

# The Patient Voice Can't Be Ignored in Clinical Research

October 22-23, 2019 | Marriott Wardman Park Hotel, Washington, DC

Now is the time to mobilize and support Patient Advocacy Groups, their constituents & key stakeholders to insist upon meaningful change in clinical research.

## Tuesday, October 22nd

5:00-8:00 pm      **Registration, Reception and Networking**

## Wednesday, October 23rd

7:00 am      **Registration, Breakfast and Networking**

8:00 am      **It's Time to Mobilize – Enhancing the Voice of Advocacy, Patients and Caregivers**  
*Steve Smith, President, Patient Advocacy, WCG*

8:15 am      **Patient's Experiences: We're Missing a Critical Part of the Development Team**  
*Mary Elizabeth Williams, Journalist and Author*

8:45 am      **Ensuring Diversity, Inclusion and Meaningful Participation in Clinical Trials**  
**Moderator:** *Lori Abrams, Sr. Director, Patient Advocacy, WCG*  
**Panelists:** *Jonca Bull, MD, Former Assistant Commissioner, FDA*  
*Kimberly Richardson, Ovarian Cancer survivor; Research Advocate*  
*Dorelia Rivera, Parent of child with Ultra Rare Disease; Patient Advocate*

- 9:45 am **Compensation for Research Participation: Should We Worry About Too Little Rather Than Too Much?**  
**Moderator:** David Borasky, *VP of IRB Compliance, WCG*  
**Panelists:** Elisabeth M. Oehrlein, *Sr. Director, National Health Council*  
Jeanne Regnante, *NMQF, and Founder & CEO of Patient3i*  
Leslie Hanrahan, *SVP, Lupus Foundation of America*
- 10:45 am **Break**
- 11:15 am **Improving the Informed Consent Process: How Do We Make Real Changes?**  
**Moderator:** Lindsay McNair, *Chief Medical Officer, WCG*  
**Panelists:** Mary Elizabeth Williams; *Journalist and Author*  
Kristina Wolfe, *Eversana, Our Odyssey PAG, and Patient Advocate*  
Alyssa Lanzi, *Speech-Language Pathologist and Clinical Researcher*
- 12:00 pm **Lunch**
- 1:00 pm **Demanding Patient-Friendly Studies – Effective Input Along the Drug Development Continuum**  
**Moderator:** Danya Kaye, *Director of Business Development R&D and Innovation, Inspire*  
**Panelists:** Steven Taylor, *President & CEO, Sjogren's Foundation*  
Pat Furlong, *Founding President & CEO of Parent Project Muscular Dystrophy*
- 2:00 pm **Break**
- 2:15 pm **It's About Time – Let's Return Study Results to Participants**  
**Moderator:** Behtash Bahador, *Sr. Manager, Quality & Compliance, CISC RP*  
**Panelists:** Seth Rotberg, *Living with Huntington's Disease, Our Odyssey PAG*  
Rene Roach, *Living with Colorectal Cancer*  
Amy Joosten-Butler, *Living with Colon Cancer*
- 3:15 pm **Closing Remarks & Action Items**  
Steve Smith, *President, Patient Advocacy, WCG*
- 3:30 pm **Conclude**