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

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| 11:00 a.m. - 11:15 a.m. | Overview & Family Resources  
Gina Peattie, MPA – Director, Family Support & Outreach, Children’s Cardiomyopathy Foundation | Overview & Resources for Adult Patients  
Debbie Gordon, MSS, LCSW – Penn Medicine |
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| 11:15 a.m. - 11:35 a.m.| Medical & Surgical Management  
Matthew O’Connor, MD – Medical Director, Heart Transplant Program, CHOP                                                                                                                                     | Medical & Surgical Management  
Nosheen Reza, MD – Advanced Heart Failure and Transplantation Fellow, Penn Medicine  
Pavan Atluri, MD – Director, Cardiac Transplantation and Mechanical Circulatory Support Program, Penn Medicine                                                                                         |
| 11:35 a.m. - 11:55 a.m.| Exercise & Sports Guidelines  
Danielle Burstein, MD – Assistant Professor, Sections of Exercise Physiology and Cardiomyopathy/Heart Transplantation, CHOP                                                                                       | Exercise & Sports Guidelines  
Sharlene Day, MD – Associate Professor of Medicine, Division of Cardiology, Penn Medicine                                                                                                                  |
| 11:55 a.m. - 12:15 p.m.| Teen Years & Transition to Adult Care  
Debra Lefkowitz, PsyD – Assistant Professor of Clinical Psychology, CHOP                                                                                                                                         | Living with Your Disease Long Term  
Amy Marzolf, CRNP, MSN – Penn Center for Inherited Cardiovascular Disease and Nosheen Reza, MD – Advanced Heart Failure and Transplantation Fellow, Penn Medicine |
| 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)

**Coping Strategies for Children and Teens**  
*Abigail Demianczyk, PhD – Cardiac Center Psychologist, CHOP*

**Taking Control of Healthcare (for parents and teenagers)**  
*Debra Lefkowitz, PsyD – Assistant Professor of Clinical Psychology, CHOP*

**School and Camp Considerations**  
*Rachel White, BSN, RN, CCTC – Transplant Nurse Coordinator, CHOP  
Lynn Ha, CRNP*

**Exercise and Sports Guidelines**  
*Danielle Burstein, MD – Assistant Professor, Sections of Exercise Physiology and Cardiomyopathy/Heart Transplantation, CHOP  
Sharlene Day, MD - Associate Professor of Medicine, Division of Cardiology, Penn Medicine*

**Genetic Testing and Family Screening**  
*Laura Vann, BSN, RN, PCCN – Nurse Coordinator, Penn Center for Inherited Cardiovascular Disease  
Jessica Chowns, MS, LCGC – Genetic Counselor, Penn Center for Inherited Cardiovascular Disease  
Lily Hoffman-Andrews, MS, LCGC – Genetic Counselor, Penn Center for Inherited Cardiovascular Disease  
Alyssa Ritter, MS, LCGC – Genetic Counselor, Familial Cardiomyopathy Program, CHOP*

**Arrhythmia, Ablation, Pacemakers, and ICDs**  
*David Frankel, MD – Director, Cardiac Electrophysiology Fellowship Program, Penn Medicine  
Christopher Janson, MD – Assistant Professor, Section of Electrophysiology, CHOP*

**Nutrition and Diet**  
*Danielle Campbell, MS, RD, LDN – Clinical Dietician, Preventive Cardiovascular Program, CHOP  
Brittany Marano, RD, CNSC, LDN – Clinical Dietician, Penn Medicine*