

Rare Disease Cures Accelerator- Data and Analytics Platform

2021 Virtual Workshop

Agenda

- 10:00-10:10 a.m.** **Introduction & Welcome**
Jeff Barrett (C-Path), Sydney Devlin (C-Path)
- 10:10-10:20 a.m.** **Opening Remarks**
Theresa Mullin (FDA)
- 10:20-11:00 a.m.** **How RDCA-DAP is Working to Break Down Silos**
Jeff Barrett (C-Path), Amanda Borens (C-Path); Paul Howard (Amicus), Terry Jo Bichell (COMBINEDBrain), Raj Madabushi (FDA)
- 11:00-11:15 a.m.** **RDCA-DAP: Patients' Contributions of Data, and a Physician's Perspective**
Edward Neilan (NORD)
- 11:15-11:30 a.m.** **RDCA-DAP Community Engagement and Data Acquisition**
Alexandre Bétourné (C-Path)
- 11:30-12:05 p.m.** **Panel Discussion: Making the Case for Sharing Data**
Alexandre Bétourné (C-Path), Ramona Walls (C-Path); Andrew Mulberg (Consultant), Art Caplan (NYU)
- 12:05-12:10 p.m.** **Break**
- 12:10-12:30 p.m.** **Platform Development, Aridhia: Platform Foundation, Plans and Capabilities of the RDCA-DAP**
Aridhia Team
- 12:30-1:15 p.m.** **RDCA-DAP: Beta Testing and Platform Development**
Victoria Theurer Crider (C-Path), Megan Cala (C-Path), Justin Moy (Worcester Polytechnic Institute)
- 1:15-1:35 p.m.** **Connecting the Dots: How We Bring Data Platforms Together**
Will Roddy (C-Path), Prashant Goel (NORD)
- 1:35-1:55 p.m.** **Benefits of Integrating Multiple Data Sets for Rare Disease: Duchenne Muscular Dystrophy**
Terina Martinez (C-Path); Joanne Donovan (Edgewise Therapeutics)
- 1:55-2:10 p.m.** **Break**
- 2:10-2:30 p.m.** **Panel Discussion– Successful Importation of Data into DAP: Lessons Learned from Importing Registry Data into RDCA-DAP**
Amanda Borens (C-Path) Will Roddy (C-Path), Theresa Strong (FPWR), Karim Azer (Axcella)
- 2:30-3:00 p.m.** **RDCA-DAP Facilitating Collaboration in the Pre-Competitive Space: Case Study in Friedreich's Ataxia**
Megan Cala (C-Path), Christian Rummey (FARA)
- 3:00-3:30 p.m.** **Roundtable– RDCA-DAP Facilitating Collaboration in the Pre-Competitive Space: Case Study in Friedreich's Ataxia**
Jeff Barrett (C-Path), Megan Cala (C-Path), Michelle Campbell (FDA), Jen Farmer (FARA), Christian Rummey (FARA), David Lynch (CHOP)
- 3:30-3:45 p.m.** **What's next for RDCA-DAP, Closing Remarks**
Jeff Barrett (C-Path), Peter Saltonstall (NORD), Billy Dunn (FDA)