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**CMSS & NHC Patient-Centered Partnerships Summit:**

**Building Meaningful Collaboration to Advance Patient Care and Research**

**October 8, 2024**

**Hybrid Meeting – Virtual/Hopkins Bloomberg Center**

**Kenney Link Room - 4th Floor**

**555 Pennsylvania Avenue NW, Washington, DC 20001**

Fostering collaboration among stakeholders, and introducing and building relationships among clinicians, researchers, patients, and caregivers is paramount to ensuring research is meaningful to all communities. This hybrid summit aims to bring together patient organizations, physician societies, and thought leaders to discuss strategies and tools, including the Patient-Led Scorecards developed by the Patient-Led Research Coalition and CMSS, to enhance collaboration and partnership in patient-centered research. The summit will also focus on targeted strategies to engage minoritized and historically underrepresented patient communities with the clinical community in patient-centered research.

**AGENDA**

**Tuesday, October 8 – Meeting 8:30 AM – 4:30 PM**

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| **Time and Location** | **Session title and description** |
| 8:30 AM – 9:00 AM | **Check in and networking breakfast** |
| 9:00 AM – 9:10 AM | **Welcome and Opening Remarks** |
| * Helen Burstin, MD, MPH, MACP, Chief Executive Officer, Council of Medical Specialty Societies * Randall L. Rutta, MA, Chief Executive Officer, National Health Council |
| 9:10 AM – 9:20 AM | **Meeting Objectives** |
| * Donna Cryer, JD, Chief Executive Officer, Global Liver Institute * Guy Eakin, PhD, Chief Scientific & Medical Officer, National Psoriasis Foundation |
| 9:20 AM – 10:20 AM | **Patient-Centered and Led Research: Where are We Now?** |
| Introduction: Helen Burstin, MD, MPH, MACP, Chief Executive Officer, Council of Medical Specialty Societies  Moderator: Guy Eakin, PhD, Chief Scientific & Medical Officer, National Psoriasis Foundation  Keynote Speaker:   * Susannah Fox, Health and Technology Strategist and Author of Rebel Health   Reactor Panel   * Jennifer Bright, MPA, President, International Consortium for Health Outcomes Measurement (ICHOM) * Venus Ginés, MA, P/CHWI, Founder, Día de la Mujer Latina, Inc. * Harold (Harv) Feldman, MD, MSCE Deputy Executive Director, Patient-Centered Research Programs, Patient-Centered Outcomes Research Institute |
| 10:20 AM – 10:35 AM | **Morning Break** |
| 10:35 AM – 11:35 AM | **Equity Issues: How to Foster Equitable Patient Engagement of Diverse Communities** |
| Panel Speakers:   * Arnie Joseph, President and Founder, Chroma Health Solutions * Suzanne Watnick, MD, American Society of Nephrology (ASN) Inaugural Health Policy Scholar in Residence * Lisa Fitzpatrick, MD, MPH, MPA, CEO, Grapevine Health   Moderator: Omar A. Escontrías, DrPH, MPH, Senior Vice President, Equity, Research & Programs, National Health Council |
| 11:35 AM – 12:30 PM | **Opportunities and Challenges: Case Studies: Round 1** |
| **Case Study 1: Patient-Led Research Scorecards: How well are you able to work collaboratively?**   * Gina Assaf, Co-Founder and Co-Lead, PLRC * Helen Burstin, MD, MPH, MACP, Chief Executive Officer, Council of Medical Specialty Societies   **Case Study 2: Education and Training for Patients and Clinicians**   * Clifford Hudis, MD, CEO, American Society of Clinical Oncology (ASCO) * Michelle Tregear, PhD, Director of Education and Training Programs, National Breast Cancer Coalition   Moderator: Kira Baldonado, MPH, Vice President of Public Health and Policy, Prevent Blindness |
| 12:30 - 1:30 PM | **Networking Lunch** |
| 1:30 PM – 2:30 PM | **Opportunities and Challenges: Case Studies: Round 2** |
| **Case Study 3: Use of Technology in Patient Engagement and Research**   * John Whyte, MD, Chief Medical Officer, WebMD * Christian Rubio, MBA, Executive Director and Head of Development, Everything ALS   Moderator: Donna Cryer, JD, Founder, Global Liver Institute  **Case Study 4: New Models of Patient Engagement in Clinical Registries and Research**   * Charles Abrams, MD, Francis C. Wood Professor, Chief, Non-Malignant Hematology, University of Pennsylvania School of Medicine, Vice Chair for Research & Chief Scientific Officer, University of Pennsylvania School of Medicine * Justine Nicholas, MS, Senior Manager, SCD Community Engagement, ASH Research Collaborative * Kevin Wake, CMR, CHW, MS, President, Uriel E. Owens Sickle Cell Disease Association of the Midwest   Moderator: Kathy McDonald, PhD, MM, Bloomberg Distinguished Professor of Health Systems, Quality and Safety, Johns Hopkins School of Nursing and Medicine |
| 2:30 PM - 3:30 PM | **Reflections on Case Studies: Roundtable Discussions** (facilitated by Advisory Panel members: Donna Cryer, Guy Eakin, Kathy McDonald, Kira Baldonado, Venus Ginés, Cliff Hudis, Kevin Wake and CMSS/NHC staff) |
| 3:30 PM – 3:45 PM | **Afternoon Break** |
| 3:45 PM – 4:15 PM | **Roundtable Report-Out: Promising Collaboration Strategies** |
| 4:15 AM – 4:25 PM | **Discussion of Next Steps** |
| * Donna Cryer, JD, Chief Executive Officer, Global Liver Institute * Guy Eakin, PhD, Chief Scientific & Medical Officer, National Psoriasis Foundation |
| 4:25 PM - 4:30 PM | **Concluding Remarks** |
| * Kathy McDonald, PhD, MM, Bloomberg Distinguished Professor of Health Systems, Quality and Safety, Johns Hopkins School of Nursing and Medicine |

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