

Meeting	Date of meeting	Host Organization(s)	Meeting Report	Agenda	Rec. 1	Rec. 2	Rec. 3	Rec. 4	Pre or post-meeting survey	Report Author(s)	Consultant(s)
Niemann-Pick Type C PFDD	3/18/2019	Ara Parseghian Medical Research Fund		Agenda							
Major Depressive Disorder PFDD	11/16/2018	Depression and Bipolar Support Alliance			Recordings						
Charcot-Marie-Tooth PFDD	9/28/2018	Hereditary Neuropathy Foundation			Recordings						
Chemotherapy-induced Hearing Loss in Pediatric Oncology Patient-Focused Drug Development Workshop	9/13/2018	Children's Case for Cancer Advocacy; Children's Brain Tumor Foundation; Mattie Miracle Cancer Foundation; Momcology			Recording						
Alport Syndrome PFDD	8/3/2018	Alport Syndrome Foundation; National Kidney Foundation		Agenda							
Juvenile Idiopathic Arthritis	8/2/2018	Arthritis Foundation; Childhood Arthritis and Rheumatology Research Alliance (CARRA)			Part 1	Part 2					
Barth Syndrome PFDD	7/18/2018	Barth Syndrome Foundation	Report	Agenda	Recording				Post-meeting questionnaire	Valerie M. Bowen, Emily Milligan, Susan McCormack, Kate McCurdy, and Matthew Toth (Barth Syndrome Foundation); Theo Smart (technical writer); James Valentine (Hyman, Phelps & McNamara, P.C.)	Hyman, Phelps & McNamara, P.C.
Chronic Pain PFDD	7/9/2018	FDA									
Sleep Apnea Patient-Focused Medical Product Development (PFMPD)	6/8/2018	American Sleep Apnea Association	Report	Agenda	Recording				Pre-meeting survey; partnered with 12 nonprofits and Evidation Health	Author: Kim McCleary (The Kith Collective); design: Julie Rathjens (Hello Brand)	The Kith Collective
Opioid Use Disorder PFDD	4/17/2018	FDA		Agenda	Part 1	Part 2	Part 3				
Pachyonychia Congenita (PC) & Epidermolysis Bullosa (EB) PFDD	4/6/2018	Pachyonychia Congenita (PC) Project and debra	Report	Agenda	Recording (PC)					PC Project (Internal)	Hyman, Phelps & McNamara, P.C.
Hypereosinophilic Syndromes Patient Education and Drug Development Conference	3/23/2018	American Partnership for Eosinophilic Disorders (APFED)		Agenda	Recording						
Duchenne Patient-Focused Compass Meeting	3/5/2018	Parent Project Muscular Dystrophy (PPMD)	Report		Recording					Kim McCleary (The Kith Collective)	Faegre Baker Daniels; The Kith Collective; RTI International
Hyperhidrosis PFDD	11/13/2017	International Hyperhidrosis Society	Report & Agenda		Recording				Pre-meeting poll	Angela Ballard and Lisa Pieretti (International Hyperhidrosis Society)	
Lupus PFDD	9/25/2017	Lupus and Allied Diseases Association, Inc. (LADA); Lupus Foundation of America (LFA); Lupus Research Alliance (LRA)	Report & Agenda		Recording				Pre-meeting survey	Not listed (likely internal)	Yes, Faegre Baker Daniels Consulting
Hereditary Angioedema PFDD	9/25/2017	FDA		Agenda	Part 1	Part 2					
Alopecia areata PFDD	9/11/2017	FDA	Report	Agenda	Part 1	Part 2					
C3G PFDD	8/4/2017	National Kidney Foundation	Report	Agenda	Recording				Post-meeting survey	David L. Feldman (National Kidney Foundation); Andrew Bomback (Columbia University Medical Center; meeting Co-chair); Carla Nester (University of Iowa, Carver College of Medicine; meeting Co-chair)	Hyman, Phelps & McNamara, P.C.
Tuberous Sclerosis Complex (TSC) & Lymphangioleiomyomatosis (LAM) PFDD	6/21/2017	Tuberous Sclerosis Alliance	Report	Agenda	Morning 1	Morning 2	Afternoon 1	Afternoon 2	Pre-meeting survey	Calvin N. Ho, Kari Luther Rosbeck, and Steven L. Roberds (Tuberous Sclerosis Alliance); Gabrielle Rushing (Vanderbilt University); James E. Valentine (Hyman Phelps & McNamara, P.C.)	Hyman, Phelps & McNamara, P.C.
Friedreich's Ataxia PFDD	6/2/2017	Friedreich's Ataxia Research Alliance; Muscular Dystrophy Association; National Ataxia Foundation; Cure FA Foundation	Report & Agenda		Recording				Collected content from web platforms with permissions	Friedreich's Ataxia Research Alliance, Muscular Dystrophy Association, National Ataxia Foundation, and Cure FA Foundation (internal)	Hyman, Phelps & McNamara, P.C.
Autism PFDD	5/4/2017	FDA	Report	Agenda	Part 1	Part 2					
Spinal Muscular Atrophy PFDD	4/18/2017	cure SMA	Report	Agenda	Recording				Post-meeting survey	Rosangel Cruz, Megan Lenz, Lisa Belter, Kenneth Hobby, Jill Jarecki (Cure SMA); Theo Smart (medical writer)	Hyman, Phelps & McNamara, P.C.
Sarcopenia PFDD	4/6/2017	FDA	Report	Agenda	Recording						
Osteoarthritis PFDD	3/8/2017	Arthritis Foundation	Report	Agenda	Recording				None	Arthritis Foundation (internal)	Hyman, Phelps & McNamara, P.C.
Patients who have received an organ transplant PFDD	9/27/2016	FDA	Report	Agenda	Part 1	Part 2	Part 3	Part 4			
Myotonic Dystrophy (DM) PFDD	9/15/2016	Myotonic Dystrophy Foundation	Report & Agenda		Part 1	Part 2			Pre-meeting survey; in partnership with Silicon Valley Research Group	Myotonic Dystrophy Foundation (internal)	Hyman, Phelps & McNamara, P.C.
Neuropathic patina associated with peripheral neuropathy PFDD	6/10/2016	FDA	Report	Agenda	Part 1	Part 2	Part 3	Part 4			
Psoriasis PFDD	3/17/2016	FDA	Report & Agenda		Part 1	Part 2					

