



National Disability Forum **“Compassionate Allowances and Rare Diseases”**

Conference Room A – C, 1100 New York Avenue, NW, Washington, DC

Tuesday, November 7, 2017

1:00 p.m. - 3:00 p.m. EST

Participant Call-in Number: (202) 838-7992

Conference ID: 49380875#

Agenda

Welcome

Stephen Evangelista

Acting Assistant Deputy Commissioner for Retirement and Disability Policy
Social Security Administration (SSA)

Opening Remarks

Bea Disman

Acting Chief of Staff, SSA

Panel Discussion

Moderator: **Marshall Summar, M.D.**

Director, Rare Disease Institute and Division Chief, Genetics and Metabolism,
Children’s National Health System; Board of Directors (Chairman), National
Organization for Rare Disorders (NORD)

Anne Pariser, M.D.

Deputy Director, Office of Rare Diseases Research, National Center for
Advancing Translational Sciences, National Institutes of Health

Eddy Yang, M.D., Ph.D

Professor and Vice Chair of Radiation Oncology, University of Alabama at
Birmingham & Chair of the Congenital Central Hypoventilation Syndrome
Network Research Advisory Board (Congenital Central Hypoventilation
Syndrome)

Teryn Suhr

Executive Director and Co-Founder, MLD Foundation (Juvenile
Metachromatic Leukodystrophy)

Glenna Steele

Executive Director, Glut1 Deficiency Foundation (Glut1 Deficiency)

Brief Condition Overview

Krista Hemming - Vice President, HSN1E Society

John Hopper – President, Fibrolamellar Cancer Foundation

Trish Stoltzfus – Mentee Coordinator, PSC Partners Seeking a Cure

Emily Fields – Executive Director, PRISMS

Open Discussion

All

Closing Remarks

Stephen Evangelista