



# Invited Participants

## ISPOR 7<sup>th</sup> Patient Representatives Roundtable

(Supported by Merck, Pfizer and Takeda)

Monday, May 22, 2017 – 12:30 PM – 5:00 PM

John B. Hynes Veterans Memorial Convention Center – Room 200

Boston, MA, USA

### Patient Representatives

#### North America

**Alice Bast, BS**

Chief Executive Officer

**Beyond Celiac**

Ambler, PA, USA

**Liz Bevilacqua**

Associate Director, Alliance Management & Member Relations

**T1D Exchange**

Boston, MA, USA

**Louise Binder**

Health Policy Consultant

**Save Your Skin Foundation**

Toronto, Canada

**Tim Boyd**

Director of State Policy

**National Organization for Rare Disorders (NORD)**

Washington, DC, USA

**Donna Cryer, JD**

President and CEO

**Global Liver Institute**

Washington, DC, USA

**Mary B. Dwight**

Senior Vice President for Policy and Patient Assistance Programs

**Cystic Fibrosis Foundation**

Washington, DC, USA

**Megan Feeney, MPH**

Manager, Community Engagement

**Parkinson's Foundation**

New York, NY, USA

**Elizabeth Franklin, LGSW, ACSW**

Senior Director, Policy and Advocacy

**Cancer Support Community**

Washington, DC, USA



**Pat Furlong**

Founding President and CEO

**Parent Project Muscular Dystrophy (PPMD)**

Middletown, OH, USA

**Robert McBurney, PhD, BSc**

Chief Executive Officer, **Accelerated Cure Project for Multiple Sclerosis**

Founder and Director, **Optimal Medicine Ltd.**

Waltham, MA, USA

**Allison Moore**

Founder and CEO

**Hereditary Neuropathy Foundation**

New York, NY, USA

**Lisa Schill**

Vice President

**RASopathies Network USA**

New Jersey, USA

**Suzanne Schrandt, J.D.**

Chair, Patient Representative Roundtable, **ISPOR**

Director, Patient Engagement, **Arthritis Foundation**

Atlanta, GA, USA

**Maureen Smith, M. Ed.**

Patient Member, **Ontario Committee to Evaluate Drugs**

Patient Member, **Ontario Health Technology Advisory Committee**

Secretary, **Canadian Organization for Rare Disorders (CORD)**

Ontario, Canada

**Durhane Wong-Rieger**

President and CEO

**Canadian Organization for Rare Diseases (CORD)**

Toronto, ON, Canada

**Latin America**

**Angela Chaves, JD**

President

**Colombian Federation of Rare Diseases (FECOER)**

Colombia

**Migdalia Denis**

President, **Latin America Pulmonary Hypertension Society**

Board Member, **International Alliance of Patients' Organizations (IAPO)**

Venezuela



### Patient Focused Organizations

**Chinenye Anyanwu, PharmD, MPH**

Patient Engagement Officer

**Patient-Centered Outcomes Research Institute (PCORI)**

Washington, DC, USA

**Marcy Fitz-Randolph**

Manager, Research Operations

**PatientsLikeMe**

Cambridge, MA, USA

**Kim McCleary**

Managing Director, Strategic Initiatives

**FasterCures**

Washington, DC, USA

### Research Stakeholder Representatives

**John F. P. Bridges, PhD**

Associate Professor

**Johns Hopkins Bloomberg School of Public Health**

Baltimore, MD, USA

**Nancy Devlin, PhD**

Director, **ISPOR Board of Directors**

Director of Research, **Office of Health Economics**

London, UK

**Manuel Espinoza, MD, MSc, PhD**

Director, **ISPOR Board of Directors**

Professor, Department of Public Health & Chief, HTA Unit, **Catholic University of Chile**

Honorary Visiting Fellow, Centre for Health Economics, **University of York**

Santiago, Chile and York, UK

**Ken Getz, MBA**

Director of Sponsored Research, **Tufts Center for the Study of Drug Development (CSDD)**

Founder, **Center for Information & Study on Clinical Research Participation (CISCRP)**

Boston, MA, USA

**Matthew Harker**

Associate Director Health Policy

**Duke Margolis Center**

Washington, DC, USA



### **Eleanor Perfetto, PhD, MS**

Leadership Member, Patient Centered Special Interest Group, **ISPOR**  
Senior Vice President, Strategic Initiatives, **National Health Council**  
Professor, Pharmaceutical Health Services Research, **University of Maryland - School of Pharmacy**  
Baltimore, MD, USA

### **Shelby D. Reed, RPh, PhD**

President-Elect (2016-2017), **ISPOR Board of Directors**  
Professor, **Duke University**  
Durham, NC, USA

### **Europe**

#### **Sandra Nestler-Parr, PhD, MSc**

Co-Chair, Rare Disease Special Interest Group, **ISPOR**  
Head of Rare Diseases, **Roboleo & Co**  
Trustee, Strategy and External Relations, **Alpha-1 UK Support Group**  
London, United Kingdom

### **Government Representatives**

#### **Martin Ho, MS, PhD**

Associate Director, Quantitative Innovation, Center for Devices and Radiological Health (CDRH)  
**US Food and Drug Administration**  
Silver Spring, MD, USA

#### **Megan Moncur, MS**

Scientist, Center for Biologics Evaluation and Research (CBER)  
**US Food and Drug Administration**  
Silver Spring, MD, USA

#### **Anindita Saha**

Director, External Expertise and Partnerships, Center for Devices and Radiological Health (CDRH)  
**US Food and Drug Administration**  
Silver Spring, MD, USA

#### **Million Tegenge, PhD**

Scientist, Center for Biologics Evaluation and Research (CBER)  
**US Food and Drug Administration**  
Silver Spring, MD, USA

### **Payer Representatives**

#### **Sean Karbowicz, PharmD**

General Manager  
**MedSavvy**  
Portland, OR, USA



**John Watkins, PharmD, MPH, BCPS**  
Director, **ISPOR Board of Directors**  
Pharmacy Manager, Formulary Development, **Premera Blue Cross**  
Mountlake Terrace, WA, USA

**Karen Worley, PhD**  
Research Leader, Comprehensive Health Insights  
**Humana, Inc.**  
Cincinnati, OH, USA

### **Industry Stakeholder Representatives**

**Jill A. Bell, PhD**  
Associate Director, Global Outcomes Research  
**Takeda Oncology, Takeda Pharmaceuticals International, Inc.**  
Cambridge, MA, USA

**Sachin Kamal-Bahl, PhD**  
Vice President and Head - Innovation Center, Global Health and Value  
**Pfizer Inc.**  
Collegeville, PA, USA

**Allison Martin Nguyen**  
Senior Principal Scientist, CORE-Patient Reported Outcomes & Study Endpoints (PRO&SE)  
**Merck**  
North Wales, PA, USA

**Vanessa Perez, PhD**  
Associate Director, Global Outcomes Research  
**CNS Therapeutic Area, Takeda Development Center Americas, Inc.**  
Deerfield, IL, USA

### **ISPOR Staff – Lawrenceville, NJ, USA**

**Nancy Berg**, CEO and Executive Director  
**Nadia Naaman**, Senior Director, Scientific & Health Policy Initiatives  
**Theresa Tesoro, MSN**, Associate Director, Scientific & Health Policy Initiatives  
**Clarissa Cooblall, MPH**, Manager, Scientific & Health Policy Initiatives