Partnering to improve real-world outcomes that matter to patients

Patient Engagement & Experience

16 & 17 May 2018 | Hotel Casa Amsterdam
Your prestigious speaker panel

**Wim Goettsch**  
ZIN, Netherlands  
Director EUnetHTA

**Sarah Richards**  
NICE, UK  
Technical Analyst

**Jason DeGoes**  
Teva, Netherlands  
Senior Vice President Global Patient Solutions

**Przemyslaw Kardas**  
Medical University of Lodz, Poland  
Head of the Department Family Medicine

**Andreas Christodoulou**  
EPF’s Youth Group, Cyprus  
President

**Silvia Bakkers**  
Janssen - J&J, Netherlands  
Director Value-Based Healthcare

**Robert Thomas**  
Cambridge University Hospitals, UK  
Consultant Oncologist and Professor of Biological and Exercise Science

**Ana Maria Arboleda**  
Teva, Spain  
Director of European Operations, Patient Solutions

**Annamarie Dillon**  
ProQR Therapeutics, Netherlands  
Senior Director, Patient & Medical Community Engagement

**Marleen Kaatee**  
PSC Patients Europe, Netherlands  
Founding President

**Grainne Crowley**  
Biogen, Belgium  
Head Patient Advocacy Europe & Canada  
(to be confirmed)

**Wendy Olser**  
Netherlands  
Board Member of Youth-R-Well.com and representative of Young PARE

**Andreas Christodoulou**  
EPF’s Youth Group, Cyprus  
President

**Martynas Gedminas**  
Lithuania  
Chairman Junior Doctors Association

**Ana Maria Arboleda**  
Teva, Spain  
Director of European Operations, Patient Solutions

**Veerle Aertsens**  
EUPATI Fellow, Belgium  
Co-chair and spokesperson for Eupati Expert Parkinson’s Disease Patient

**Stefan Florentinus**  
AbbVie, Netherlands  
Medical Director  
Chair of the project group at the Dutch Association of Innovative Medicine

**Jessica Leygues**  
Celgene, France  
Patient Associations and Patient Institutional Programs Manager

**Alexandra Moutet**  
UCB, Belgium  
Global Head of Patient Affairs

**Vanessa Ferreira**  
Santhera, Switzerland  
Head Patient Advocacy Europe

**Geoff Rollason**  
Pfizer, UK  
Patient Experience & Service Director Oncology

**Stefan Florentinus**  
AbbVie, Netherlands  
Medical Director  
Chair of the project group at the Dutch Association of Innovative Medicine

**Anna Szopa**  
J&J, Poland  
Head of Patient Advocacy & Engagement

**Michaela Dinboeck**  
Novartis, Switzerland  
Senior Director, Group Patient Advocacy & Communications

**Dawn Richards**  
Canadian Arthritis Patient Alliance, Canada  
Vice President, Director of Patient & Public Engagement, Clinical Trials Ontario

**Ruth Wilson**  
Teva, Netherlands  
Global Head of Patient Advocacy

**Richard Jones**  
The EarthWorks, UK  
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**Esther Wong**  
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Remarks from the conference chairman:

Søren Skovlund
Denmark
Chief Patient Officer, Drugstars
Senior Research Scientist, Aalborg University, Denmark

‘The “Patient Adherence and Engagement” conference, organized in May 2017 in Amsterdam, provided a fantastic platform for collaborative discussion amongst internationally leading patient advocates, patient organizations, payers, pharma, regulators, health technology companies and adherence researchers.

The unique focus of this event was the convergence points for “patient adherence and patient engagement” - a focus which turned out to be very timely and appropriate for all involved.

We believe that the way forward is to define, strengthen and unify the field of multi-disciplinary scientific research for medicine optimization.

Let’s meet again together with different stakeholders in May 2018 in Amsterdam to further establish the best wins that can be gained through partnering with patients as equal partners across the value chain to improve the real-world use of medicines.’

