

Meeting	Date of meeting	Host Organization(s)	Meeting Report	Agenda	Rec. 1	Rec. 2	Rec. 3	Rec. 4	Pre or post-meeting survey?	Consultants
Major Depressive Disorder PFDD	11/16/2018	Depression and Bipolar Support Alliance								
Charcot-Marie-Tooth PFDD	9/28/2018	Hereditary Neuropathy Foundation								
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								
Alport Syndrome PFDD	8/3/2018	Alport Syndrome Foundation; National Kidney Foundation								
Juvenile Idiopathic Arthritis	8/2/2018	Arthritis Foundation; Childhood Arthritis and Rheumatology Research Alliance (CARRA)								
Barth Syndrome PFDD	7/18/2018	Barth Syndrome Foundation		Agenda	Recording					
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				Yes, pre-meeting survey; partnered with 12 nonprofits and Evidation Health	Yes, 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 Project and debra		Agenda	Recording (PC)					Yes, 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					No
Hyperhidrosis PFDD	11/13/2017	International Hyperhidrosis Society	Report & Agenda		Recording				Yes, pre-meeting poll	
Lupus PFDD	9/25/2017	Lupus and Allied Diseases Association, Inc. (LADA); Lupus Foundation of America (LFA); Lupus Research Alliance (LRA)	Report & Agenda		Recording				Yes, pre-meeting survey	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				Yes, post-meeting survey	Yes, Hyman, Phelps & McNamara, P.C.
Tuberous Sclerosis Complex (TSC) & Lymphangi leiomyomatosis (LAM) PFDD	6/21/2017	Tuberous Sclerosis Alliance	Report	Agenda	Morning 1	Morning 2	Afternoon 1	Afternoon 2	Yes, pre-meeting survey	Yes, Hyman, Phelps & McNamara, P.C.
Friedreich's Ataxia PFDD	6/2/2017	Friedreich's Ataxia Research Alliance	Report & Agenda		Recording				No, but analyzed comments on social media	Yes, 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				Yes, post-meeting survey	Yes, Hyman, Phelps & McNamara, P.C.
Sarcopenia PFDD	4/6/2017	FDA	Report	Agenda	Recording					
Osteoarthritis PFDD	3/8/2017	Arthritis Foundation	Report	Agenda	Recording				No	Yes, 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			Yes, pre-meeting survey; in partnership with Silicon Valley Research Group	Yes, 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			Yes, post-meeting survey	
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		
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* = 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



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