



# DYSAUTONOMIA INTERNATIONAL 7TH ANNUAL CONFERENCE

PHILADELPHIA, PA • JULY 26-28, 2019

## Friday, July 26, 2019

**4:30pm-6:30pm** Interactive Dysautonomia Mural Painting with  
Legendary Philly Graffiti Artist MECRO  
East Market on Ludlow Street (across the street from the hotel – see map)

All activities below are in the Millennium Ballroom.

**6:00pm-9:00pm** Registration & Welcome Reception (light refreshments)  
#PickleShotChallenge Booth  
POTS Research Study Info Booth & Enrollment  
POTS Portrait Project Info Booth  
POTS Pals Info Booth

**6:00pm-8:00pm** Red Wheelbarrow Live Jazz Band (check out Dr. Boris playing bass)

**6:00pm-10:00pm** Board Games for All Ages

**7:00pm-9:00pm** Ice Cream Sundae Bar

**8:00pm-10:00pm** Karaoke



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**Saturday, July 27, 2019**

**8:00am-5:00pm**    **POTS Research Study**  
Research Room (Commonwealth C)

**8:30am-5:30pm**    **Vendor Fair**  
Commonwealth Hallway

**9:00am-9:10am**    **Welcome Remarks**  
Regency Ballroom

**Kirsten Slowey &  
Lauren Stiles, JD**  
Dysautonomia International

**9:10am-9:20am**    **Conference Research Project Q&A**  
Regency Ballroom

**Jonas Axelsson, MD, PhD**  
Karolinska Institutet

**9:20am-10:00am**    **Overview of Autonomic Disorders**  
Regency Ballroom

**Blair Grubb, MD**  
University of Toledo

**10:05am-10:45am**    **The New Horizons of Autoimmune POTS**  
Regency Ballroom

**Artur Fedorowski, MD**  
Skåne University

**Gastrointestinal Disorders in Dysautonomia:  
From Dysmotility to Immunology**  
Millennium Ballroom

**Laura Pace, MD, PhD**  
University of Utah

**Patient to Provider: How to Successfully  
Enter the Healthcare Industry**  
Breakout Room (Commonwealth B)

**Sara Cohen, OTS**, Thomas Jefferson University; **Alexa Herrera, OTD, OTR/L**, Rehab for All; **Emily Rich, MOT, OTR/L**, Tucson Medical Center

**Teen Program: Ice Breaker Games  
& Scavenger Hunt Kickoff**  
Teen Room (Commonwealth D)

**Laura Rusczyk &  
Patricia Prentis**  
Dysautonomia International

**11:00am-11:45am Exercise Rehabilitation in Dysautonomia**  
Regency Ballroom

**Tae Chung, MD**  
Johns Hopkins University

**POTS 101**  
Millennium Ballroom

**Satish Raj, MD, MSCI**  
University of Calgary

**Maintaining Healthy Family & Social Relationships During Chronic Illness**  
Breakout Room (Commonwealth B)

**Elyse Schwartz, MSW, LCSW**  
Dysautonomia International

**Teen Program: MythBusters: POTS Edition**  
Teen Room (Commonwealth D)

**Katherine Hut**  
Northeastern University

**11:45am-1:00pm Buffet Lunch & State/Country Meet Ups**  
Millennium Ballroom

**Silent Auction (11:45am-8pm)**  
Millennium Hallway

**1:00pm-1:45pm Managing Refractory Mast Cell Activation Syndrome in Dysautonomia**  
Regency Ballroom

**Anne Maitland, MD, PhD**  
Icahn School of Medicine at Mt. Sinai

**Autonomic Testing & Small Fiber Neuropathies**  
Millennium Ballroom

**Kamal Chémali, MD**  
Eastern Virginia Medical School

**Panel Discussion: Pregnancy & Parenting with Dysautonomia**  
Breakout Room (Commonwealth B)

Panelists:  
**Katie Morrissey**, Dysautonomia International; **Svetlana Blitshteyn, MD**, University of Buffalo School of Medicine & Biomedical Sciences; **Jaclyn Cinnamon**, Dysautonomia International

**Teen Program: Scavenger Hunt**  
Teen Room (Commonwealth D)

**Shannon Linford**  
Dysautonomia International

**2:00pm-2:45pm Sjögren's Syndrome and the Autonomic Nervous System**  
Regency Ballroom

**Brent Goodman, MD**  
Mayo Clinic

**Ehlers-Danlos Syndrome, Cognition & Dysautonomia**  
Millennium Ballroom

**Amanda Miller, PhD**  
Penn State Hershey Medical Center

**Panel Discussion: Parenting a Child with a Complex Chronic Illness (parents only please)**  
Breakout Room (Commonwealth B)

**Jane Taft**, POTSibilities Parents & **Jeffrey Boris, MD**, Pediatric Cardiologist

**Teen Program: Coping Skills for Teens**  
Teen Room (Commonwealth D)

**Elyse Schwartz, MSW, LCSW**  
Dysautonomia International

**3:00pm-3:45pm** **Vitamin Deficiencies and POTS:  
The Tip of the Iceberg**  
Regency Ballroom

**Svetlana Blitshteyn, MD**  
University of Buffalo School of  
Medicine & Biomedical Sciences

**Overview of Orthostatic Disorders:  
A Pictorial Guide**  
Millennium Ballroom

**Julian Stewart, MD, PhD**  
New York Medical College

**Advocacy Training Session: How to  
Organize a Dysautonomia International  
Support Group or Fundraising Event**  
Breakout Room (Commonwealth B)

