

Workshop#3 Agenda (3rd of 4 Part Series)
Developing Collaborative Research Networks

OCTOBER 24 -25, 2019

Notary Philadelphia Downtown, Autograph Collection • 21 North Juniper Street, Philadelphia, PA, 19107

The learning objectives for this third in a series of four workshops are to enable patients and patient advocates to:

- ⌘ Generate interest among clinicians and researchers
- ⌘ Grow and manage your scientific network
- ⌘ Exert control over the destiny of your community's research

THURSDAY, OCT 24

3:00 pm – 5:00 pm ET

Collaboration Insights and Live Q/A with Parent Project Muscular Dystrophy (PPMD)

Speakers:

- **Ryan Fischer**, Senior Vice President, Community Engagement, PPMD
- **Eric Camino, PhD**, Director, Research & Clinical Innovation, PPMD

5:00 pm – 7:00 pm ET

Welcome Reception

FRIDAY, OCT 25

8:00 am – 8:45 am ET

Registration & Breakfast

8:45 am – 9:00 am ET

Introduction to Workshop 3: Developing Collaborative Research Networks

Speaker: **Christian Rubio**, Vice President, Community Development and Engagement, Global Genes

9:00 am – 10:00 am ET

The Collaborative Network Approach: A Model for Advancing Patient-Centric Research

Speaker: **David Fajgenbaum, MD, MBA, MSc, FCPP**, Co-founder & Executive Director, Castleman Disease Collaborative Network & Assistant Professor of Medicine, University of Pennsylvania

10:00 am – 11:00 am ET

Understanding the Researcher's and Clinician's Points of View

Panel Facilitator: **Stephen C. Groft, PharmD**, Senior Advisor to the Director, Office of the Director, National Center for Advancing Translational Sciences, National Institutes of Health

Panelists:

- **David Fajgenbaum, MD, MBA, MSc, FCPP**, Co-founder & Executive Director, Castleman Disease Collaborative Network
- **F. Bradley Johnson, MD, PhD**, Professor of Pathology and Laboratory Medicine, University of Pennsylvania Perelman School of Medicine
- **Benjamin Prosser, PhD**, Assistant Professor of Physiology, University of Pennsylvania Perelman School of Medicine
- **Edwin Weeber, PhD**, Former Professor of Molecular Pharmacology and Physiology, University of South Florida

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11:00 am – 11:15 am ET

11:15 am – 12:00 pm ET

12:00 pm – 1:00 pm ET

1:00 pm – 1:15 pm ET

1:15 pm – 2:15 pm ET

2:15 pm – 2:45 pm ET

2:45 pm – 3:00 pm ET

3:00 pm – 4:00 pm ET

4:00 pm – 5:00 pm ET

Break

How National Center for Advancing Translational Sciences Can Help You Jumpstart Your Research Agenda

Speakers:

- **Stephen Groft, PharmD**, Senior Advisor to the Director, Office of the Director, National Center for Advancing Translational Sciences, National Institutes of Health
- **Eric Sid, MD, MHA**, Program Officer, National Center for Advancing Translational Sciences, National Institutes of Health

Lunch

Welcome Back

Speaker: **Christian Rubio**, Vice President, Community Development and Engagement, Global Genes

Creating a Global Network

Speakers:

- **Meagan Cross**, FAST Australia Chairperson, Project Manager and International Liaison, Global Angelman Syndrome Registry
- **Allyson Berent**, Chief Science Officer, Foundation for Angelman Syndrome Therapeutics
- **Edwin Weeber, PhD**, Former Professor of Molecular Pharmacology and Physiology, University of South Florida

Using Guerilla Marketing to Advance Research

- Speaker: **Kristin Smedley**, Chief Executive Officer, Curing Retinal Blindness Foundation

Break

Managing and Maintaining Your Network: What it Takes to Keep Moving

Panel Facilitator: **Liz Horn, PhD, MBI**, Principal, LHC Biosolutions

Panelists:

- **Meagan Cross**, FAST Australia Chairperson, Project Manager and International Liaison, Global Angelman Syndrome Registry
- **Allyson Berent**, Chief Science Officer, Foundation for Angelman Syndrome Therapeutics
- **Kristin Smedley**, Chief Executive Officer, Curing Retinal Blindness Foundation
- **Mileva Repasky**, Chief Patient & Development Officer, Castleman Disease Collaborative Network
- **Mary Zuccato, MBA**, Chief Operating Officer, Castleman Disease Collaborative Network

Wrap Up, Final Questions and Roundtable Discussions

Speaker: **Christian Rubio**, Vice President, Community Development and Engagement, Global Genes

