DAY ONE - Monday, June 12, 2023

8:15 am

Breakfast and Registration

8:45 am

Co-Chairs Welcoming Remarks and Patient Perspective

Victoria DiBiaso
VP, Global Head Patient Informed Development & Health Value Translation, **Sanofi**

Rosamund Round
Vice President, Patient Engagement, **Parexel**

Alfred Samuels
Patient Advocate

PATIENT ENGAGEMENT STRATEGY, EXECUTION & DEMONSTRATING IMPACT

9:00 am

The Evolution of Patient Informed Research

Significant advancements in patient-informed drug development, and the consistency with which it is employed, have been evolving over the past decade. Frameworks that outline milestones for patients and their stakeholders to inform decision points are recognized by industry, regulators, payers and advocacy organizations. Methods to elicit key insights, and contribute to evidence generation, include direct engagement of patient advocates and their individual communities, protocoled qualitative research with patients, use of patient preference studies, surveys and registry capabilities, use of natural language processing, and use of patient-generated real-world evidence.

While these advancements and recognition are evolving, measures to quantify the direct impact on research, development decision making, inclusive of health value generation, remain somewhat elusive. This session aims to discuss the importance of measuring the impact of patient informed medicines development and provide a case study of Sanofi's key performance indicators (KPI), metrics, methodology and results.

Victoria DiBiaso
VP, Global Head Patient Informed Development & Health Value Translation, **Sanofi**

9:30 am

Novartis' Global Approach to Mapping What and How to Measure Patient Engagement

In this keynote presentation, Novartis' Marc Boutin shares a global approach to implementing systematic and consistent patient engagement across the medicine lifecycle with a focus on measurement. More specifically:

- Framework for measurement across the lifecycle of medicines development
- Deploying change management strategy to embed patient engagement in existing processes
- Establish Patient Engagement as a must have function

Marc Boutin, JD
Global Head, Patient Engagement
Novartis

10:00 am

Patient Burden-Reducing Solutions & Technologies, An Audience"Pop-Up" Session

A select group of companies will share solutions in one minute pop-up sessions that reduce the burden to patients in clinical trials. At the end of these quick fire sessions, the audience is welcome to visit these companies at their respective tables to learn more.

Moderated by:
Victoria DiBiaso
VP, Global Head Patient Informed Development & Health Value Translation, **Sanofi**

COREVITAS™ Excellence in Evidence

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A LIFE IN A DAY

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10:20 am
Grand Opening of the Patients as Partners Networking Break

- Tea/Coffee and Morning Refreshments
- Meet the Exhibitors
- Networking

10:50 am
How Servier is Engaging the Patient in Every Step of the Medicine Development Process

- Case example of a new site opening
- The steps involved in developing a new research and development process
- Working with a patient Board
- The impact of involving patient voice on R&D

Marta Garcia Manrique
R&D, Chief Patient Officer, **Servier**

Thomas Smith, BSc BA Hons
Life Sciences Public Engagement Specialist, Independent Chairman, Speaker, Thought Leader, Consultant and Plain Language Expert

11:15 am
Understanding What Matters Most to Patients at Lundbeck

- Generating insights through engagement with patient communities
- Making patient input actionable for medicines development
- Sharing insights and scientific knowledge

Anders Blaedel Lassen
Patient Insights, **Lundbeck**

11:45 am
Leading Patient Engagement Strategy: What is Your Superpower?

Join VOZ Advisors for an interactive session on determining your key patient engagement priorities, identifying barriers to advancing these priorities and channeling your inner superpower to drive change.

