



# ISPOR PATIENT REPRESENTATIVES ROUNDTABLE

## ISPOR 6<sup>th</sup> Patient Representatives Roundtable

(Supported by Novartis, Pfizer and Roche)

Monday, 31 October 2016, 12:30 – 17:00

*ISPOR 19<sup>th</sup> Annual European Congress - Vienna, Austria*

### List of Participants

#### PATIENT REPRESENTATIVES

**Biljana Dodeva-Hristovska**

President

**BORKA**

Skopje, Macedonia

**Dominique Hamerlijnc**

Patient Representative

**Lung Foundation Netherlands (Longfonds)**

Amersfoort, the Netherlands

**Marleen M. Kaatee**

Founding President

**PSC Patients Europe**

Bennebroek, the Netherlands

**Alastair Kent**

Director

**European Genetic Alliance Network (EGAN)**

London, UK

**Michael Längsfeld**

Working Group Head Choroideremia / Head of Department Regional Groups, **Pro Retina Germany**

Member of Board of Directors, **Choroideremia Research Foundation United States of America**

Bad Nauheim, Germany

**Zorana Maravic**

Director, Group and Project Development

**EuropaColon**

Belgrade, Serbia

**Robert McBurney, PhD, BSc**

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

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

Waltham, MA, USA

**Jamie O'Hara**

Chairman Health Economics

**European Haemophilia Consortium (EHC)**

Brussels, Belgium

**Ananda Plate**

Operations Manager

**Myeloma Patients Europe**

Brussels, Belgium

**Chris Sotirelis**  
Trustee Advisor  
**UK Thalassaemia Society (UKTS)**  
London, United Kingdom

**Russell Wheeler**  
Patient Advocate  
**Leber's Hereditary Optic Neuropathy**  
Merusac, France

#### **PATIENT-FOCUSED ORGANIZATIONS**

**Nicola Bedlington**  
Executive Director  
**European Patients' Forum**  
Vienna, Austria

**Rob Camp**  
Communications Manager  
**European Patients' Academy on Therapeutic Innovation (EUPATI)**  
Barcelona, Spain

**Jan Geissler**  
Chair / Co-Founder, **CML Advocates Network**  
Founder and CEO, **Patvocates**  
Director, **European Patients' Academy on Therapeutic Innovation**  
Munich, Germany

**Witold Michalek**  
Director  
**Polish Patient Federation**  
Warsaw, Poland

**Flóra Raffai**  
Executive Director  
**Findacure**  
Cambridge, UK

#### **RESEARCH STAKEHOLDER PARTICIPANTS**

**Todd Berner, MD**  
Co-Chair, **ISPOR Patient-Centered Special Interest Group**  
Medical Director, Head Global Medical Affairs Strategy, Immunology, **Baxalta, Inc.**  
Bannockburn, IL, USA

**Sandra Nestler-Parr, PhD, MSc**  
Head of Rare Diseases, **Roboleo & Co**  
Trustee, Strategy and External Relations, **Alpha-1 UK Support Group**  
London, United Kingdom

**Lisbeth Ørtenblad**  
HTA and Health Services Research, DEFACTUM – Public Health and Health Services Research  
**Central Denmark Region**  
Aarhus, Denmark

**Eleanor Perfetto, PhD, MS**

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

Senior Vice President, **Strategic Initiatives, National Health Council**

Professor, Pharmaceutical Health Services Research, **University of Maryland - School of Pharmacy**  
Baltimore, MD, USA

**Gurmit Sandhu, BPharm (Hons), MBM, MPH**

Member, **ISPOR Code of Ethics**

Patient Engagement Specialist, **Gurmit Sandhu Consulting GbmH**

Basel, Switzerland

**Jessica Santos, PhD**

Co-chair, **ISPOR Code of Ethics**

Global Compliance and Quality Director, **Kantar Health**

Cambridge, Wales, UK

**PAYER STAKEHOLDER PARTICIPANTS**

**Francis Arickx**

Head, Directorate Pharmaceutical Policy

**National Institute for Health and Disability Insurance (RIZIV INAMI)**

Brussels, Belgium

**Dragana Atanasijevic, MD**

Director, Pharmacoeconomics

**National Health Insurance Fund of Serbia**

Belgrade, Serbia

**Ingrid Wilbacher, PhD**

Senior Researcher, Department for Evidence Based Economic Health Care

**Main Association of Austrian Social Security Institutions**

Vienna, Austria

**REGULATORY AND HTA STAKEHOLDER PARTICIPANTS**

**Michael Barry, MD, PhD, FRCPI**

Clinical Director, National Centre for Pharmacoeconomics

**St. James's Hospital**

Dublin, Ireland

**François Meyer, MD**

Advisor to the President, International Affairs

Director, Health Technology Assessment Division

**Haute Autorité de Santé (HAS)**

Saint-Denis La Plaine, France

**Alric Rüther, MD, PhD**

Head of Department of Health Care Quality

**Institute for Quality and Efficiency in Health Care (IQWiG)**

Cologne, Germany

**Victoria Thomas, MSc**

Head, Patient and Public Involvement Program

**National Institute for Health and Care Excellence (NICE)**

London, United Kingdom

**Sara Twaddle, PhD**  
Director of Evidence  
**Healthcare Improvement Scotland**  
Glasgow, Scotland

**INDUSTRY STAKEHOLDER PARTICIPANTS**

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

**Ivana Cattaneo**  
Director Market Access and External Affairs  
Rare Disease Franchise; Oncology Region Europe  
**Novartis Farma S.p.A.**  
Origgio, Italy

**Donatella Decise**  
Head, Patient Strategy Solid Tumors  
Oncology Region Europe  
**Novartis Farma S.p.A.**  
Origgio, Italy

**Dr. Claudine Sapede, Pharm.D, MSc**  
Global HTA and Payment Policy Lead  
**F. Hoffmann-La Roche Ltd**  
Basel, Switzerland

**ISPOR BOARD MEMBER**

**John Watkins, PharmD, MPH, BCPS**  
Pharmacy Manager, Formulary Development  
**Premera Blue Cross**  
Mountlake Terrace, WA, USA

**Nancy Devlin, PhD**  
Director of Research  
**Office of Health Economics (OHE)**  
London, United Kingdom

**Manuel Espinoza, MD, MSc, PhD**  
Professor, Department of Health and Chief, HTA Unit  
**Catholic University of Chile**  
Santiago, Chile

**ISPOR STAFF – LAWRENCEVILLE, NJ, USA**

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