



2019 PURA SYNDROME CONFERENCE - BOSTON

Friday June 21, 2019 **Global Research Network Meeting**

7:00 AM – 9:00 AM
Salon C **GRN Breakfast**
Continental Breakfast Provided

9:00 AM – 12:00 PM **GRN Morning Session**
Salon C

12:00 PM – 1:00 PM
Salon C **LUNCH**
Box Lunches

1:00 AM – 3:00 PM
Salon C **GRN Afternoon Session**

3:00 PM – 5:00 PM
Salon C **Conference Registration Setup**

6:00 PM – 8:00 PM
Basalt Room **GRN Dinner**

8:00 PM – 10:00 PM
Basalt Room **Board Meeting**

Friday June 21, 2019 **General Session - Conference Registration**

5:00 PM – 8:00 PM
Salon C Registration and Reception
Refreshments will be available

8:00 PM +
Hotel Lounge Social Time



SATURDAY
June 22, 2019

General Session – Day 1

7:00 AM – 9:00 AM
Salons 1, 2, 3

Breakfast
Continental Breakfast Provided

8:30 AM – 5:00 PM
Salon A

Hospitality Room
Available during the day

8:45 AM – 9:00 AM
Salons 1, 2, 3

Welcome Remarks
Dominic Spadafore
President, PURA Syndrome Foundation

9:00 AM – 9:30AM
Salons 1, 2, 3

An Overview of PURA-Research Activities
Prof. Dr. Dierk Niessing
Helmholtz Zentrum München, Germany

MODEL SYSTEMS

9:30 AM – 10:10 AM
Salons 1, 2, 3

Why Use Model Systems For Research?
Part I: Mouse and Xenopus
Prof. Dr. Jennifer Gordon
Temple University, Philadelphia, PA

10:10 AM – 10:40 AM
Salons 1, 2, 3 Foyer

BREAK
Refreshments available

10:40 AM – 11:20 AM
Salons 1, 2, 3

Why Use Model Systems For Research?
Part II: Zebrafish and Human cells
Lena Molitor
Helmholtz Zentrum, München, Germany

BIOMARKERS

11:20 AM – 11:50 AM
Salons 1, 2, 3

Can RNA Help Us understand PURA Syndrome?
Dr. Andrew Douglas
University of Southampton, UK

11:50 PM – 12:20 PM
Salons 1, 2, 3

Using Metabolomics to Understand Health and Disease
Prof. Dr. Jerzy Adamski
Helmholtz Zentrum München, Germany

12:30 PM – 2:00 PM
Salons 1, 2, 3

LUNCH
Box lunch



2:00 PM – 2:30 PM <i>Salons 1, 2, 3</i>	Genome Editing and Gene Therapy Speaker TBD from Helmholtz Zentrum Helmholtz Zentrum München, Germany
2:30 PM – 3:00 PM <i>Salons 1, 2, 3</i>	Genetics of PURA Syndrome Dr. Jin Yun (Helen) Chen Massachusetts General Hospital, Boston, US
3:00 PM – 3:30 PM <i>Salons 1, 2, 3</i>	The PURA Syndrome Longitudinal Study: Using a Patient Registry to Improve our Understanding of PURA Syndrome Dr. Rebecca Mawby University of Southampton, UK
3:30 PM – 4:00 PM <i>Salons 1, 2, 3</i>	BREAK Refreshments available
4:00 PM – 4:30 PM <i>Salons 1, 2, 3</i>	PURA Foundation / GRN Q&A Dominic Spadafore President, PURA Syndrome Foundation Prof. Dr. Dierk Niessing Helmholtz Zentrum München, Germany Prof. Dr. Jennifer Gordon Temple University, Philadelphia, PA Dr. Rebecca Mawby University of Southampton, UK
4:30 PM – 5:00 PM <i>Salons 1, 2, 3</i>	Closing Remarks Dominic Spadafore President PURA Syndrome Foundation
5:00 PM – 6:00 PM	OPEN TIME
6:00 PM – 8:00 PM <i>Salons 1, 2, 3</i>	DINNER All registered guests are welcome



SUNDAY
June 23, 2019

General Session – Day 2

7:00 AM – 9:00 AM <i>Hotel Dining Room</i>	Breakfast Continental Breakfast Provided
8:30 AM – 5:00 PM <i>Salon A</i>	Hospitality Room Available during the day
9:00 AM – 9:15 AM <i>Salons 1, 2, 3</i>	Day 2 Welcome Dominic Spadafore President PURA Syndrome Foundation
9:15 AM – 10:00 AM <i>Salons 1, 2, 3</i>	Augmentative Communications Matt Modzlewski TobiiDynavox
10:00 AM – 10:45 AM <i>Salons 1, 2, 3</i>	Behavior Strategies for Children with Special Needs Kelly Kelm Behavior Specialist, Certified Autism Specialist and Board Certified Cognitive Specialist. South Shore Collaborative School, Hingham, MA, USA
10:45 AM – 11:00 AM	BREAK
11:00 AM – 11:45 AM <i>Salons 1, 2, 3</i>	Financial Planning and Management Shepherd Financial Advisors
11:45 AM – 12:30 PM <i>Salons 1, 2, 3</i>	Caregiving and Relationships Amanda Shanks Licensed Professional Counselor
12:30 PM – 2:00 PM <i>Salons 1, 2, 3</i>	LUNCH Box Lunches Provided
2:00 PM – 2:30 PM <i>Salons 1, 2, 3</i>	Parent Panel Discussion Experiences and Challenges of Parenthood Moderator – Amanda Shanks
2:30 PM – 3:00 PM <i>Salons 1, 2, 3</i>	PURA Syndrome Foundation Review and Closing Dominic Spadafore President, PURA Syndrome Foundation