Sharon Dion, MBA
Senior Vice President, **VOZ Advisors**

Veronica "Ronnie" Todaro, MPH
President and CEO, **VOZ Advisors**

12:15 pm
Luncheon and Networking

- Lunch
- Meet the Exhibitors
- Networking

IMPROVING DIVERSITY, ACCESS & INCLUSION IN CLINICAL RESEARCH

1:20 pm
Patient Perspective Fireside Chat

Sukhjeen Kaur
FRSA, Founder/Director, **Chronically Brown**

Andrew Garvey
Global Patient Advocacy Lead (ex US), **GSK**

1:40 pm
Diversity in Research: How to Advance Health Equity in the EU

- With the FDA bringing diversity plans into Federal Law, the impact will be Global, therefore Europe also needs to be prepared
- The maturity of DE&I initiatives in Europe is behind the US, what needs to be done – and why it needs to be a priority in 2023
- With the advancement of precision medicine, genomic based studies are lagging behind, with over 80% of the data based on people of European descent. What initiatives are in place in Europe to remedy this?

Led by:
Ash Rishi
Founder, **COUCH Health**

Panelists:
Xoli Belgrave
Senior Director at Parexel, Head of Patient Inclusion, **Parexel**

Suhkjeen Kaur
FRSA, Founder/Director, **Chronically Brown**

Tara Gipp
Associate Director Clinical Trial Optimization-Recruitment & Retention, **Regeneron Pharmaceuticals, Inc.**

2:15 pm

Understanding Barriers to Community Engagement in Clinical Research

This session provides six perspectives representing different communities and the challenges they face in participating in clinical trials. Afterwards, we will have a moderated session to bring forward ideas to help break down barriers to get more communities access to clinical trials. Participants include:

With Shauna Whisenton, ASH Research Collaborative; Calvin Roberts, MD, Lighthouse Guild; Scout, National LGBT Cancer Network; Angie Fedele, Autism Speaks; and Amy Hess, Autism Speaks

This session will be followed by an interactive breakout group exercise.

Led by:
Andrew Garvey
Global Patient Advocacy Lead (ex US), **GSK**

3:00 pm
Afternoon Networking Break

- Afternoon Tea with Sweets and Scones
- Meet the Exhibitors
- Networking

3:30 pm

Sanofi Case Study on How to Effectively Communicate to Diverse Populations

In this presentation, Sanofi's Global Behavioral Science Directors team shares a behavioral science approach to implementing motivational interview for patient engagement in clinical trials. More specifically:

- How to leverage behavioral science to address challenges of treatment adherence
- How to build trust and support site teams when talking about participating in a clinical trial
- Understand how unconscious bias can negatively impact clinical study recruitment and retention and how best to engage with patients from different cultural background

Laurence Bondoux
Global Behavioral Science Director – Patient Informed Development & Health Value Translation (PID & HVT), **Sanofi**

4:00 pm

Identify Actions to Increase Diversity in Clinical Research by Understanding the Reality of Underrepresented Communities

This session brings forward ideas to help break down barriers to get more communities access to clinical trials.

Moderator:
Rosamund Round
Vice President, Patient Engagement, **Parexel**

Panelists:
Seth Halvorson
General Manager, Site Solutions, **WCG**

Jennifer Kinnebrew
Paralegal, Patient Advocate, DEI Committee Member, **mdgroup**

Daniel Newman
Expert Type 1 Diabetes Patient Advocate

Daphnee Pushparajah
Director, Patient Advocacy UK & Ireland, **Alexion Pharmaceuticals**

4:30 pm

Navigating Patient Engagement and Compliance: Risks, Opportunities and Available Tools

- Understand the primary challenges and considerations in navigating healthcare compliance for interactions between pharmaceutical companies and patient communities
- Explore co-created approaches and tools for patient engagement remuneration, contracting and navigating Codes of Conduct that support patient engagement partners, fostering trust and transparency
- Preliminary learnings of champions who are implementing such approaches and by how this provokes a shift from risks to opportunities for all the partners involved

Nicole Wicki
Program Director, **PFMD**

5:00 pm - 6:00 pm

Networking and Cocktail Reception

DAY TWO - Tuesday, June 13, 2023

8:20 am

Breakfast

8:45 am

Co-Chairs Welcoming Remarks

Deirdre BeVard
SVP, R&D Strategic Operations, **CSL Behring**

Rosamund Round
Vice President, Patient Engagement, **Parexel**

Alfred Samuels
Patient Advocate

8:55 am

Managing Mental Health for Patients in Clinical Trials

- Awareness
- Action
- The communication element
- How mental health can make all the difference for the patient

