, LEOPARD syndrome, Legius syndrome and Noonan syndrome. Because the Ras/MAPK pathway is an attractive target in the treatment of cancer, the same molecular inhibitors may provide opportunities to therapeutically treat the developmental disorders caused by genetic alteration of the Ras/MAPK. Recent news and information in the area of research on CS will be discussed.

Session One Costello Syndrome: An Overview Elizabeth Hopkins MSc Genetic Counseling

This introductory presentation will review the manifestations of Costello Syndrome with an emphasis on practical suggestions for screening of potential medical issues through the life stages.

Session One Cancer Risks in Costello Syndrome Dr. Bronwyn Kerr

Session Two The Heart of Costello: Research Advances Dr. Angela Lin

A recent publication in the AJMG summarizes the clinical, molecular and pathologic findings from persons in the longitudinal (natural history) study. The information about Costello syndrome is also compared to the other syndromes in the "ras/MAPK pathway", which are known as a group as the "rasopathies". It has taken many years to assemble this and I look forward to sharing it with you.

Session Two Vision Issues in Costello Syndrome Dr. Suma Shankar with Dr Deborah Orel-Bixler

It has been noted that ocular findings are common in individuals with Costello, Cardiofaciocutaneous, Noonan syndromes. Recent studies in cell culture and animal models have demonstrated the role of Ras/MAPK cascade in the development of the eye. Our work with the families and individuals with Ras/MAPK syndromes has expanded our knowledge of the ophthalmic manifestations in these syndromes. We will summarize our findings and discuss current treatment options. This study will increase our understanding of the eye development and disorders by learning from the similarities and differences among the individuals who share a mutation in a common pathway, common gene, or even a common mutation. We hope to use this information in developing newer treatment options.

Session Three Dental Issues in CS Dr. Alice Goodwin

Findings from research done at the 2009 CS conference will be presented.

Session Three Development of Normative Growth Curves in Costello Syndrome Dr. Dan Doyle

This presentation will be about growth, growth hormone and the growth charts we recently developed for CS.

Session Four Geneticist-Genotype Phenotype Correlations in Costello Syndrome Elizabeth McCormack-MS

Several different mutations in the HRAS gene can lead to Costello syndrome. Different changes in this gene may lead to different manifestations of Costello syndrome, but a more detailed look into this possible genotype-phenotype correlation is needed. In order to assess this possible correlation, a severity scoring system was developed that can be used to compare phenotypic severity of Costello syndrome to the specific mutation present

Session Four The Skin in Costello Syndrome-What to Expect Dr. Dawn Siegel

Skin issues in Costello syndrome based on our study of 47 individuals.

Session Five Research Findings on Brain Abnormalities, Rare Mutations and Clinical Management Dr Karen Gripp

Our research focuses on the clinical problems seen in individuals with Costello syndrome, and how the different Costello syndrome causing mutations present. During the last meeting we asked you about brain malformations and hydrocephalus. We have learned that a Chiari I malformation, a herniation of the lowest part of the brain, occurs frequently in individuals with Costello syndrome. We think that this is due to overgrowth of the cerebellum, the hindbrain. This has implications for clinical care. We have also learned more about patients a rare Costello syndrome causing mutation, p.G13C. These individuals are somewhat taller than other individuals with Costello syndrome and they often have extremely long eye lashes.

Session Five Interactive Workshop on Health Care Transitions: Getting Ready for Adult Focused Care


Dr Kate Rauen with Dr Megie Okumura This workshop will acquaint families with the issues that arise with transitioning from pediatric to adult based health care. We will discuss ways to plan on issues of growing up with a chronic condition, and what families can do to help the process. We will also discuss a model system of genetic based care and transitioning done at UCSF as an illustration of what can support families with health care transitioning.

Session Six The Cognitive Profile in Costello syndrome: What we have learned Dr. Marni Axelrad

This talk will include information gained from assessments in 2009 as well as information gained about behavior (specifically anxiety), adaptive skills, and cognitive skills since the beginning of the study in 2003. A review of what is known about cognitive, adaptive, and behavior will be provided and clinical implications will be discussed.

