



The professional society for health
economics and outcomes research

Improving healthcare decisions

Invited Participants

ISPOR 10th Patient Representatives Roundtable [North America]

(Supported by Merck, Pfizer, and Takeda)

Monday, May 21, 2018 – 12:00PM – 4:45PM

Baltimore Convention Center

Baltimore, MD, USA

Patient Representatives:

Catherine Davis Ahmed, MBA

Vice President, Policy and Outreach

The FH (Familial Hypercholesterolemia) Foundation

Pasadena, CA, USA

Gail Attara

Co-founder and President

GI Society: Canadian Society of Intestinal Research

Vancouver, BC, Canada

Alice Bast, BS

Chief Executive Officer

Beyond Celiac

Ambler, PA, USA

Angela Chaves, JD

Chair, Patient Representative Roundtable – Latin America, **ISPOR**

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

Bogota, Colombia

Cindy Coney, MEd, BSc

President and Patient Advocate

Monarch Training and Consulting

Tampa, FL, USA

Ratna Devi, MBA, MBBS

CEO and Co-founder, **Dakshama Health and Education**

Board member, **International Alliance of Patients' Organizations**

New Delhi, India

Elizabeth Franklin, LGSW, ACSW

Senior Director, Policy and Advocacy

Cancer Support Community

Washington, DC, USA

Invited Participants

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

Paul Melmeyer, MPP

Director of Federal Policy

National Organization for Rare Disorders (NORD)

Washington, DC, USA

Kelly D. Myers

Chief Technology Officer

The FH (Familial Hypercholesterolemia) Foundation

Pasadena, CA, USA

Lisa J. Pieretti, MBA

Founder and Executive Director

International Hyperhidrosis Society

Flemington, NJ, USA

Suzanne Schrandt, JD

Chair, Patient Representative Roundtable – North America, **ISPOR**

Director, Patient Engagement, **Arthritis Foundation**

Atlanta, GA, USA

Leonard Schwartz, JD

Patient-Centered Research Advocate

Parkinson's Disease Foundation

Baltimore, MD, USA

Maureen Smith, MEd

Patient Member, **Ontario Committee to Evaluate Drugs; Ontario Health Technology Advisory Committee**

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

Ontario, Canada

Yu Wang, MB, PhD

Data Scientist, Real-World Evidence

The LifeRaft Group - GIST

Wayne, NJ, USA

Invited Participants

Lorna Warwick

Director, Strategic Communications and Engagement

Lymphoma Coalition

Mississauga, ON, Canada

Durhane Wong-Rieger

President and CEO

Canadian Organization for Rare Diseases (CORD)

Toronto, ON, Canada

Academicians/Researchers/Collaborators:

Ricky C. Brathwaite, PhD, MS, MSHS

Director, Health Economics

Bermuda Health Council

Hamilton, Bermuda

Laurie Burke, MPH

Affiliate Associate Professor

University of Maryland – School of Pharmacy

Royal Oak, MD, USA

Stephanie Christopher, MA

Program Director

Medical Device Innovation Consortium (MDIC)

Arlington, VA, USA

Cynthia Grossman

Director, Science of Patient Input

FasterCures

Washington, DC, USA

Zachary Hallinan

Project Manager

Clinical Trials Transformative Initiative (CTTI)

Durham, NC, USA

Rachel Harrington

Chair, Patient Centered Special Interest Group, **ISPOR**

PhD Candidate, Dept. of Pharmacy Systems, Outcomes, & Policy, **University of Illinois at Chicago**

Chicago, IL, USA

Invited Participants

Sandra Nestler-Parr, PhD, MSc

Managing Director, **Rare Access Ltd.**
Trustee, **Alpha-1 UK Support Group**
London, United Kingdom

Eleanor Perfetto, PhD, MS

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, PhD, RPh

Professor, **Duke University**
Durham, NC, USA

Lisa Stewart, MA

Patient Engagement Officer
Patient-Centered Outcomes Research Institute (PCORI)
Washington, DC, USA

Sara Traigle van Geertruyden, JD

Executive Director
Partnership to Improve Patient Care (PIPC)
Washington, DC, USA

Government Representatives:

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

Pujita Vaidya, MPH

Director (Acting), Decision Support and Analysis Team, Office of Strategic Programs/Office of Program and Strategic Analysis, Center for Drug Evaluation and Research (CDER)
US Food and Drug Administration
Silver Spring, MD, USA

Invited Participants

HTA/Payer Representative:

Suzanne Belinson, PhD

Executive Director

Blue Cross and Blue Shield Association

Chicago, IL, USA

Professor Finn Børlum Kristensen, MD, PhD

Professor, Faculty of Health Sciences

University of Southern Denmark

Odense, Denmark

Brian O'Rourke, PharmD

President and Chief Executive Officer

Canadian Agency for Drugs and Technologies in Health (CADTH)

Ottawa, ON, Canada

John Watkins, PharmD, MPH, BCPS

Pharmacy Manager, Formulary Development

Premera Blue Cross

Mountlake Terrace, WA, USA

Kevin Wilson

Vice President, Population Health

Saskatchewan Cancer Agency

Regina, SK, Canada

Karen Worley, PhD

Research Leader, Comprehensive Health Insights

Humana, Inc.

Cincinnati, OH, USA

Industry Representatives:

Aaron Galaznik, MD

Senior Director, Global Outcomes & Epidemiology Research

Takeda Oncology

Cambridge, MA, USA

Sachin Kamal-Bahl, PhD

Vice President and Head of the Global Health and Value Innovation Center

Pfizer Inc.

Collegeville, PA, USA

Invited Participants

Cristina Masseria, MSc, PhD

Methods & Capabilities Lead, PHI

Pfizer Inc.

New York, NY, USA

Allison Martin Nguyen

Senior Principal Scientist, Patient-Centered Endpoints & Strategy (PaCES)

Merck

North Wales, PA, USA

Fatima Scipione

Senior Director, Patient Advocacy

Takeda Oncology

Cambridge, MA, USA

ISPOR Staff – Lawrenceville, NJ, USA

Richard Willke, PhD, Chief Science Officer

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

Robert Selby, MBA, Director, Global Networks (Asia-Pacific)