AGENDA

7:30 a.m. Registration and Poster/Exhibit Booth Setup

8:30 a.m. First Morning Session

NIH Director Remarks
Francis S. Collins, M.D., Ph.D. — Director, National Institutes of Health (NIH)

NIH Clinical Center (CC) Remarks
John I. Gallin, M.D. — Director, CC, NIH

Congressional Remarks
Video Remarks from Senator Orrin Hatch (R-UT) — Co-Chair, Rare Disease Congressional Caucus

National Center for Advancing Translational Sciences (NCATS) Director Remarks
Christopher P. Austin, M.D. — Director, NCATS, NIH

Office of Rare Diseases Research (ORDR) Director Remarks
Petra Kaufmann, M.D., M.Sc., FAAN — Director, ORDR, NCATS, NIH

National Organization for Rare Disorders (NORD) Updates
Martha L. Rinker, J.D. — Vice President of Public Policy, NORD

10:00 a.m. Break

10:20 a.m. Second Morning Session

International Collaboration

The 2014-15 Ebola Crisis: The NIH Response
Richard T. Davey, Jr., M.D. — Deputy Clinical Director, National Institute of Allergy and Infectious Diseases, NIH

International Classification of Diseases, 11th revision (ICD-11)
Donna Pickett, M.P.H., R.H.I.A. — Chief, Classifications and Public Health Data Standards, National Center for Health Statistics, Centers for Disease Control and Prevention

B2B Update: Telomeres and Lifestyle in Li-Fraumeni Syndrome Outcomes
Sharon A. Savage, M.D., FAAP — Chief, Clinical Genetics Branch, Division of Cancer Epidemiology and Genetics, National Cancer Institute (NCI), NIH

Undiagnosed Diseases Network (UDN) Update and International Collaborations
Anastasia L. Wise, Ph.D. — Program Director, Division of Genomic Medicine, National Human Genome Research Institute (NHGRI), NIH
William A. Gahl, M.D., Ph.D. — Clinical Director, NHGRI, NIH
**Food and Drug Administration (FDA)**

**FDA Updates**
Gayatri Rao, M.D., J.D. — Director, Office of Orphan Products Development, FDA
Jonathan Goldsmith, M.D. — Associate Director, Rare Diseases Program, Office of New Drugs, Center for Drug Evaluation and Research, FDA

12:00 p.m. **Lunch and Poster Session/CC Tours**

1:30 p.m. **Afternoon Session**

**Congressional Remarks**
Congressman Leonard Lance (R-NJ 7th District) — Co-Chair, Rare Disease Congressional Caucus

**Patient’s Voice**

**Session Moderator:** Commander Margaret Bevans, Ph.D., R.N., AOCN®, FAAN — United States Public Health Service, Clinical Nurse Scientist and Program Director, Scientific Resources, CC, NIH

**Genetic Alliance Updates**
Sharon Terry, M.A. — President and CEO, Genetic Alliance

**Using Public Policy to Accelerate Biomedical Innovation for Rare Disease Patients**
Max G. Bronstein, M.P.P. — Senior Director, Advocacy and Science Policy, EveryLife Foundation for Rare Diseases

**Finding the Help You Need**
Suzanne P. Ripley, Ph.D.

**Global Genes™ Updates**
Kym Kilbourne — Vice President, Patient Advocacy, Global Genes™

**NIH CC Patient Advisory Group (PAG)**
Beatrice A. Bowie — Facilitator, Sickle Cell Support Group, Adventist HealthCare Shady Grove Medical Center, and Board Member, NIH CC PAG

**Uplifting Athletes Update**
Scott Shirley — Executive Director, Uplifting Athletes

**The Mighty**
Mike Porath — Founder and CEO, The Mighty

**Caregiver Research: Understanding the Perceived Influence of Childhood Cancer on the Parents’ Relationship**
Lori Wiener, Ph.D. — Co-Director, Behavioral Health Core, Pediatric Oncology Branch, Center for Cancer Research, NCI, NIH

**Session Wrap-up**
Commander Margaret Bevans, Ph.D., R.N., AOCN®, FAAN

3:15 p.m. **Wrap-Up**

3:30 p.m. **Adjourn**