Key topics
- Effective methods and tools for patient engagement
- Evidence-based strategies for patient activation and motivation
- Maximizing patient experience across the health care continuum
- Building and deploying sustainable patient support programmes
- Multi-stakeholder collaboration for people-centred healthcare
- Patient-centric use of digital health, big data analytics and mobile technologies

Key take-aways:
- Keys to overcome legal, compliance and regulatory challenges for effective patient engagement
- Best practices to partner with payers and patient advocacy groups
- Increasing patient voice in decision making
- Tips for patient activation
- Applying evidence to real-world settings
- Measuring patient outcomes and the business value of patient support programs
- Next steps to achieve an integrated approach to patient support strategy in a fragmented multi-stakeholder environment
- Innovation in drug design and packaging for greater patient adherence
- Examples of tools for utilizing digital engagement
- Defining critical actions to maximize patient experience
- Shaping the roles of different stakeholders to improve patient outcomes
- Guiding patients through the complexity and variety of different patient services

Special features
- HCPs, Patients, Payers, Government, Pharmacists and Industry under one roof
- 360 Multi-stakeholder Breakout Discussions
- On-stage interview
- Patient Engagement Panel

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DAY 1  
16 May 2018

8:30  Registration & morning coffee

9:00  Welcoming note from Fleming.

9:05  Opening remarks from the chair

From adherence to improved patient outcomes

9:10  **KICK-OFF PANEL:** Defining the "burning platform": A multi-stakeholder call to action to improve the real world use of medicines for better patient outcomes

- What is the urgent case for action across different stakeholders?
- Key factors influencing optimal real world use of medicines
- Discuss & define shared challenges, goals and expectations across stakeholders

**PANELISTS:**

- **Silvia Bakkers**, Janssen - J&J, Netherlands, Director Value Based Healthcare
- **Marleen Kaatee**, PSC Patients Europe, Netherlands, Founding President
- **Søren Skovlund**, Drugstars, Denmark, Chief Patient Officer
- **Michaela Dinboeck**, Novartis, Switzerland, Senior Director, Group Patient Advocacy & Communications

9:40  **KEYNOTE:** How to embed patient-reported outcome measurements in a pragmatic way in value-based health care and what do we really want to achieve with it?

- Which PROMs are of what use to which patient and when? The threat of paralysis by analysis!
- Who else than the patient him-/herself can benefit from a better and real-time focus on PROM's?
- Value-based health-care as merely a stepping stone towards transparent, data-driven, subjective well-being

**Silvia Bakkers**, Janssen - J&J, Netherlands, Director Value-Based Healthcare

11:00 **CASE STUDY:** Partnering to improve the outcomes that matter to patients

- Exploring patient engagement strategies in the outcomes-based healthcare
- Defining the expected outcomes and measures
- KPIs and measuring the impact on patient outcomes
- Examples of tools to engage patients and achieve better outcomes

**Ruth Wilson**, Teva, Netherlands, Global Head of Patient Advocacy

11:30 **HCP’S VIEW:** Patient involvement in clinical research is essential to create successful and relevant lifestyle strategies

- Exploring real-world scientific research
- A greater understanding of patient needs allows the development of lifestyle strategies to empower patients with the evidence to make informed lifestyle choices
- Benefits of involving patients in the design of trials

**Robert Thomas**, Cambridge University Hospitals, UK, Consultant Oncologist and Professor of Biological and Exercise Science

12:00 **BREAKOUT DISCUSSION:** Industry & patient views: The way forward - Effective tools & approaches for better patient outcomes

- Patient-centric approaches to improving patient outcomes
- Moving from a Declaration to a Commitment – Novartis success story
- Embedding patient views into daily work of the entire organization
- Measuring the impact on patient outcomes, society and business value

**Lode Dewulf**, Servier, Belgium, Chief Patient Officer

**Michaela Dinboeck**, Novartis, Switzerland, Senior Director, Group Patient Advocacy & Communications

12:30 Luncheon
Value-based partnering

14:00 Patients as partners
- Co-creation & increasing patient voice in decision making
- Overcoming compliance and legal challenges (transparency, data privacy) – tips
- Collaboration perspective – what kind of new partnership is driving progress for real-world patient impact?
- Measuring the success and patient impact