Moderator:
Deirdre BeVard
SVP, R&D Strategic Operations, **CSL Behring**

Panelists:
Ceinwen Giles
Co-CEO, **Shine Cancer Support**

Jonathan Moshinsky
CEO & Co-Founder, **Stitch**

Alfred Samuels
Patient Advocate

9:25 am

Working with Patient Advocates to Optimize the End-to-End Trial Experience for Patients

- How listening and engaging with patients is helping us improve the end-to-end trial experience
- Learnings and feedback from recent patient advisory council meetings
- Insights from a patients/patient advocate survey on preferences for recruitment and retention tools

Nichola Gokool
Senior Director, Patient Partnerships, **Parexel**

9:45 am

Delivering Excellence Keynote

Efforts to make clinical research more accessible and patient-centric are a top priority for R&D executives. In this keynote session, we are delighted to welcome Linda Moir, an expert in delivering excellence in customer experience. Linda headed the London 2012 dream team that delivered outstanding front of house service by 15,000 volunteer Games Makers to 9 million spectators, resulting in one of the most successful Olympic and Paralympic Games in history. Previously, she was Virgin Atlantic's Director of In Flight Services, responsible for the airline's award winning service and 'making flying fun'.Throughout the process, she oversaw significant business growth whilst consistently driving the airline's catchy promise of 'Brilliant Basics, Magic Touches'. In this keynote presentation, Linda will share some best practices in how to deliver excellence.

Linda Moir
Former Head of Virgin Atlantic Customer Service and London Olympic 2012 Head of Events Services

10:25 am

Morning Networking Break

- Tea/Coffee and Morning Refreshments
- Meet the Exhibitors
- Networking

11:00 am

How Pharma Can Better Support Sites in Challenging Times

- Post-pandemic challenges
- New technologies

Deirdre BeVard
SVP, R&D Strategic Operations, **CSL Behring**

Tamsin Callaghan
Involvement and Inclusion Manager for Research,
Royal Free London NHS Foundation Trust

TURNING INSIGHTS INTO ACTION

11:25 am

Vision vs. Reality: Overcoming Hurdles in Your Organisation to Truly Work in Partnership with Patients

Patient-centric vision statements are now commonplace across the industry, but many life sciences organizations struggle to translate this into actually partnering with patients, from research through to commercialization, and from strategy through to execution. This session will explore common barriers to partnering with patients and how leading organizations have managed to overcome these to answer the question of 'what do patients truly want and need from us?'

Moderator:
Kate Moss
Lead Partner, Pharmaceuticals & Life Sciences, **Baringa**

Panelists:
Andrew Benzie
Head, Patient Focused Development, **GSK**

Malcolm Ritchie
Patient Advocate

Karen Skinner
Chief Project and Portfolio Officer, **LifeArc**

11:55 am

How Boehringer Ingelheim Turns Patient Insights into Action

Boehringer Ingelheim will share their approach to engaging patients throughout the clinical trial and how to leverage those patient insights to improve the process. Hear how BI recruited patients in half the time based on patient feedback, and how it has resulted in a better experience for the patient and organization. More specifically:

- Simplifying clinical trial processes without compromising them
- Incorporating patient insights to adapt the trial design to make participation more accessible
- Integrating patient feedback to improve the trial experience and keeping patients motivated to stay in the trial
- Trial simulation and outcomes

Annie Gilbert
Patient and Site Engagement Lead, **Boehringer Ingelheim Ltd**

12:20 pm

How Alnylam is Bringing the Patient to Every Part of Its Organization

Learn how Alnylam has developed a top-down as well as bottom-up approach to integrating the patient perspective into the organization. Gain insights into how they're connecting the patient to all aspects of Alnylam, including areas previously untouched by patient interaction, and finding new ways to develop greater patient-centricity throughout the organization. More specifically:

- How to integrate the patient voice through the trial development process
- How to bring the patient perspective into non-patient facing departments
- Overcoming objections to facilitate greater patient-centricity

