

Fundraising Packages
Mean You
Can Attend
For Free!!!

Conference & Registration

*Noonan Syndrome Foundation's
2014 Noonan Syndrome Conference
(Overlapping RASopathies Community Welcome)*

July 18-21, 2014

*Hilton Clearwater Beach Resort
Clearwater, Florida
Reserve Your Hotel Room Today!!*

Can't Wait to Sea You on the Beach!!!

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Letter from the President

Greetings!

We're heading to Clearwater, Florida and would like you to join us on the beach! We'll be at the Hilton Clearwater Beach Resort in Clearwater, Florida from July 18 - 21, 2014. What better place to celebrate and have some fun than on the beach? Within these pages you will find all you need to know about the conference. This information is also available on our website at www.teamnoonan.org and Facebook.

An exciting new addition to this year's conference is a Teen and Young Adult Social, Ladies Night Out and Guys Night Out. We will also have two educational tracks; one for families with infants and children with Noonan Syndrome and a second track focusing on teens and adults. We understand that some families may overlap both of these tracks and encourage participants to switch tracks/ workshops as needed.

Another exciting addition to this year's conference is this - **YOU MAY ATTEND FOR FREE** when you fundraise \$2,000. We want every family to be able to attend the conference, gain invaluable information and build friendships that will last a lifetime. Any family who fundraises \$2,000 will receive four all inclusive registration tickets, four nights complimentary hotel stay at the Hilton Clearwater Beach Resort and more. How does this work? You must make your own hotel reservations (and make it soon because this hotel will sell out), fill out the conference registration form and mail your \$2,000 check to the Noonan Syndrome Foundation. If fundraising and sending multiple checks, you must send all checks to the Foundation at one time. Please call the hotel and make your reservation in the Noonan Syndrome Foundation room block (at \$129 rate) as soon as possible to guarantee your spot. Your complimentary hotel room nights will be deducted from your bill at the time of checkout from the hotel (if you sign up for the fundraising package). Complimentary hotel nights can only be used at the conference hotel, for a standard size room, at the \$129 rate, between the nights of Thursday, July 17 and Tuesday, July 21, 2014.

Last year, many families were surprised at how much fun it was to stay in the hotel all together. Staying in the conference hotel allows you more time to visit with other families, build friendships and have fun together! Families can earn complimentary hotel nights through the fundraising program or enjoy the low conference hotel rate of \$129 per night. There is an additional \$20 optional resort fee and we have negotiated complimentary parking. Again, this hotel will sell out, so please book your reservation in the Noonan Syndrome Foundation room block today!

The hotel will provide a special child care service to our families on Saturday and Sunday from 9 AM to 5 PM each day. Details are provided in the following pages. Also, we hope you will join us for a family fun day on the beach on Monday, July 21. You bring the sunscreen and refreshments and we will provide lots of games and prizes for kids and teens!

Please take time to review all the conference information, including registration and hotel deadlines. Make your hotel reservation early to be sure you get the room of your choice. Contact Rebekah at Rebekah@teamnoonan.org if you need more information or help registering. Thank you!

Sea you on the beach!



Julie Jancius
Noonan Syndrome Foundation
President and CEO
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Noonan Syndrome Foundation

Board of Directors



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About the Hotel

Hilton Clearwater Beach Resort
400 Mandalay Avenue
Clearwater, Florida 33767
(727)461-3222



Hotel rate: \$129 plus tax per night
Parking: Free (for conference participants staying at the hotel)
Resort Fee (Optional): \$20 per night

Rates are available on a first come first serve basis for stays from July 15 to July 25, 2013. These rates are good until Friday, June 14, 2013 and only if rooms are still available. There is an early departure fee for anyone who departs early, from their stay at the hotel. This fee must be paid by the conference participant.



PLEASE BOOK EARLY to ensure availability. This hotel will sell out.

For hotel reservations call 1-800-HILTONS and identify yourself as a member of the 2014 Noonan Syndrome Foundation Conference.