Alexandra Moutet, UCB, Belgium, Global Head of Patient Affairs
Marleen Kaatee, PSC Patients Europe, Netherlands, Founding President

14:50 Afternoon tea & networking

15:20 Maximizing the patient experience across the healthcare as a whole - Where and how do all stakeholders step in?
- Sharing responsibility – taking charge of your health
- Collaborative work with patients & families – communication and interventions based on a patient type
- Empowering the patients for optimal treatment decisions
- The real informed consent
- Opportunities for improved adherence and outcomes – success factors for optimizing RW use of medicines
- Exploring the role of a prescribing pharmacist in the UK
- Optimising patient therapy though pharmacist led clinics
- Examples – a doctor’s, nurse’s, pharmacist’s and industry view

Martynas Gedminas, Lithuania, Chairman Junior Doctors Association
Geoff Rollason, Pfizer, UK, Patient Experience & Service Director Oncology
Esther Wong, Chelsea and Westminster Hospital, UK, Pharmacist

16:10 The power of words: changing patient behaviors
- Using behaviour change theories to shape content
- Reframing positive and negative messaging
- Engaging patients in content creation

Richard Jones, The EarthWorks, UK, Managing Director

16:40 Value-based Patient Support Programs
- featuring industry and patient views
- Designing & implementing sustainable patient support programs
- PSP ownership
- How to partner with other stakeholders for optimal implementation
- Planning & execution of PSP – driving awareness about a PSP
- Measuring the value of PSPs
- Patient feedback – what does a PSP bring to me?
- Results & outcomes achieved

Grainne Crowley, Biogen, Belgium, Head Patient Advocacy Europe & Canada (to be confirmed)
Jessica Leygues, Celgene, France, Patient Associations and Patient Institutional Programs Manager
Veerle Aertsen, EUPATI Fellow, Belgium
Co-chair and spokesperson for Eupati Expert Parkinson’s Disease Patient
Wendy Olsder, Netherlands, Board Member of Youth-R-Well.com and representative of Young PARE

17:30 BREAKOUT DISCUSSION: Action planning for multi-stakeholder collaboration for better outcomes
- Primary and secondary non-adherence, reasons for non-adherence
- Personalization of the PSP programs
- The most effective strategies for working together with other stakeholders to improve outcomes
- PSP ownership – accountability and responsibilities/roles of all stakeholders
- Measuring the value of PSPs

Ana Maria Arboleda, Teva, Spain
Director of European Operations, Patient Solutions

18:00 Evaluation of Day 1 and conclusions
Speakers & delegates are cordially invited to attend a Networking Cocktail Reception
8:30 Registration & morning coffee

9:00 Opening remarks from the chair

Patient Involvement in HTA and Payers Decisions

9:10 On-stage interview – Optimizing patient involvement in decision-making bodies

Veerle Aertsen, EUPATI Fellow, Belgium
Co-chair and spokesperson for Eupati
Expert Parkinson's Disease patient
Wim Goettsch, ZIN, Netherlands
Director EunetHTA
Andreas Christodoulou, EPF's Youth Group, Cyprus, President
Sarah Richards, NICE, UK, Technical Analyst

9:40 Patient involvement in EUnetHTA activities

Wim Goettsch, ZIN, Netherlands
Director EunetHTA

10:10 PAYER’S VIEW: Outcomes-based people-centric healthcare – success factors

• Evidence-based strategies to measure outcomes
• Including the patient's voice in the payer's decision
• Tackling adherence & treatment cost-effectiveness
• Steps to achieve shared goals
Sarah Richards, NICE, UK, Technical Analyst

10:40 Morning coffee & networking

11:10 Effective Patient Engagement

Quality guidance for effective patient engagement: Outcomes from the Patient Focused Medicines Initiative (PFMD)

• Key guiding criteria for effective patient engagement
• Good practices and key learnings
• Patient engagement tools and resources
• Multi-stakeholder expectations to patient engagement

