

Day 1 - Wednesday, July 19

Research Roundtable & Registration Pick-Up

9:00 am - 5:00 pm - Research Roundtable (Invite Only), **Constitution BR**

5:00 pm - 7:00 pm - Cocktail / Apps for Professionals (Invite Only)

2:00 pm - 5:00 pm - Registration & Packet Pick-Up, **5th Fl 'Boston Com'**

3:00 pm - 5:00 pm - Families Only Conference Prep Session with the FamilieSCN2A Foundation Board Members, **5th Fl 'Riverway'**

**Kids Hospitality Rooms, 5th Floor:
'Public Gardens' & 'The Fens'**

- Thursday - 8 am - 4 pm
- Friday - 8 am - 4 pm

Check the schedule of activities planned for the kids on Thursday and join in on the fun!

10:00 am - Music Therapy
Music Therapy by Arthur



11:00 am - Pet Therapy
Meet Sydney & Hayden



1:00 pm - Pet Therapy
Meet Cindi & Bowie



3:00 pm - Pet Therapy
Meet Kathryn & Ola



Help us capture the event!

Any great pictures that you would like to share with us for use in future Foundation communications, please scan the QR code or email them to Carla.Forbes@SCN2A.org. Thank you for your support in raising awareness!



STAY SOCIAL! Use hashtags: #SCN2A
#cureSCN2A #SCN2AConference

Day 2 - Thursday, July 20 Constitution Ballroom, 2nd Floor

8:00 am - Breakfast & Registration

9:00 am - Welcome & Introduction

9:15 am - FamilieSCN2A Foundation Board Introductions & History

9:30 - 10:40 am - Session #1 SCN2A 101

- WHY we are all here / Family Story
 - Colin's Story
 - Evolution of the SCN2A Spectrum
 - Heather Olson, MD, Boston Children's Hospital
 - Unraveling the Genetic Code: Understanding Your SCN2A Variant
 - Stacey Cohen, MS, LCGC, Children's Hospital of Philadelphia
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10:40 - 11:00 am - Break

11:00 - 12:00 pm - Session #2 Variant Interpretation

- WHY we are all here / Family Story
 - Miles's Story
- Gene variant effects across sodium channelopathies - implications for treatment planning
 - Al George, MD, Northwestern
- Variant interpretation using bio-informatics and web applications now and in the future.
 - Dennis Lal, PhD, Broad, UT Houston
- Gene variant effects across sodium channelopathies - implications for treatment planning
 - Andreas Brunklaus, MD
- Panel Discussion, Moderator, Stephan Sanders, BMBS, PhD

12:00 - 1:00 pm - Lunch

1:00 - 2:00 pm - Session #3 Industry Fireside Chat

- WHY we are all here / Family Story
 - Carson's Story
 - Regel - Perry Spratt, PhD
 - Longboard - Randall Kaye, MD
 - Praxis - Brian Pfister, MD
 - Neurocrine - Carolyn McMicken, PsyD
 - Panel Discussion, Moderator, Shawn Egan, PhD
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2:00 - 2:15 pm - Break

2:15 - 3:00 pm - How clinical care is expanding to be more inclusive

- Telemedicine in rare diseases
 - John Millichap, MD, Precision Epilepsy
- What is an n-of-1 clinical trial & why do they matter to everyone
 - Wendy Chung, MD, Boston Children's Hospital
- Session #3 Q&A

3:00 - 4:15 pm - Session #4 Risk / Benefit of participating in a CT

- WHY we are all here / Family Story
 - Lyanna's Story
 - Pals Care - what are your goals for your loved one's care?
 - Brittany M. Kelly, CNP, Massachusetts General Hospital
 - What Does 'Better' Look Like in SCN2A?
 - Natasha Ludwig, PhD, Kennedy Krieger Institute
 - Skit/Role Play
 - Wrap-Up / Takeaways
 - Session #4 Q&A
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4:15 - BIG GROUP PHOTO

4:30 - 5:00 pm - Break

5:00 - 9:00 pm - Awards Dinner Aquarium

- Charter Buses to Aquarium at 5:00 pm & 5:45 pm
- Dinner on the water 6-7 pm
- The aquarium is open to explore 6-9 pm
- Awards Ceremony 7-8 pm
- Buses back to hotel 8-10 pm
- Dad's Night Out (Seaport) 8-11 pm @ SPIN Boston

Day 3 - Friday, July 21 Constitution Ballroom, 2nd Floor

8:00 am - Breakfast

9:15 am - Super Sibling Project

- Christina SanInocencio - meet in lobby

10:00 -11:30 am - Younger Super Sibling Project to Firehouse

- Derrick Campbell - meet in hotel lobby
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9:00 - 9:15 - Beyond the Diagnosis- putting a face to rare disease

- Patricia Weltin
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9:15-10:55 am - Session # 1 Clinical Challenges with SRD

- WHY we are all here - Family Story
 - Harry's Story
 - The SCN2A CTRS Update & Emerging Findings
 - Anne Berg, PhD, Northwestern University
 - Cognitive Assessment in SCN2A-Related Disorders
 - Natasha Ludwig, PhD, Kennedy Krieger Institute
 - The Gut-Brain Relationship
 - Maireade McSweeney, MD, Boston Children's Hospital
 - Q&A Panel
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10:55-11:15 am - Break

11:15-1:00 pm - Session # 2

- WHY we are all here - Family Story
 - Bennett's Story
 - Cortical Visual Impairment (CVI) foundational knowledge
 - Emily Cantillon, Perkins School for the Blind
 - How to advocate for CVI - your rights
 - Lacey Smith, Perkins School for the Blind
 - Accessing resources in your state - knowledge is power
 - Pat Cameron, Federation for Children with Special Needs
 - Q&A Panel
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1:00-2:00 pm - Network Lunch

2:00 pm - 4:00 pm - Optional Sessions

- OPTIONAL: Self Care is NOT Selfish
 - Julie Doran & Pat Cameron
 - OPTIONAL: First Aid & CPR Certification (Limited Seats)
 - Derrick Campbell
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6:00- 9:00 pm - Warrior Spotlight Party

8:00 - 11:00 pm - Mom's Night Out @ Dillons Boston

8:00 - 10:00 pm - Grandparents Gathering @ hotel suite TBA

THANK YOU!

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