At the Hilton Clearwater Beach Resort you are right on the beach able to stroll 10 acres of powder soft white sand overlooking the Gulf of Mexico. This hotel is an easy stroll away from dining, shopping and water sports and has a Kids' Club program available to keep children entertained with a variety of fun-filled activities. The resort provides daily and nightly activities for every age including pool side activities, refreshments, bon fires, s'mores, movies on the beach and glow-in-the-dark games. Activities change daily and may require a \$20 per day per room resort charge. Plunge into one of two refreshing pools and enjoy the sunset with a refreshing drink from the Coasters Lounge Bar and Grill on the beach!

Fun at the Hotel

Kid Zone

Daily activities scheduled for kids such as Beach Soccer, Wiffle Ball, Sand Dollar Art, Sand Castle Contest and many more scheduled from 10am - 3pm. Ask the front desk for details.

Family Fun Nights

Each weekend night the hotel will have an event for the entire family, including: Beach Fire & S'mores; Trivia Night; Sports Night and more!



Fun for Grown-Ups!

Daily Adult Activities, Sports, Games and much more. Details at the Fun Zone located North of the Swimming Pools.



Sunset Picnic for Two:

Includes Cabana with two chairs.

Dinner Menu: BBQ Chicken, potato salad, fruit and cheese plate, shrimp cocktail and a choice of Champagne.

Dessert Menu: Chocolate Strawberries or mini cakes. \$65

Call (727) 461-3222 extension 454 for more information.

These activities are not included in conference price.

More Fun Stuff To Do!

Pier 60 is located right next to the Hilton Clearwater Beach Resort and provides free nightly entertainment, sunset celebrations, music and more (weather permitting). Pier 60 also provides free movies on a jumbo screen every Friday and Saturday night. Visit www.sunsetatpier60.com for details.



discover

and

explore

Visit Winter the Dolphin, whose story was told in the movie Dolphin Tale, at the Clearwater Marine Aquarium.

(727)441-1790 or www.seewinter.com



High Times Parasail and Watersports offer parasailing, waverunners, kayaks, banana boats and paddle boats. For more information call (727)410-6443 or visit www.hightimesparasail.com.



COME AWAY....COME AWAY WITH CAPTAIN MEMO'S Original PIRATE CRUISE to the less traveled road of briny buccaneers and seafaring seadogs. Set your course with the cool reggae island & steel band music playing throughout the rigging of the PIRATES RANSOM. Every passenger will enjoy their choice of free soft drinks, beer, wine, and champagne, while searching for the bountiful dolphins, while aboard ship. The spirited pirates may belly on up to our full service bar to purchase their favorite libation.

Get lost in the pirate antics of treasure hunts, face painting, water gun games, stories and dancing for all.

(727) 446-2587 or www.captainmemo.com

Sightseeing



These activities are not included in Conference prices.

Conference Menu

Breakfast Buffets

To include assorted one major hot item (chef's choice - to change daily), breakfast breads or muffins and condiments, sliced fruit, cereal and milk, oatmeal, assorted juices, regular/decaf coffee, and hot tea. *Hot item suggestions - scrambled eggs, breakfast sandwich, breakfast burrito, etc.

Lunch Buffets

Lunch 1 - mixed greens (assorted toppings and dressings), soup (chef's choice), baked ziti, chicken parmesan, pasta with meat sauce, vegetable option (chef's choice), bread sticks/Italian bread, Italian themed dessert (chef's choice), iced tea, lemonade and coffee.

Lunch 2 - mixed greens with assorted toppings and dressing, fajita soup, chicken and beef soft taco station with shredded cheese, diced tomatoes, lettuce, sour cream, salsa, and guacamole, starch (chef's choice), vegetable option (chef's choice), iced tea, lemonade, and coffee.

Family Reception/Social

Vegetable crudité trays, cheese/cracker/fruit trays, 3 hot items (chef's choice), ice cream station with toppings, lemonade, coffee, tea and decaf coffee.