Tiffany Patrick, MPH, MBA
VP of Patient Advocacy and Engagement,
Alnylam Pharmaceuticals

12:40 pm
Luncheon and Networking

- Lunch
- Meet the Exhibitors
- Networking

1:45 pm

How Powerful Data Enables Us to Better See Patients as People and Supercharge Clinical Trial Engagement

Defining patients by solely their clinical features results in clinical trial recruitment and engagement being generalised and non-specific, often speaking to only the largest group. By seeing and treating patients more like individuals, Sanofi and Langland, together are pushing for true health equity and inclusivity. This case study will discuss how we are using data to deliver hyper targeted communications that use messaging that matters and connects with patient segments who may have otherwise not been engaged previously - and in doing so, delivering a more effective outreach campaign.

Victoria DiBiaso
VP, Global Head Patient Informed Development & Health Value Translation, **Sanofi**

Sarah McKeown-Cannon
Vice President, Growth, **Langland**

2:10 pm

CSL: Delivering on our Promise to Patients and Public Health through 30,000+ Chief Patient Officers

- Advancing patient outcomes from bench to bedside through coordinated and connected patient engagement
- Partnering across R&D and Commercial
- Learning from patient's lived experience to drive decisions and delivery
- Patient perspectives at global, regional and functional meetings

Deirdre BeVard
SVP, R&D Strategic Operations, **CSL Behring**

2:35 pm

Reducing the Gaps Between Patient Organizations and Pharmaceutical Companies

- What UK patient organizations are doing to better understand the way they can work with industry
- Why reducing gaps between companies and patient organizations is so important
- Explore recommendations of a project led by UK charities with representatives from the patient organization sector and pharmaceutical industry

Claire Nolan
Head of Engagement, **International Bureau for Epilepsy**

Sally-Anne Dews
Senior Medical Patient Partnership Manager, **Pfizer UK**

3:05 pm

Consolidation of Patient Experience Data (PED) through the Holistic Patient Experience Mapping (PEM)

This session focuses on the sources and consolidation of patient experience data and how it shapes drug development and real-world evidence. More specifically:

- Methods and sources for gathering patient experience data
- Digital approaches to capture patient experience data
- Methodologies to consolidate patient experience data
- Regulatory considerations
- Communication considerations
- Partnership considerations

Led by:
Oleksandr Gorbenko, MD, PhD, BCMAS
Global Patient Affairs Director, Neurosciences, **Ipsen Biopharm Limited**

Panelists:
Jessica Braid
Principal PCOR Scientist, Head of Digital Innovation Chapter, EDEN Co-Lead, **Roche**

Sarah Griffiths
Communications Director, **Oxford PharmaGenesis**

3:35 pm

Pfizer's Approach to Real World Data and Evidence

Involving patients and carers in the design and execution of real world data studies is essential for the pharmaceutical industry to conduct true patient centric research. Making sure that those involved are representative of the wider population and include people that are harder to reach, experience health inequality or have lower health literacy is essential in making sure data and the evidence generated from it aligns with what is important to all. This session will provide an overview of work conducted in this area to develop a pragmatic framework, to ensure meaningful involvement.

Adit Bassi
UCL medical student and young person representative, **Pfizer UK**

Sally-Anne Dews
Senior Medical Patient Partnership Manager, **Pfizer UK**

Polly Westergaard
Senior Innovation Consultant, **UK National Innovation Centre for Ageing**

4:05 pm

Case study: Lessons Learned from Direct Engagement with Breast Cancer Patients

- How NIHR is supporting Pfizer's patient-focused approach to breast cancer trial planning and design
- Prioritising the patient experience to optimise your engagement opportunity
- Common barriers to patient engagement and how to overcome them
- A framework for future engagement – incorporating the patient insights at every stage of the medicine development process

Kim Down
Business Development Manager, **National Institute for Health and Care Research (NIHR)**

Anna Louise Barry
Senior Medical Affairs Advisor, **Pfizer Oncology UK**

Mary Rose Ropner
Market Access Senior Manager, UK Health & Value, **Pfizer Oncology UK**

4:35 pm

Conference Concludes