Session Six The Musculoskeleton in Costello Syndrome and Walking in Costello Syndrome Dr David Stevenson with Dr. Susan White

The syndromes of the Ras/MAPK pathway have some overlapping features including problems with the musculoskeleton. Some individuals with Costello syndrome have been reported to have problems with tight heel cords, flat feet, clubfeet, scoliosis, chest wall anomalies, low muscle tone, hip problems, contractures of joints, and osteoporosis. A review of these musculoskeletal problems will be discussed. In addition, new research investigating the function of the cells that make up the bones in Costello syndrome that may contribute to osteoporosis will also be discussed.



FRIDAY NIGHT FAMILY DINNER PARTY

Grand Ballroom B & C, Lobby Level

- 6:15 pm Meet in the Hotel Lobby – Group Photo
- 6:30 pm Dining & Dancing
- 7:30 pm Announcements
Drawing for Free Room
Recognition of Fundraisers
Awards
- 7:45 – 9:30 pm Shopping!!
◊ Handmade Crafts
◊ Conference T-Shirts
◊ Raffle Ticket Sales
- 8:00 pm Symposium Dessert Reception & Poster Session
Grand Ballroom A, Lobby Level
- 9:30 pm Winners of Raffle Tickets Announced
- 11:00 pm Head off to our rooms for a good night's sleep!

SATURDAY - JULY 30, 2011

7:00 AM – 8:00 AM	Breakfast Buffet GRAND C (Lobby Level)	
8:00 AM – 8:30 AM	<i>Drop off to Camp RAS (Hotel Lower Level) – CS Lounge (O’Hare Room 2nd floor) Sibshop Program (Renewal, 2nd Floor) All open promptly at 8:00am.</i>	
8:30 AM – 9:45 AM	MORNING WORKSHOP SESSION 1 – CHOOSE ONE	
Overview of Assistive Technology Tools and Programs	<i>Kelly Key</i>	MADISON (Lobby Level)
Parent to Parent, Heart to Heart - Special Needs Legal & Future Planning...It Is Not Optional	<i>Brian Rubin</i>	LASALLE B (Lobby Level)
Government Benefits	<i>Sherri Schneider</i>	LASALLE A (Lobby Level)
Genetic Testing 101: Advances, Advantages and Insights	<i>Dr. Eric Johnson</i>	DIVISION (Lobby Level)
The GI System: Impact on Feeding and Nutrition	<i>Dr. Charles Dumont, Char Laursen & Cindy Baranoski</i>	DEARBORNE (Lobby Level)
Taming the Tiger: Basic Principles to Address Behavioral Issues	<i>Dr. Melinda Wolford</i>	LASALLE C (Lobby Level)
9:45am – 10:00am	BREAK	
10:00am – 11:15am	MORNING WORKSHOP SESSION 2 – CHOOSE ONE	
Overview of Assistive Technology Tools and Programs	<i>Kelly Key</i>	MADISON (Lobby Level)
Parent to Parent, Heart to Heart - Special Needs Legal and Future Planning...It Is Not Optional	<i>Brian Rubin</i>	LASALLE B (Lobby Level)
Government Benefits	<i>Sherri Schneider</i>	LASALLE A (Lobby Level)
Feeding/Nutrition/GI Question & Answer Session	<i>Dr. Charles Dumont, Char Laursen & Cindy Baranoski</i>	DEARBORNE (Lobby Level)
Growing Up With a RASopathy syndrome (CFC, Costello, or Noonan)	<i>Martha Goodwin, Darcie Robinson, Jessica Bushman and Jill Taylor</i>	DIVISION (Lobby Level)
Taming the Tiger: Basic Principles to Address Behavioral Issues	<i>Dr. Melinda Wolford</i>	LASALLE C (Lobby Level)
11:30am – 11:45am	<i>Pick-up from Camp RAS (Hotel Lower Level) & CS Lounge (O’Hare Room 12th floor) Both will be closed 11:45 – 12:45PM</i>	
11:45am – 12:45pm	Lunch Buffet GRAND B (Lobby Level)	
12:45pm – 1:00pm	<i>Drop off to Camp RAS (Hotel Lower Level) – CS Lounge (O’Hare Room 12th floor) Sibshop Program (Renewal, 2nd Floor) All open promptly at 12:45pm.</i>	
1:00pm – 2:15pm	AFTERNOON WORKSHOP SESSION 3 – CHOOSE ONE	
A Day in the Life of a Child with a Visual Impairment	<i>Karen Windy</i>	MADISON (Lobby Level)
Genetic Testing 101: Advances, Advantages and Insights	<i>Dr. Eric Johnson</i>	DIVISION (Lobby Level)
Sexuality: Helping Your Children to Understand	<i>Dr. Miriam Kalichman</i>	LASALLE A (Lobby Level)
Parent to Parent Round Table	<i>Parents & Genetic Counselor</i>	To Be Determined
2:15pm – 2:30pm	BREAK	
2:30 pm – 3:45pm	AFTERNOON WORKSHOP SESSION 4 – CHOOSE ONE	
A Day in the Life of a Child with a Visual Impairment	<i>Karen Windy</i>	MADISON (Lobby Level)
Special Education Rights & Laws	<i>Matt Cohen</i>	DIVISION (Lobby Level)
Sexuality: Helping Your Children to Understand	<i>Dr. Miriam Kalichman</i>	LASALLE A (Lobby Level)
3:45pm – 4:00pm	<i>Pick-up from Camp RAS (Hotel Lower Level) & CS Lounge (O’Hare Room 12th floor). Both close promptly at 4:00pm.</i>	
5:30pm – 6:30pm	CSFN Board Meeting <i>Nomination & Election of New Board Members and Officers</i>	O’Hare Room (12 th Floor)
Dinner on your own		