Systemic Amyloidosis PFDD	11/16/2015	Amyloidosis Research Consortium (ARC)	Report & Agenda	Part 1	Part 2	Post-meeting survey	Isabelle Lousada, Dena Heath, Mary Ellen Thomas, Merielle Stamm (Amyloidosis Research Consortium)
Non-tuberculous mycobacterial lung infections PFDD	10/15/2015	FDA	Report & Agenda		Meeting Slides		
Alpha-1 Antitrypsin Deficiency PFDD	9/29/2015	FDA	Report & Agenda		Transcript		
Parkinson's Disease and Huntington's Disease PFDD	9/22/2015	FDA	Report & Agenda		Meeting Slides		
Functional GI Disorders PFDD	5/11/2015	FDA	Report	Agenda	Transcript		
Chagas Disease PFDD	4/28/2015	FDA	Report & Agenda				
Breast Cancer PFDD	4/2/2015	FDA	Report				
Female Sexual Dysfunction PFDD	10/27/2014	FDA	Report				
Idiopathic Pulmonary Fibrosis PFDD	9/26/2014	FDA	Report	Agenda	Transcript		
Hemophilia A, Hemophilia B, von Willebrand disease and Other Heritable Bleeding Disorders PFDD	9/22/2014	FDA	Report & Agenda				
Neurological Manifestations of Inborn Errors of Metabolism PFDD	6/10/2014	FDA	Report & Agenda				
Pulmonary Arterial Hypertension PFDD	5/13/2014	FDA	Report	Agenda	Transcript		
Fibromyalgia PFDD	3/26/2014	FDA	Report	Agenda	Transcript		
Sickle Cell Disease PFDD	2/7/2014	FDA	Report	Agenda	Transcript		
Narcolepsy PFDD	9/24/2013	FDA	Report	Agenda	Transcript		
Lung Cancer PFDD	6/28/2013	FDA	Report	Agenda	Transcript		
Human Immunodeficiency Virus (HIV) PFDD	6/14/2013	FDA	Report	Agenda	Transcript		
Chronic Fatigue Syndrome and Myalgic Encephalomyelitis PFDD	4/25/2013	FDA	Report				

* = In person and webcast attendance not delineated

This tracker is a work in progress. If you can contribute additional information, please email: jrashid@fastercures.org