Dawn Richards, Canadian Arthritis Patient Alliance, Canada, Vice President, Director of Patient & Public Engagement, Clinical Trials Ontario
Søren Skovlund, Denmark, Chief Patient Officer, Drugstars, Senior Research Scientist, Aalborg University, Denmark

11:50 THE YOUTH FACTOR: The value of engaging with the next generation of empowered patients

• Understanding patient engagement
• Creating a culture of engagement in young adults and children
• Project: EPF’s STYPA
Andreas Christodoulou, EPF’s Youth Group, Cyprus, President

12:20 CODE OF CONDUCT: Cooperation with patients and patient organisations

• Compliance, governance and legal framework of patient engagement
• Ways to engage - avenues, methods and strategies
• Strategies for patient activation & motivation
Stefan Florentinus, AbbVie, Netherlands, Medical Director, Chair of the project group at Duch Association Innovative Medicine

12:50 Luncheon
13:50 **CASE STUDY: Patient engagement in rare diseases R&D**
- Patient centric approach to R&D
- Opportunities and challenges for engagement—a young biotech perspective
- Examples of methods for effective patient engagement

**Annamarie Dillon, ProQR Therapeutics, Netherlands, Senior Director, Patient & Medical Community Engagement**

14:20 **CASE STUDY: Key learnings from a patient-centric activity in the development and lifecycle of medicines led by Santhera Pharmaceuticals**
- Defining ways to engage with patient advocacy groups that represent Duchenne Muscular Dystrophy (DMD)
- Identifying projects that serve the DMD patient groups needs
- Impact of an International DMD Patient Group advisory board on company decisions
- Final recommendations transferable across rare diseases

**Vanessa Ferreira, Santhera, Switzerland**
*Head Patient Advocacy Europe*

14:50 **BREAKOUT DISCUSSION: Engaging & empowering patients**
- Navigating patients in a fragmented environment
- The new role of patients
- Shaping the future

**Jason DeGoes, Teva, Netherlands, Senior Vice President Global Patient Solutions**
**Ruth Wilson, Teva, Netherlands, Global Head of Patient Advocacy**
**Anna Szopa, J&J, Poland, Head of Patient Engagement & Advocacy**
**Andreas Christodoulou, EPF’s Youth Group, Cyprus, President**
**Annamarie Dillon, ProQR Therapeutics, Netherlands, Senior Director, Patient & Medical Community Engagement**
**Wendy Olsder, Netherlands, Board Member of Youth-R-Well.com and representative of Young PARE**

15:30 **Afternoon tea & networking**
DAY 2
17 May 2018

16:00 **CASE STUDY: Skills4Adherence Project – Improving patient adherence in the elderly**
- Interventions to improve patient adherence in the elderly
- Interventions to prevent polytherapy in the elderly
- Motivating the elderly to take action to improve adherence to therapeutic recommendations and to prevent polytherapy

**Przemyslaw Kardas, Medical University of Lodz, Poland, Head of the Department, Department of Family Medicine**

16:30 **Digital adherence solutions**
- Engagement possibilities brought by digital solutions – overcoming challenges in real life application
- Utilizing real-time data
- Utilizing digital tools in clinical research and clinical practice to inform decision-making
- How to measure patient engagement via digital channels

17:00 **How digital & mobile improve the patient experience**
- Leveraging digital and mobile technologies to better connect with and engage patients
- Balancing technology with the personal touch
- KPIs and measures for digital patient engagement
- Utilizing big data and analytics for better & personalized patient services

17:30 **WRAP-UP DISCUSSION: Joining forces and integrated approach**
- Revisiting the outputs from previous breakout discussions
- Defining top priority actions
- Concrete actions & steps for the upcoming year
- Defining measurement of the progress related to key actions & to the overall aim of improving real world patients outcomes and real world use of medicines

18:00 Evaluation of the day & closing remarks from the chair

I would like to thank everyone who has helped with the research and organization of this event, especially the speakers, for their support and commitment.

**Dasa Janosikova, Production Manager Life Sciences**
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