DAY ONE - TUESDAY, JANUARY 23, 2018

8:00 am
Registration & Breakfast

8:45 am
Chair's Opening Remarks
Tony Hoos, MD, PhD, MBA
Head of Medical, **Amgen Europe**

9:00 am
How to Get the Patient More Involved in Medicines Development: A Multi-stakeholder POV on What Good Patient Involvement Looks Like
This multi-stakeholder panel will address:

- How have best practices advanced in 2017?
- What does good patient practice look like?
- What approaches have been successful? What does this success look like?
- Update on the quality of patient involvement in:
  - Drug development
  - Licensing
  - Reimbursement

Moderator:
Tony Hoos, MD, PhD, MBA
Head of Medical, **Amgen Europe**

Panelists:
Sharon Allin
Senior Manager, Feasibility, Enrollment and Retention Optimization, **Biogen**

Jan Geissler
Director, **EUPATI**

David Haerry
European AIDS Treatment Group (EATG)

Bettina Ryll, PhD
Founder, **Melanoma Patient Network Europe**

9:30 am
How to Make Patient Involvement Systemic and Sustainable Throughout Medicines Development
To prevent ticking off a box and to ensure that patient involvement is systemic and sustainable, we have to move into patient-centricity 2.0. What does this mean and how to do this so we can turn the patient voice into value, impact and benefit? This session demonstrates best practices from Hoffman La Roche, Melanoma Patient Network, Patient Focused Medicines Development and European Patients Forum.

Nicola Bedlington
Secretary General, **European Patients Forum**

Nicholas Brooke
Chief Executive, **Patient Focused Medicines Development (PFMD)**

Irmi Gallmeier
Senior International Health Policy Leader, Patient Relations, **F. Hoffman La Roche**

Bettina Ryll, PhD
Founder, **Melanoma Patient Network Europe**

10:10 am
CISCRP's Global Assessment of Patient Perceptions of Clinical Research - A Stakeholders Call to Action
Every two years since 2013, CISCRP has collaborated with key stakeholders to monitor trends and identify opportunities to better inform and engage the public and patients as partners in the clinical research enterprise.
Topics addressed include:

1. Views on the risks, benefits, and safety of clinical research
2. An assessment of general awareness & comprehension
3. The impact of a well-informed healthcare professional on perceptions
4. The clinical trial volunteer experience.

In this session, Annick Anderson, Director of Research Services reports on the 2017 Perceptions & Insights study findings and describes how industry stakeholders can leverage the insights to make a difference. For example:

- Raising awareness and shaping perceptions among patients - a strategy for all stakeholders to engage local healthcare professionals in the process
- The impact of educational initiatives on the value of clinical research - when to implement and who should lead?
- Close the loop to maintain patient engagement after participation with patient access to study results
- Nullify lost enrollment opportunities - better communicate why patients don't qualify for a study

Annick Anderson
Director, Research Service, **CISCRP**

10:50 am
Networking Break

11:20 am
Patient Engagement and Partnering Along the Medicine Life Cycle Continuum
In this session, Dr Alexandra Moutet, Global Head of Patient Affairs at UCB, will walk the audience through how they've incorporated the patient into every stage of the medicine life cycle and how this has enhanced their development strategy. Key focus areas will include:

- UCB's roadmap to holistic patient engagement
- Differentiating between patient engagement and patient experience
- Review of tools used

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

11:45 am
How to Implement Patient Opinion Leader Advisory Boards in the Drug Development Continuum

- What does it take to create a council?
- Criteria for selecting the right patients
- Understanding the role of the patient
- Knowing the right patient for clinical and commercial programs
- Factors for consideration

Jennifer Kelly
VP, **HealthiVibe LLC**

12:00 pm
Case Study: The Impact of a Patient Advisory Board at Santhera Pharmaceuticals
In this session, Dr Vanessa dos Reis Ferreira, Patient Advocacy Manager at Santhera Pharmaceuticals will walk the audience through how they implemented a first time patient advisory board and why it was so impactful.