**Taylor Kulp & Erin Harten**  
Dysautonomia International

**Teen Program: Japanese Kintsugi Pottery Decorating**  
Teen Room (Commonwealth D)

**BetteMarie Bond**  
Dysautonomia International

**4:00pm-4:45pm** **Stories of Hope & Recovery**  
Regency Ballroom

**Juliana Nitis**, Columbia  
University Medical Student;  
**Sarah Renberg**, University of  
Michigan Student; **Adam  
Jacobs**, Adam Jacobs  
Photography

**Managing CRPS, Fibromyalgia & Chronic Pain**  
Millennium Hall

**Paola Sandroni, MD, PhD**  
Mayo Clinic

**Overview of Autonomic Failure & Neurogenic  
Orthostatic Hypotension**  
Breakout Room (Commonwealth B)

**David Goldstein, MD, PhD**  
National Institute of Neurologic  
Disorders and Stroke

**Teen Program: Stories of Hope & Recovery**  
Regency Ballroom

**6:30pm-10:30pm** **Awards Dinner, Keynote Address,  
Photo Booth, Silent Auction & Quizzo  
Trivia Game with Johnny Goodtimes**  
Millennium Hall

Keynote Speaker:  
**Matt Pacifici**  
Ex-Professional Athlete  
Patient Advocate

The Silent Auction closes at 8pm.  
Be sure to get your final bids in before the auction closes!



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**Sunday, July 28, 2019**

**8:00am-4:00pm**    **POTS Research Study**  
Research Room (Commonwealth C)

**8:30am-4:30pm**    **Vendor Fair**  
Commonwealth Hallway

**9:00am-9:45am**    **Seizures & Syncope: What's the Relationship?**  
Regency Ballroom

**Robert Sheldon, MD**  
University of Calgary

**Overlap Between POTS and  
Chronic Fatigue Syndrome**  
Millennium Ballroom

**Italo Biaggioni, MD**  
Vanderbilt University

**Overview of the Autonomic Nervous System:  
Where is it? What does it do?**  
Breakout Room (Commonwealth B)

**David Goldstein, MD, PhD**  
National Institute of Neurologic  
Disorders and Stroke

**Teen Program: Finish Painting Kintsugi Pottery**  
Teen Room (Commonwealth D)

**BetteMarie Bond**  
Dysautonomia International

**10:00am-10:45am**    **Autoimmune Autonomic Ganglionopathy**  
Regency Ballroom

**Steve Vernino, MD, PhD**  
University of Texas  
Southwestern

**Median Arcuate Ligament Syndrome  
Presenting as POTS**  
Millennium Ballroom

**Hasan Abdallah, MD**  
The Children's Heart Institute

**From Doctor to Patient: An Immunologist's  
Experience with POTS, Ehlers-Danlos  
Syndrome and Cerebral Spinal Fluid Leaks**  
Breakout Room (Commonwealth B)

**Taylor Doherty, MD**  
University of California, San  
Diego

**Teen Program: Dysautonomia Jeopardy**  
Teen Room (Commonwealth D)

**Shannon Linford**  
Dysautonomia International

**11:00am-11:45am Sleep Dysfunction in POTS**

Regency Ballroom

**Mitchell Miglis, MD**

Stanford University

**Autonomic Testing Demonstration**

Breakout Room (Commonwealth B)

**Kamal Chémali, MD**

Eastern Virginia Medical School

**Teen Program: “Ask Abdallah Anything!”**

**Family Q&A Session** (teens & parents welcome)

Teen Room (Commonwealth D)

**Hasan Abdallah, MD**

The Children’s Heart Institute

**11:45am-1:00pm Buffet Lunch & State/Country Meet Ups**

Regency Ballroom

**1:00pm-1:45pm Headaches & Migraines in POTS**

Regency Ballroom

**Melissa Cortez, DO**

University of Utah

**School Accommodations for**

**Students with Dysautonomia**

Breakout Room (Commonwealth B)

**Jeffrey Boris, MD**

Pediatric Cardiologist

**Teen Program: School Accommodations**

**for Students with Dysautonomia**

Breakout Room (Commonwealth B)

**2:00pm-2:45pm** 15 Minute Research Updates in Regency Ballroom:

**Adrenergic Antibodies in POTS: 2014**

**Conference Study Update**

**Satish Raj, MD, MSCI**

University of Calgary

**Adrenergic & Muscarinic Antibodies in POTS**

**Blair Grubb, MD**

University of Toledo

**Do Compression Garments Work in POTS?**

**Kate Bourne, BSc**

University of Calgary

**Treating Post-Concussive Dysautonomia**

Breakout Room (Commonwealth B)

**Glen Cook, MD**

Walter Reed National Military  
Medical Center

**Teen Program: Surviving & Thriving**

**in College with Chronic Illness**

Teen Room (Commonwealth D)

**Kyla Jones**

Dysautonomia International

**3:00pm-4:00pm Q&A with the Experts  
and Closing Ceremony**

Regency Ballroom