



LIVING WITH CARDIOMYOPATHY: A FAMILY CONFERENCE

(updated 9.17.19)

Friday, October 11, 2019

5:00 p.m. - 6:30 p.m. Welcome Reception

Saturday, October 12, 2019

8:30 a.m. - 9:15 a.m. Registration and Breakfast

9:15 a.m. - 9:30 a.m. Welcome Remarks

Lisa Yue, Executive Director, Children's Cardiomyopathy Foundation

9:30 a.m. - 10:00 a.m. Current State of Medical Management

Anjali Tiku Owens, MD – Medical Director, Center for Inherited Cardiovascular Disease, Penn Medicine

Joseph Rossano, MD, MS – Chief, Division of Cardiology, The Children's Hospital of Philadelphia (CHOP)

10:00 a.m. - 10:30 a.m. Developments in Research and Clinical Trials

Kimberly Lin, MD – Medical Director, Cardiomyopathy Program, The Children's Hospital of Philadelphia

Kenneth Margulies, MD – Professor of Medicine, Heart Failure and Transplant Section, Penn Medicine

10:30 a.m. - 10:45 a.m. Physician Q & A Session

10:45 a.m. - 11:00 a.m. Coffee Break

Time	Pediatric Tract	Adult Tract
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>



Time	Pediatric Track	Adult Track
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> <i>Pavan Atluri, MD – Director, Cardiac Transplantation and Mechanical Circulatory Support Program, 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, patient and motivational speaker
- 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 (choose 3)
<p>Coping Strategies for Children and Teens <i>Abigail Demianczyk, PhD – Cardiac Center Psychologist, CHOP</i></p>
<p>Taking Control of Healthcare (for parents and teenagers) <i>Debra Lefkowitz, PsyD – Assistant Professor of Clinical Psychology, CHOP</i></p>
<p>School and Camp Considerations <i>Rachel White, BSN, RN, CCTC – Transplant Nurse Coordinator, CHOP</i> <i>Lynn Ha, CRNP</i></p>
<p>Exercise and Sports Guidelines <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 <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 <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 <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>