- The creation of the vision, buy-in and support across divisions
- Challenges, obstacles and getting through them
- Impact on company decisions post the patient advisory group
- Be prepared for and encourage honest feedback from patients
- Recommendations

Vanessa dos Reis Ferreira, PhD MBA
Patient Advocacy Manager, **Santhera Pharmaceuticals**

12:30 pm
Lunch

1:30 pm
Pfizer Case Study TBD
David Leventhal, MBA
Director, Clinical Innovation, Worldwide R&D, **Pfizer, Inc** *(invited)*

2:00 pm
How Advocacy is Working with Pharma in a Meaningful Way to Involve Patients in Medicines Development
In this session, hear an update on how Arthritis Research UK and Parkinson's UK supports pharma with valuable tools and patient insights. Advocacy groups can offer principled approaches, supported by evidence, on how to meaningfully involve patients in medicines development. Specifically:

- How to optimize patient networks
- Patient insights on when and how they want to be engaged
- International access to patient opinions
- Education on cultural differences
- Showcase the shift in attitude towards pharma

Claire Nolan, PhD
Research Involvement Manager, **Parkinson's UK**
with
Chris MacDonald
Research Involvement Manager, **Arthritis Research UK**

2:35 pm
Networking Break

3:05 pm
Tackling the Legal Barriers of Patient Involvement with Co-Designed Contracts and Agreements: A PFMD, MPE and WECAN Collaboration
In order to overcome the legal barriers surrounding the partnership between patients, advocacy groups and pharma, PFMD, MPE and WECAN have collaborated to provide a framework, guidance and templates for reasonable agreements between patient organisations, patient advocates and the pharmaceutical industry. These contracts address the responsibilities of both parties, including:

- Confidentiality
- Intellectual property
- Copyright
- Data protection
- Compensation

In this session, hear from PFMD's Chief Executive, Nicholas Brooke on factors that were taken into consideration in developing the framework and the impact it can have on expediting and scaling up patient involvement in medicines development.

Nicholas Brooke
Chief Executive, **Patient Focused Medicines Development (PFMD)**

3:40 pm
Patient POV on the Progress of Patient Involvement
This panel will include both patients and advocates in a review of how industry is doing when it comes to implementing patient involvement in their research and development initiatives. The panel will identify areas that need improvement.

Moderator:
Alastair Kent
Ambassador, **Genetic Alliance UK**

Panelists:
Mathieu Boudes, PhD
Project Development & Strategic Alliances Senior Manager, **EURODIS**

Jan Geissler
Director, **EUPATI**

4:15 pm
Patient Engagement Sources and Solutions (Quickfires)

4:45 pm
Cocktail Reception

DAY TWO - WEDNESDAY, JANUARY 24, 2018

8:00 am
Registration & Breakfast

8:45 am
Chair's Opening Remarks
Andrew Garvey
Global Patient Advocacy Lead, **GlaxoSmithKline**

9:00 am
What Does a Truly Patient Centered Healthcare System Look Like in 5-10 Years?
What would have to change to make a patient-centric healthcare system a reality? How can this be achieved, given the huge resistance to change built into current systems? In this session, Alastair Kent, Director of Genetic Alliance UK, addresses the impact on the industry of:

- New opportunities to intervene
- Demographic change
- Constrained funding right across Europe
- The introduction of Expert Reference Networks
- And, how can we work through this collaboratively?

Alastair Kent
Director, **Genetic Alliance UK**

9:30 am
Town Hall Meeting on Patient Engagement Metrics and Value
This portion of the program will be a town hall style session that addresses the following questions:

- What are companies measuring? What metrics will be used to measure success?
- What do these measurements reveal and what can we do about it?
- Are these metrics different depending on the stakeholder? Why and how to we close that gap?
- What and how to benchmark and determine market value?
- How do we determine Return on Engagement? What does that really mean?
- How are we moving forward in a team approach- regulators, etc - on policies, guidance?
- What are some of the centralized set of information about patient involvement?