Buffet Dinner

Buffet dinner to include mixed greens with toppings and dressings, 3 entrees (chicken/beef, fish, and vegetarian - chef's choice), starch, veggie, bread, desserts, iced tea, lemonade, coffee, decaf coffee.

*25% of the group will be Gluten Free.

*All food menus may vary slightly at the time of the conference.

Conference Details

Airport Transportation - SuperShuttle

They offer two service types: Share Ride service and ExecuCar service. Our Share Ride service is our most economical means of transportation. Similar to carpooling, you will be on a shuttle with others who are traveling in the same direction but not with your group.

If you're looking for more VIP, exclusive transportation, then our ExecuCar service is for you. By booking a sedan or SUV, we will provide private transportation from the Tampa Airport to the Hilton Clearwater Beach hotel.

<http://groups.supershuttle.com/noonansyndromefoundation.html>

Wristbands

All conference registrants will receive a wristband at registration. They must be worn to attend sessions, meals and social activities.



Photography and Video



The Noonan Syndrome Foundation (NSF) and International RASopathies Foundation (IRF) will be taking pictures and videos throughout the conference. Your participation in the 2nd Annual Conference gives us permission to use the photos and videos for NSF and IRF use. There will be absolutely no names used in association with a photograph or video. If you do not want the Foundation's using your photo or video, please send a written request to the Noonan Syndrome Foundation, Attn: Rebekah Busbee, 124 Joshua Lane, Aiken, SC 29801 prior to the start of the conference.



Conference Schedule



Friday

- 8:00 AM - 12:00 PM Set Up - Volunteers Needed*
- 1:00 PM - 5:00 PM Set Up - Volunteers Needed*
- 5:30 PM - 7:30 PM Registration
- 6:00 PM - 7:30 PM "We're Glad to Sea You"
Family Social & Fun
Welcoming Remarks & Overview of
Schedule
- 8:00 PM - 10:00 PM Ladies Night Out (All Women 21+)
Beach Side Social & Games

*If interested in volunteering please e-mail Rebekah in
advance at rebekah@teamnoonan.org.

All Workshop Sessions May Be Video Recorded For Foundation Use.

Saturday Morning

- 7:00 AM - 8:00 AM Private Breakfast for Adults with NS & Doctors (18+):
- 8:00 AM - 12:00 PM Registration Table Open
- 8:00AM - 8:50 AM Family Breakfast
- 9:00AM - 5:00 PM Brave Kids Camp (Pre-registration Mandatory)

Combined Educational Workshops:

- 9:00 AM - 9:15 AM Welcoming Remarks
- 9:15 AM - 9:45 AM Noonan Syndrome Research: A Glimpse of the Future
- 9:45 AM - 10:00 AM Break

Track 1: Introductions by Stacie Borrero

- 10:00 AM - 10:30 AM Noonan Syndrome 101: An Overview of Health Issues
Caused By Noonan Syndrome
- 10:30 AM - 11:00 AM Post Traumatic Stress Disorder & Caring for the
Caregiver
- 11:00 AM - 11:30 AM GI and Feeding Issues: Therapies that Can Help
- 11:30 AM - 12:00 AM Cardiology and Noonan Syndrome

Track 2: Introductions by Ann Yurcek

*Teens & Young Adults Participate in Sessions

- 10:00 AM - 10:30 AM Pain and Treatments for Pain
- 10:30 AM - 11:00 AM Chiari Malformation & Neurology
- 11:00 AM - 11:30 AM What Do Teens & Adults with NS Face?
What tools and resources are available to help?
- 11:30 AM - 12:00 PM ADHD and NS

Saturday Afternoon/Evening

12:00 - 1:00 PM Lunch

Educational Workshops

Track 1: Introductions by Stacie Borrero

1:15 PM - 1:45 PM Autistic Tendencies & NS

1:45 PM - 2:15 PM Hematology & Bleeding Issues In NS

2:15 PM - 2:45 PM Sleep Issues & Noonan Syndrome

2:45 PM - 3:00 PM Break

3:00 PM - 4:00 PM Endocrinology, Growth Disorders & How to Determine the Right Course of Therapy

