2017 Chief Medical/Scientific Officers Conference

Lessons Learned and Pathways Forward:
Practical Experiences in Patient Engagement

OMNI Shoreham Hotel
2500 Calvert Street NW
Washington, DC 20008

September 18-19, 2017

Speakers will profile examples of the science of patient engagement in research and care delivery. Case examples will highlight emerging good practices, successful methods, shortcomings identified, and gaps to be filled. A product of the meeting will be a white paper on emerging good practices in the science of patient input, focusing on not only what is working, but also cautions on areas with limitations. The white paper will recommend future directions for enhancing emerging good practices. In addition, a portfolio of emerging good practices will be developed and made available on the NHC website.

Monday, September 18

2:00 p.m.  Chief Medical/Scientific Officers Affinity Group Meeting
(All conference attendees are invited to join the Affinity Group meeting)
Welcome and Introductions
- Katharine Knobil, MD, Chief Medical Officer, Pharmaceuticals, GlaxoSmithKline, and Conference Co-Chair
- Guy Eakin, PhD, Senior Vice President, Scientific Strategy, Arthritis Foundation, and Conference Co-Chair

2:30 p.m.  Moderated Panel: Understanding research portfolios and strategy
Ensuring the impact of research investments is essential in today’s challenging environment. This session will explore how different organizations develop and leverage their research portfolios to drive strategy and achieve impact.
Moderator: Tim Coetzee, PhD, Chief Advocacy, Services, and Research Officer, National Multiple Sclerosis Society
- Robert McBurney, President & Chief Executive Officer, Accelerated Cure Project
• Invited Sarah Hollingsworth Lisanby, MD, Director of Translational Research, NIMH

3:30 p.m.  Stakeholder perspectives: What is actionable?
To make decisions all organizations rely on data, yet may have different viewpoints of what is required to make decisions, particularly with data related to behavior. This session explores the patient behaviors that organizations seek to understand, and how they balance rigor and rapidity when it comes time to make business decisions.
Moderator: Aran Maree, MD, Chief Medical Officer, Janssen Pharmaceuticals
  • Andy Crighton, Vice President and Chief Medical Officer, Prudential Financial

4:30 p.m.  Break

6:00 p.m.  Reception and Dinner

Tuesday, September 19

7:30 a.m.  Breakfast Buffet

8:30 a.m.  Welcome and Overview
  • Katharine Knobil, MD, Chief Medical Officer, Pharmaceuticals, GlaxoSmithKline, and Conference Co-Chair
  • Guy Eakin, PhD, Senior Vice President, Scientific Strategy, Arthritis Foundation, and Conference Co-Chair

8:45 a.m.  Opening keynote: From talking about patients, to communicating with patients: Lessons learned from the American Heart Association
  • Patrick Dunn, PhD, MS, MBA, Center for Health Technology and Innovation, American Heart Association
  • Jennifer Volland, AHA ConnectedHeart Health participant

9:30 a.m.  Patient engagement in drug co-development part 1: Efforts to obtain the voice of the patient
Moderator: Guy Eakin, PhD, Senior Vice President, Scientific Strategy, Arthritis Foundation, and Conference Co-Chair
  • Theresa Mullin, PhD, Director, Office of Strategic Programs, FDA
- Dory Kranz, Chief Executive Officer, National Alopecia Areata Foundation
- Mike Siegel, PhD, Vice President, Research Programs, National Psoriasis Foundation

10:30 a.m.  Networking Break

10:45 a.m.  Patient engagement in drug co-development part 2: Case studies
Moderator: Guy Eakin, PhD, Senior Vice President, Scientific Strategy, Arthritis Foundation, and Conference Co-Chair
- **Abstract selection:** Trial Simulation Workshops to Gather Input from Phase II Investigators, Sites, and Patient in the Netherlands, Spain, and the United States, Janssen, HealthiVibe.
  - Abbe Steel, Chief Executive Officer, HealthiVibe
- **Abstract selection:** Patients Improving Clinical Trials: Partnership Between Pfizer and Parkinson’s Foundation, Parkinson’s Disease Foundation and Pfizer
  - Karlin Schroeder, Director, Community Engagement, Parkinson’s Foundation

11:30 a.m.  Patient engagement in quality of care measurement
This session will present best practice examples in patient engagement in measure development and quality of care improvement.
Moderator: Kate Knobil, MD, Chief Medical Officer, Pharmaceuticals, GSK, and Conference Co-Chair
- Reena Duseja, MD, Director, Division of Quality Measurement, Quality Measurement and Value-Based Incentive Group, Center for Clinical Standards and Quality, Centers for Medicare and Medicaid Services
- Eugene Nelson, DSc, MPH, Director, Population Health and Measurement Program, The Dartmouth Institute

12:30 p.m.  Luncheon discussion - Hand and Glove: Leveraging Consumerism Experiences to Improve Patient Engagement
- Hal Paz, MD, Executive Vice President & Chief Medical Officer, and Gary Loveman, PhD, Executive Vice President, Consumer Health & Services, Aetna Inc.

1:45 p.m.  Patient engagement and capturing the whole patient
People experiencing a specific health condition are more than just that condition. Quality of life, associated health conditions, overall health and
aspirations for their health and life are all critical components of research and medical care in general. This is an opportunity to learn about the importance and impact of including people with lived experience in the research team.

**Moderator: Jill Harkavy-Friedman, PhD, Vice President of Research, American Foundation for Suicide Prevention**

- Steve Iselin, Acting Assistant Secretary of the Navy for Energy, Installations, and Environment
- **Abstract selection:** Multi-Step Advocacy Collaboration: How Patient Feedback Loops Inform Program Development, Alkermes
  - Nikki Levy, Vice President, Patient Engagement, Alkermes

2:45 p.m.  Networking break

3:00 p.m.  Patient engagement and public policy

**Moderator: Lisa Simpson, President and Chief Executive Officer, AcademyHealth**

- Susan Sheridan, DHL, MIM, MBA, Patient and Family Engagement Advisor in the Quality Improvement and Innovation Group, Center for Clinical Standards and Quality, Center for Medicare and Medicaid Services
- Anna Hyde, Vice President, Advocacy and Access, Arthritis Foundation
- **Abstract selection:** Engagement of Advocacy Organizations in an ICER Analysis: the MS Coalition Experience, National Multiple Sclerosis Society, Institute for Clinical and Economic Review, MS Coalition, and Accelerated Cure
  - Bari Talente, JD, Vice President, MS Coalition and Executive Vice President, Advocacy, National Multiple Sclerosis Society

4:00 p.m.  Wrap-up and adjournment