Nathalie Bere, MSc
Patient Relations Coordinator, **European Medicines Agency (EMA)**

Andrew Garvey
Global Patient Advocacy Lead, **GlaxoSmithKline**

Paula Wray
Senior Public Involvement Manager, INVOLVE, **NIHR**

10:00 am
How to Generate Value Through Patient Involvement from Development and Beyond
Mohammad Ali
Global Head Digital Development, Global Clinical Operations, **Boehringer-Ingelheim**

10:30 am
A Metrics Case Study: How BMS Measured the Impact of Patient Engagement Clinical Trial Recruitment
In this session, Pinal Patel, Strategic Recruitment Lead of Bristol-Myers Squibb, will walk the audience through how they have approached quantifying the outcome of patient engagement.

- Tactics and pathways taken to partnering with advocacy groups
- How measurement tools were implemented
- Key performance indications
- Outcomes

Pinal Patel
Strategic Recruitment Lead, **Bristol-Myers Squibb**

11:00 am
Networking Break

11:40 am
An Update from EMA on their 1st Public Hearing with Patients, Care Givers, Healthcare Professionals and Academia on Risk Assessment

- How to create a framework and method through public hearings to enrich scientific evidence and add value to the PRAC assessment
- Goals, challenges and recommendations

Nathalie Bere, MSc
Patient Relations Coordinator, **European Medicines Agency (EMA)**

12:10 pm
How is Digital/Mobile Changing the Patient Organization Paradigm?

12:44 pm
Lunch

1:45 pm
Patient View on Mobile Technology to Help Patients in Clinical Trials: Clinical Trials Transformation Initiative's Stakeholder Perceptions Project
In this session, hear from cancer survivor and patient advocate, Cindy Geoghegan, who collaborated with industry on recommendations for the use of mobile technology in clinical trials. With digital and mobile frameworks being increasingly incorporated into clinical trial design and operations, Cindy highlights the importance of the patient's role in sharing insights into the appropriate use and need for technology in a patients daily routine. Topics addressed include:

- Potential impacts of mobile on participant experiences in clinical trials
- Patient willingness to share personal health data
- Important attributes for designing trials that address patient preferences and expectations
- Implications for the research enterprise

Cindy Geoghegan
Patient Advocate and Cancer Survivor

2:15 pm
What Impact Will Payers Have on the Future of Patient Engagement/Involvement?
If outcomes based payment becomes the norm how will it change the way industry views the patient? In this session we address:

- Will this negatively or positively impact patient involvement and engagement?
- Does it damage or accelerate the progress made thus far?
- If pharma knows their payment chances rely solely on outcomes, does this increase the value of the patient perspective?
- What role can payers play in advancing patient involvement?

2:50 pm
Empowering the Public to Sign Up for Clinical Research – the UK Clinical Trials Gateway
Matt Cooper, PhD
Business Development and Marketing Director, **NIHR Clinical Research Network**

3:15 pm
Panel Discussion: Where Does Industry See Patient Involvement in 10 Years?

- How can we bridge the gap between industry, advocacy, patients and regulatory?
- How can industry and patients better collaborate?
- What do patients want from pharma? And, how can pharma help?
- Propose solutions for any outstanding barriers; legal, cultural, access etc.

Moderator:
Richard Stephens
Patient/ Consumer Lead, Chair Consumer Forum, **National Cancer Research Institute**

Panelists:
Liz Clark
VP, Medical Affairs, **Norgine**

Pooja Merchant, MPH
Head, External Medical Affairs, **Bayer**

Paul Robinson
Executive Director, Scientific Medical and Patient Perspective, **Merck**

4:00 pm
Conference Concludes