COSTELLO SYNDROME FAMILY NETWORK

AGENDA FOR BOARD MEETING

Saturday, July 30 @ 6:30 pm

O'Hare 2, 12th Floor

1. Call to Order & Roll Call
2. Proof of Notice of Meeting
3. Approval of Minutes from Board Meeting of June 26, 2011
4. Treasurer's Report
5. Committee Reports
6. Election of Board Members/Officers for 2011-2013 term
7. Unfinished business
8. New business
9. Comments/Questions
10. Adjourn

Board meetings are held quarterly. The next CSFN Board Meeting is scheduled for September 18, 2011 at 8:00 pm Eastern Time by telephone conference call. Should you wish to attend the meeting, please contact one of the Board members for information. Board members and visitors are responsible for any long distance charges incurred.

SUNDAY - JULY 31, 2011

12:30 pm – 2:30 pm

Post Symposium Panel, Madison, Lobby Level

Costello Syndrome professionals who attended the symposium have been invited to share what they learned at the Symposium as it relates to our children. Please join us so you can learn what research is being done, and to answer your questions.

Box lunch provided for those who registered to attend.

Thank you for attending the 7th International Costello Syndrome Family Forum. We hope you enjoyed your time with the families, experts and researchers, and that you feel better equipped with knowledge and support to face the challenges ahead.

Have a safe journey home and we'll see you on the ListServe.



RESOURCES

Costello Syndrome Family Network

A 501(c)(3) non-profit organization

<http://www.CostelloSyndromeUSA.org>

Tammy Moore, President, mother of Kelsi

costellosyndrome@gmail.com

Family Voices: Family Voices aims to achieve family-centered care for all children and youth with special health care needs and/or disabilities.

<http://www.familyvoices.org/>

GeneTests.org: a publicly funded medical genetics information resource developed for physicians, other healthcare providers, and researchers, available at no cost to all interested persons. Here are the four major categories of information:

- GeneReviews – type the name of the syndrome to see expert-authored peer-reviewed disease descriptions
- Laboratory Directory - International directory of genetic testing laboratories
- Clinic Directory - International directory of genetics and prenatal diagnosis clinics
- Education Materials - Illustrated glossary, information on genetic services, PowerPoint® presentations, annotated Internet resources

<http://www.ncbi.nlm.nih.gov/sites/GeneTests/>

ICSSG (International Costello Syndrome Support Group)

UK Registered Charity Number 1085605

Colin Stone, Webmaster and Founder, father of Helaina

<http://costellokids.com>

90, Parkfield Rd North

New Moston M/C40 3RQ

UNITED KINGDOM

National Disability Rights Network: NDRN's mission is to promote the integrity and capacity of the P&A/CAP national network and to advocate for the enactment and vigorous enforcement of laws protecting civil and human rights of people with disabilities.

<http://www.napas.org/>

Parent-to-Parent USA: Promotes access, quality and leadership in parent to parent support across the country.

<http://www.p2pusa.org/p2pusa/sitepages/p2p-home.aspx>

RASopathies Network USA

a 501(c)(3) Non-profit organization

Chair, Lisa Schoyer, mother of Quin Johnson

rasopathies@earthlink.net

244 East Taos Road

Altadena CA 91001-3953