### NIH Workshop on Enrollment and Retention of Participants in NIH-funded Clinical Trials

**Friday, July 25, 2014, 8:15 a.m.–5:45 p.m.**  
Porter Neuroscience Research Center, Rooms 630 and 640  
National Institutes of Health  
Bethesda, Maryland

<table>
<thead>
<tr>
<th>Time</th>
<th>Session</th>
</tr>
</thead>
<tbody>
<tr>
<td>7:00 a.m.–8:00 a.m.</td>
<td><strong>Poster Viewing and On-site Registration</strong> (in atrium)</td>
</tr>
</tbody>
</table>
| 8:15 a.m.–8:30 a.m. | **Welcome and Introduction**  
*Pamela McInnes, D.D.S.*  
Deputy Director, National Center for Advancing Translational Sciences, NIH |
| 8:30 a.m.–9:15 a.m. | **Current Challenges in Clinical Trial Participant Enrollment**  
*Mary Woolley, M.S.*  
President, Research!America  
*Veronica Todaro, M.P.H.*  
Vice President, National Programs, Parkinson’s Disease Foundation |
| 9:15 a.m.–9:50 a.m. | **Cultural and Social Considerations in Clinical Trial Enrollment and Outreach**  
*Moon Chen, Ph.D., M.P.H.*  
Associate Director for Population Research and Cancer Disparities, University of California, Davis  
*Joseph Ravenell, M.D., M.S.*  
Assistant Professor, Center for Healthful Behavior Change, New York University Medical Center |
| 9:50 a.m.–10:25 a.m. | **Recruitment and Outreach Considerations for Underrepresented and Vulnerable Populations**  
*Jonathan Ellen, M.D.*  
President, All Children’s Hospital, Johns Hopkins University  
*Sybil Hosek, Ph.D.*  
Clinical Psychologist, Department of Psychiatry, John H. Stroger, Jr. Hospital of Cook County |
| 10:25 a.m.–10:45 a.m. | **Break**                                                   |
10:45 a.m.–11:45 a.m.  
**Moderated Panel Discussion on Enrollment Issues for Clinical Trial Participants**

**Marva Moxey-Mims, M.D.** (Moderator)  
Deputy Director for Clinical Research, Division of Kidney, Urologic, and Hematologic Diseases, National Institute of Diabetes and Digestive and Kidney Diseases, NIH

**Nancy King, J.D.**  
Co-director, Center for Bioethics, Health, and Society and Graduate Program in Bioethics, Wake Forest University

**Jill Abell, Ph.D.**  
Senior Director, Clinical Effectiveness and Safety, GlaxoSmithKline

**Edith Mitchell, M.D., FACP**  
Director, Center to Eliminate Cancer Disparities, Thomas Jefferson University Hospital

**Gary Puckrein, Ph.D.**  
President and Chief Executive Officer, National Minority Quality Forum

**Samuel Simha, M.D., FACOG, CPI**  
President, Academy of Physicians in Clinical Research

**John Walsh**  
Founder, COPD Foundation

11:45 a.m.–12:30 p.m.  
**Moderated Discussion with Panelists, Speakers, and Audience**

**Jamie Roberts, M.A., CCRP, M.P.H.[c]** (Moderator)  
Clinical Trials Specialist, Office of Clinical Research, National Institute of Neurological Disorders and Stroke, NIH

12:30 p.m.–1:30 p.m.  
**Lunch** (on your own)  
**Poster Viewing** (in atrium)

1:30 p.m.–1:45 p.m.  
**Roles for Public Foundations in Clinical Trial Enrollment and Retention**

**Maria Freire, Ph.D.**  
President, Foundation for NIH
1:45 p.m.–2:30 p.m.  Public Private Partnerships to Improve Patient and Public Awareness and Engagement

Vanessa Arnedo, M.P.H.
Associate Director, Research Partnerships, Michael J. Fox Foundation

Jeff Vigne
President, Board of Directors, Friends of the Clinical Center

Joe V. Selby, M.D., M.P.H.
Executive Director, Patient-Centered Outcomes Research Institute

2:30 p.m.–3:00 p.m.  Models to Identify and Support Clinical Trial Participants

Joseph Unger, M.S., Ph.D.
Staff Scientist, Fred Hutchinson Cancer Research Center

Cynthia Bower, R.N., M.S.
Associate Managing Director, Michigan Clinical Research Unit, University of Michigan

3:00 p.m.–3:30 p.m.  Strategies for Tracking and Monitoring Clinical Trial Participation and Post-trial Communication

Alan S. Go, M.D.
Director, Comprehensive Clinical Research Unit, Kaiser Permanente Medical Group

Ann Partridge, M.D., M.P.H.
Associate Professor of Medicine, Harvard Medical School

3:30 p.m.–3:45 p.m.  Break

3:45 p.m.–4:45 p.m.  Moderated Panel Discussion on Clinical Trial Partnerships and Participant Support

Carl V. Hill, Ph.D., M.P.H. (Moderator)
Director, Office of Special Populations, National Institute on Aging, NIH

Emil Chiauzzi, Ph.D.
Research Director, Client Services, PatientsLikeMe

Mildred Cho, Ph.D.
Associate Director, Stanford Center for Biomedical Ethics, Stanford University
Jonathan Davis, M.D.
Vice-chair of Pediatrics for Academic Affairs, Chief of Newborn Medicine, Floating Hospital for Children at Tufts Medical Center

Dana Dornsife
President, Lazarex Cancer Foundation

Virginia Howard, Ph.D.
Professor of Epidemiology, University of Alabama at Birmingham

Jocelyn Ulrich, M.P.H.
Director, Scientific and Regulatory Affairs, PhRMA

4:45 p.m.–5:30 p.m. Moderated Discussion with Panelists, Speakers, and Audience

Betty Tai, Ph.D. (Moderator)
Director, Center for Clinical Trials Network, National Institute on Drug Abuse, NIH

5:30 p.m.–5:45 p.m. Closing Comments and Next Steps

5:45 p.m. Adjourn