



Parkinson's Advocates in Research Learning Institute

Wyndham Hamilton Park Hotel and Conference Center, Florham Park, NJ
Thursday, July 14 through Saturday, July 16, 2016

AGENDA

Wednesday, July 13

Dinner (Arrive Dining Room) 6:00 PM to 7:30 PM

Meet and Greet Dessert Reception (Arrive 1 and 2) 7:30 PM to 8:30 PM

Thursday, July 14

Breakfast (Arrive Dining Room) 6:45 AM to 8:00 AM

*All sessions will take place in the **Afton Springfield** room.*

I. Welcome to the Parkinson's Advocates in Research Learning Institute: The Power of the Patient Voice 8:15 AM to 9:00 AM

*Ronnie Todaro, M.P.H., Sr. Vice President, Chief Operating Officer
Parkinson's Foundation*

II. Models of Advocacy: The Voice of the Patient at the Food and Drug Administration 9:00 AM to 10:00 AM

*John Whyte, M.D., M.P.H., Director, Professional Affairs and
Stakeholder Engagement, U.S. Food and Drug Administration*

Break 10:00 AM to 10:15 AM

III. Learning the Basics: Making a Difference in the Research Process 10:15 AM to 12:15 PM

*Oren Levy, M.D., Ph.D., Winifred Mercer Pitkin, M.D. Assistant
Professor, Division of Movement Disorders, Department of
Neurology, Columbia University School of Medicine
Benzi Kluger, M.D., Associate Professor, Department of Neurology,
Director, Movement Disorders Center, University of Colorado
Denver School of Medicine
Eydith Comenencia-Ortiz, Ph.D., Manager of Alliance Development
Public Policy and Government Affairs, Biogen*

Lunch (Arrive Dining Room) 12:15 PM to 1:15 PM
IV. Models of Advocacy and Skill Building Part 1: Critical Skills for Collaborating with Research Teams 1:15 PM to 3:15 PM

Megan Feeney, M.P.H., Manager, Community Engagement, Parkinson's Foundation
Kirk Hall, M.B.A., Parkinson's Foundation Research Advocate
Benzi Kluger, M.D., Associate Professor, Department of Neurology, Director, Movement Disorders Center, University of Colorado Denver School of Medicine
Alit Stark-Inbar, Ph.D., Research Scholar, University of California, Berkeley, Senior Scientist, Posit Science Corporation
Ronnie Wanetick, M.L.S., Parkinson's Foundation Research Advocate

Group Photo 3:15 PM to 3:30 PM

Break 3:30 PM to 3:45 PM

V. Practice: Providing Feedback on a Protocol 3:45 PM to 5:00 PM
Jori Fleisher, M.D., M.S.C.E., Assistant Professor of Neurology and Population Health, NYU School of Medicine

Free Time 5:00 PM to 6:30 PM

Dinner (Arrive Dining Room) 6:30 PM to 7:30 PM

Friday, July 15

Breakfast (Arrive Dining Room) 6:45 AM to 8:15 AM

VI. Learning the Basics: What's in the Parkinson's Pipeline 8:30 AM to 10:00 AM

Jim Beck, Ph.D., Vice President, Chief Scientific Officer, Parkinson's Foundation

Break 10:00 AM to 10:15 AM

VII. Practice: Evaluating Research 10:15 AM to 11:45 AM

Alit Stark-Inbar, Ph.D., Research Scholar, University of California, Berkeley, Senior Scientist, Posit Science Corporation

Lunch (Arrive Dining Room) 11:45 AM to 12:45 PM

VIII. Learning the Basics: Thinking Critically About Ethics in Parkinson's Research 12:45 PM to 2:45 PM

Scott Kim, M.D., Ph.D., Senior Investigator, Department of Bioethics, Clinical Center, National Institutes of Health

Break 2:45 PM to 3:00 PM

IX. Models of Advocacy and Skills Building Part 2: Critical Skills for Collaborating with Research Teams **3:00 PM to 4:30 PM**

Karlin Schroeder, M.A., Director, Community Engagement, Parkinson's Foundation
Eydlith Comenencia-Ortiz, Ph.D., Manager of Alliance Development, Public Policy and Government Affairs, Biogen
Becky Houde, J.D., Parkinson's Foundation Research Advocate
Michael Schwarzschild, M.D., Ph.D., Professor of Neurology, Harvard Medical School, Chair, Parkinson Study Group (PSG) Executive Committee

Free Time **4:30 PM to 6:00 PM**

Dinner - Dialogue and Discussion (Arrive 1 and 2) **6:00 PM to 8:00 PM**

Saturday, July 16

Breakfast (Arrive Dining Room) **6:45 AM to 8:45 AM**

X. Skills Building: Dealing with Pitfalls and Troubleshooting **9:00 AM to 10:30 AM**

Karlin Schroeder, M.A., Director, Community Engagement, Parkinson's Foundation
Megan Feeney, M.P.H., Manager, Community Engagement, Parkinson's Foundation

Break (Checkout of Rooms) **10:30 AM to 11:30 AM**

XI. Parkinson's Foundation Resources **11:30 AM to 12:00 PM**

Karlin Schroeder, M.A., Director, Community Engagement, Parkinson's Foundation
Megan Feeney, M.P.H., Manager, Community Engagement, Parkinson's Foundation

XII. Planning: Returning to Your Community **12:00 PM to 12:45 PM**

Karlin Schroeder, M.A., Director, Community Engagement, Parkinson's Foundation
Megan Feeney, M.A. Manager, Community Engagement, Parkinson's Foundation

12:45 PM to 1:00 PM

XIII Wrap-up and Farewell **1:00 PM to 2:00 PM**

Lunch (Arrive Dining Room)

The Parkinson's Foundation wishes to thank Lundbeck for its support of the Parkinson's Advocates in Research Learning Institute.