



2019 International SADS Foundation Conference Atlanta, Georgia • October 4-6, 2019



Family Program (Rev. 9/18/19)

Friday, October 4, 2019

Registration/Check-in – Foyer

9:30 Registration/ Visit Scientific Posters and Exhibitors (Foyer) SADS Staff and Volunteers

10:15 Welcome/Plan for Weekend

Alice Lara, RN

(Introductions of SADS Family Conference Program Committee and Staff)

10:20 Research By the Patients...For the Patients interactive session Jennifer White, MD & Brynn Dechert, MSN, CPNP

11:45 Buffet Lunch

12:20 SADS 101- How Your Heart Works?

Matthew Sorensen, MD

12:40 Basic Genetics of SADS Conditions

Erin Demo, MS, CGC

1:00 Working With Your Care Team

Brynn Dechert-Crooks, NP

1:20 SADS Fundraisers

Jan Schiller, SADS Development Director

1:40 Disease Condition Breakouts

Meet & greet / introductions (with teens)

- ARVC / ARVD – Brittney Murray, Crystall Tichnell & Nate Miller (Savannah)
- Brugada – Brynn Dechert-Crooks (Buckhead A)
- CPVT – Deena McAndrew (Athens)
- LQTS1 – Lisa Mills (Suwannee)
- LQTS2 – Patti Simpson (Augusta)
- LQTS3 – Linda Knight (Buckhead A)
- Unknown SCA/SCD – Richard Lamphier (Rome)
- TSA – (Oglethorpe)

2:45 Break

3:00 Join Continuing Medical Education Session 4 - Communicating about SADS Conditions

3:15 G. Michael Vincent Tribute Lecture

Trudy Kremer

Smart Hearts: How to apply emotional intelligence and empathy to your patient family communications

4:15 Communication Panel: Jennifer White, MD; Ronald Kanter, MD; Peter Aziz, MD; Bruce Stambler, MD; Patricia Simpson, FNP-BC, RN MSN; Erin Demo, MS, CGC

5:00 Volunteer Awards/Beyond the Diagnosis Art Display/Unveiling

5:15 BINGO Get Acquainted / Wine/Cheese Reception – open for everyone

6:30 Dinner on Your Own

**Relax and Rejuvenation Room will be available from 5:00-10:00 PM

Saturday, October 5, 2019

7:30 Breakfast/Coffee/Tea Buffet

8:00 Welcome and Introductions Michael Ackerman, MD, PhD and Robert Campbell, MD

8:10 SADS...No, Make that Stop SADS: Are We Preventing Sudden Death? Michael Ackerman, MD, PhD

8:40 A View over the Horizon: Research for the Cure for LQTS, CPVT, Brugada Syndromes Dominic Abrams, MD

9:10 Get to Know Our Docs Panel – How Did You End Up in This Field? Moderator: Peter Fischbach, MD
Michael Ackerman, MD, PhD; Susan Etheridge, MD; Dominic Abrams, MD

9:40 Break

9:55 Sudden Death in the Young Registry Update Heather MacLeod, MS, CGC

10:15 LQTS Pro-Con Sports Clearance Debate Robert Whitehill, MD vs Peter Fischbach, MD

10:35 Ask the Experts Panel Moderator: Prince Kannankeril, MD
Michael Ackerman, MD, PhD & Susan Etheridge, MD

12:00 Lunch

12:45 Session 1: Concurrent breakout topics

Breakout 1: SADS Medication and Treatment Options

Breakout 2: Hands-On CPR / AED Training Certification

Breakout 3: Dealing with Grief

Breakout 4: Finding Peace Amidst the Storm – Practical Skills Session

Breakout 5: Ask a Genetic Counselor

Mary Niu, MD (Suwannee)

Richard Lamphier, RN

Alan London, MD

Jennifer Cory, MS, MAPP

Erin Demo, CGC and Linda Knight, CGC

1:35 Session 2: Concurrent breakout topics

Breakout 1: SADS Medication Issues and Treatment Options

Breakout 2: Hands-On CPR / AED Training Certification

Breakout 3: New Technology - APPS, Apple Watches, gadgets

Breakout 4: Young Adult - Managing Your Own SADS Conditions

Breakout 5: Impact of Diagnoses on Parents

Breakout 6: Investigating SCA/SCD: When We Don't Know

Mary Niu, MD (Suwannee)

Richard Lamphier, RN

Prince Kannankeril, MD

Aarti Dalal, MD (Buckhead)

Rachel Flores, RN (Augusta)

Erin Demo, CGC and Linda Knight, CGC

2:25 Session 3: Concurrent disease breakouts with assigned MD
(with teens)

- ARVC / ARVD-Brittney Murray, Crystal Tichnell & Nate Miller (Savannah)
- Brugada – Brynn Dechert-Crooks & Ron Kanter (Buckhead A)
- CPVT – Deena McAndrew & Prince Kannankeril (Athens)

- LQTS1 – Lisa Mills & Aarti Dalal (Suwannee)
- LQTS2 – Patti Simpson & Charles Berul (Augusta)
- LQTS3 – Linda Knight & Mary Niu (Buckhead A)
- Unknown SCA/SCA – Richard Lamphier & Robert Whitehill (Rome)

3:30 Break

3:40 *Hope, Health, and the Science of Human Flourishing*

Jennifer Cory, MS, MAPP

Jennifer Cory's talk will explore the impact of chronic diseases on wellbeing, and look at the gap that exists in healthcare between extending life and quality-of-life. Through the latest research in positive psychology, biology, and neuroscience, we will examine how the elements of Hope, Engagement, Action, Resources, and Thriving (**HEART**), can help confer immunity against anxiety, depression, and reduced quality-of-life, while promoting resilience and emotional wellbeing.

4:35 Personal and Family Journey

Melissa Russom

4:55 Honoring Heroes – Healing Wall ceremony

Robert Campbell, MD

6:00 Dinner on Your Own

7:00 -10:00 p.m. Family Casino Game Night

7:00 – 10:00 p.m. Relax and Rejuvenation Room available

Sunday, October 6, 2019

8:30 Coffee/Tea/Breakfast Buffet/Welcome

Robert Campbell, MD

8:45 Welcome from American Academy of Pediatrics

National President-Elect, Sally Goza, MD, FAAP

9:00 Communicating/Questions for your Doc

Aarti Dalal, MD

9:20 Advocating for You and Your Family

Patricia Simpson, MSN, FNP-C, RN

9:40 Making Your School Heart Safe

Richard Lamphier, RN

10:00 Raising a Child with SADS

Amanda Koch, Atlanta & Jennifer White, MD, Philadelphia

10:20 The Pregnancy Journey with Inherited Arrhythmias

Janette Strasburger, MD

10:40 Prenatal Genetic Diagnosis & Genetic Testing

Linda Knight, MS, CGC

11:10 Questions & Answers

11:40 What's New with CIEDs?

Charles Berul, MD

12:00 Youth and Teen Presentations

12:30 Adjourn