Track 2: Introductions by Ann Yurcek

*Teens & Young Adults Participate in Sessions

1:15 PM - 1:45 PM Future Planning: Wills & Trusts

1:45 PM - 2:15 PM Puberty & Fertility

2:15 PM - 2:45 PM NS & Behaviour Issues

2:45 PM - 3:00 PM Break

3:00 PM - 3:30 PM Career Support: Tips From the Experts

3:30 PM - 4:30 PM Open Discussion on Bullying

4:30 PM - 5:30 PM Teen Talk: Teens with NS Talk to Doctors

Dinner On Your Own

8:00 - 10:00 PM Teen & Young Adult's PJ's & Movie Night

8:00 - 10:00 PM Guys Night Out (All Dads & Men with NS 21+)

Sunday Morning

8:00 AM - 10:00 AM Breakfast

8:00 AM - 4:00 PM Registration Table Open

A Variety of Activities to Participate In:

9:00 AM - 5:00 PM Brave Kids Camp (Pre-registration Mandatory)

9:00 AM - 10:00 AM Leadership Workshop: Volunteer for the Foundation

9:00 AM - 12:00 AM Exhibitor Fair & Scavenger Hunt Family Fun Activities: Win Prizes!!!

9:00 AM - 12:00 AM Meet The Doctors & Research Stations List of Participants - Coming Soon

10:00 AM - 12:00 AM Round Table Discussions: Discuss and share what has worked and what we need researchers to focus on.

10:00 AM - 11:00 AM Gastrointestinal Issues: Let's Share What Has Worked & What We Need

11:00 AM - 12:00 PM Pain Issues: Let's Share What Has Worked & What We Need

9:00 AM - 12:00 AM Tween & Teen Group (Ages 12 - 15)

9:00 AM - 10:00 AM Ice Breakers & Welcome

10:00 AM - 11:00 AM Building Confidence 101 & Activity

11:00 AM - 12:00 AM Activity

9:00 AM - 12:00 AM Young Adult Group (Ages 16 - 24)

9:00 AM - 10:00 AM Ice Breakers & Welcome

10:00 AM - 11:00 AM Activity



Sunday Afternoon/Evening

12:00 PM - 1:00 PM Lunch

A Variety of Activities to Participate In:

1:00 PM - 5:00 PM Exhibitors Fair & Scavenger Hunt
Family Fun Activities: Win Prizes!!!

1:00 PM - 5:00 PM Meet the Doctors & Research Stations
List of Participants Coming Soon

1:00 PM - 3:00 PM Round Table Discussions: Discuss and share what
has worked and what we need researchers to focus on.

1:00 - 2:00 PM Accessing Government Services: Share & Learn Tips &
Tricks to SSI, Waivers, Medicaid, FMLA & More.

2:00 - 3:00 PM Behavioral Issues and Options: Let's Share What Has
Worked & What We Need

1:00 - 4:00 PM Tween & Teen Group (Ages 11 - 15)

1:00 - 2:00 PM Taking Care of My Health & Activity

2:00 - 3:00 PM Time Management & Tools To Take Home

3:00 - 4:00 PM Memory Makers: Make a Video

1:00 - 4:00 PM Young Adult Group (Ages 18 - 24)

1:00 - 2:00 PM Memory Makers: Make a Video on the

2:00 - 3:00 PM Taking Care of My Health & Activity

3:00 - 4:00 PM Time Management & Tools To Take Home

4:00 - 6:00 PM Volunteers: Help Set Up Banquet Dinner

6:00 - 10:00 PM Team Noonan Luau & Dinner.
Entertainment will be provided

Monday

8:00 AM - 9:00 AM Town Hall Meeting
Ask the Board of Directors/ Conference
Suggestions (Open to All)

Family Fun Day
Meet Up on the Beach!
10:00 AM - 12:00 Noon



Workshop Details

Coming Soon