



LIVING WITH CARDIOMYOPATHY FAMILY CONFERENCE

*Hosted by the Children's Cardiomyopathy Foundation
in partnership with the Children's Hospital of Philadelphia and Penn Medicine*

Friday, October 11, 2019

5:00 p.m. – 6:30 p.m. Welcome Reception (Aria, 3rd floor)

Saturday, October 12, 2019

8:30 a.m. – 9:15 a.m. Registration and Breakfast (Overture, 3rd floor)

9:15 a.m. – 11:30 a.m. Teen Program (Aria B, 3rd floor) (* teen attendees only)
Charisse Rhone, MSS – Heart Failure/Heart Transplant Social Worker, Children's Hospital of Philadelphia (CHOP)
Julia Lamotte, PhD – Psychology Fellow, CHOP
Abby Demianczyk, PhD – Pediatric Psychologist, CHOP

9:15 a.m. – 9:30 a.m. Welcome Remarks (Symphony Ballroom, 3rd floor)
Lisa Yue, Executive Director, Children's Cardiomyopathy Foundation

9:30 a.m. – 10:00 a.m. Current State of Medical Management (Symphony Ballroom, 3rd floor)
Anjali Tiku Owens, MD – Medical Director, Center for Inherited Cardiovascular Disease, Penn Medicine
Joseph Rossano, MD, MS – Chief, Division of Cardiology, CHOP

10:00 a.m. – 10:30 a.m. Developments in Research & Clinical Trials (Symphony Ballroom, 3rd floor)
Kimberly Lin, MD – Medical Director, Cardiomyopathy Program, CHOP

10:30 a.m. – 10:45 a.m. Physician Q & A Session (Symphony Ballroom, 3rd floor)

10:45 a.m. – 11:00 a.m. Coffee Break (Overture, 3rd floor)



Time	Pediatric Track (Orchestra Room, Mezzanine Level)	Adult Track (Symphony Ballroom, 3rd floor)
11:00 a.m. – 11:15 a.m.	Overview & Family Resources <i>Gina Peattie, MPA – Director, Family Support & Outreach, Children’s Cardiomyopathy Foundation</i>	Overview & Resources for Adult Patients <i>Debbie Gordon, MSS, LCSW – Penn Medicine</i>
11:15 a.m. – 11: 35 a.m.	Medical & Surgical Management <i>Matthew O’Connor, MD – Medical Director, Heart Transplant Program, CHOP</i>	Medical & Surgical Management <i>Nosheen Reza, MD – Advanced Heart Failure and Transplantation Fellow, Penn Medicine</i>
11:35 a.m. – 11:55 a.m.	Exercise & Sports Guidelines <i>Danielle Burstein, MD – Assistant Professor, Sections of Exercise Physiology and Cardiomyopathy/ Heart Transplantation, CHOP</i>	Exercise & Sports Guidelines <i>Sharlene Day, MD – Associate Professor of Medicine, Division of Cardiology, Penn Medicine</i>
11:55 a.m. – 12:15 p.m.	Teen Years & Transition to Adult Care <i>Debra Lefkowitz, PsyD – Assistant Professor of Clinical Psychology, CHOP</i>	Living with Your Disease Long Term <i>Amy Marzolf, CRNP, MSN – Penn Center for Inherited Cardiovascular Disease and Nosheen Reza, MD – Advanced Heart Failure and Transplantation Fellow, Penn Medicine</i>
12:15 p.m. – 12:35 p.m.	Patient & Physician Panel	Patient & Physician Panel

- 12:35 p.m. – 1:45 p.m. Lunch & Presentation on “Finding Inspiration with Medical Challenges”
Mike Papale – President, In a Heartbeat Foundation (Symphony Ballroom)
- 1:45 p.m. – 2:15 p.m. Breakout Session 1
- 2:20 p.m. – 2:50 p.m. Breakout Session 2
- 2:55 p.m. – 3 :25 p.m. Breakout Session 3
- 3:30 p.m. Conference Concludes



Breakout Sessions (select 3)
<p>Coping Strategies for Children and Teens (Concerto B, 3rd floor) <i>Abby Demianczyk, PhD – Cardiac Center Psychologist, CHOP</i></p>
<p>Taking Control of Healthcare (for parents and teenagers) (Aria B, 3rd floor) <i>Debra Lefkowitz, PsyD – Assistant Professor of Clinical Psychology, CHOP</i></p>
<p>School and Camp Considerations (Concerto A, 3rd floor) <i>Rachel White, BSN, RN, CCTC – Transplant Nurse Coordinator, CHOP</i> <i>Lynne Ha, CRNP, CHOP</i></p>
<p>Exercise and Sports Guidelines (Maestro B, 4th floor) <i>Danielle Burstein, MD – Assistant Professor, Sections of Exercise Physiology and Cardiomyopathy/Heart Transplantation, CHOP</i> <i>Sharlene Day, MD - Associate Professor of Medicine, Division of Cardiology, Penn Medicine</i></p>
<p>Genetic Testing and Family Screening (Maestro A, 4th floor) <i>Laura Vann, BSN, RN, PCCN – Nurse Coordinator, Penn Center for Inherited Cardiovascular Disease</i> <i>Jessica Chowns, MS, LCGC – Genetic Counselor, Penn Center for Inherited Cardiovascular Disease</i> <i>Lily Hoffman-Andrews, MS, LCGC – Genetic Counselor, Penn Center for Inherited Cardiovascular Disease</i> <i>Alyssa Ritter, MS, LCGC – Genetic Counselor, Familial Cardiomyopathy Program, CHOP</i></p>
<p>Arrhythmia, Ablation, Pacemakers, and ICDs (Minuet, 4th floor) <i>David Frankel, MD – Director, Cardiac Electrophysiology Fellowship Program, Penn Medicine</i> <i>Christopher Janson, MD – Assistant Professor, Section of Electrophysiology, CHOP</i></p>
<p>Nutrition and Diet (Rhapsody, 4th floor) <i>Danielle Campbell, MS, RD, LDN – Clinical Dietician, Preventive Cardiovascular Program, CHOP</i> <i>Brittany Marano, RD, CNSC, LDN – Clinical Dietician, Penn Medicine</i></p>

**Please note that the agenda is subject to change.*