



## THURSDAY, 28 OCTOBER – ALL TIMES EDT (NEW YORK)

|           |  |
|-----------|--|
| 10:00 AM  | <p><b>Welcome</b><br/>Terry Thompson, PhD <i>President, KDA</i></p>  |
| 10:15     | <p><b>A Brief Introduction to Kennedy's Disease</b><br/>Ed Meyertholen, PhD <i>KDA Patient Liaison</i></p>   |
| 10:40     | <p><b>KD Patient Stories and Tips</b><br/><b>Moderator:</b> Jameson Parker <i>Vice President, KDA</i><br/>Australia (Matt Benson, Rod Kent),<br/>Canada (Andrew Cassar)<br/>Italy (Gianni Fabbris, Giancarlo Talli),<br/>Russia (Dmitriy Sokolov),<br/>UK (Kim Slowe),<br/>U.S. (Simon Hill, Dale Traxler)</p>   |
| 11:35     | <p><b>Mobility Aids: What's Right for You?</b><br/>- Jim Kissling <i>President, AutoFarm Mobility</i></p>  |
| 12:05 PM  | <p><b>BREAK</b></p>  |
| 12:30     | <p><b>While Waiting for a Cure: Managing Symptoms</b></p> <ul style="list-style-type: none"> <li>• Christopher Grunseich, M.D. <i>Staff Clinician, NINDS/NIH</i></li> <li>• Carlo Rinaldi, M.D., PhD <i>Assoc. Professor Dept. of Paediatrics, Oxford University</i></li> <li>• Angela Kokkinis, RN, BSN <i>Clinical Research Nurse, NIH Neurogenetics Branch</i></li> <li>• Luca Zampedri <i>KD Research Nurse, UK National KD Clinic, UCL</i></li> </ul> |
| 1:20      | <p><b>Speech Dysfunction in KD: How to Improve Your Speech</b><br/>- Beth Solomon, MS, CCC-SLP <i>Senior Lead, Speech Language Pathology, NIH</i></p>  |
| 1:50      | <p><b>Dealing with a KD Diagnosis and Hope for the Future</b><br/>- Continuation of KD patient discussion</p>  |
| 2:15-2:30 | <p><b>Day 1 Wrap-up</b></p>  |
| 3:30-5:00 | <p><b>Optional Breakout Sessions for KD Men, Partners/Caregivers, Carriers</b><br/>- Scheduled Separately</p>  |

## FRIDAY, 29 OCTOBER – ALL TIMES EDT (NEW YORK)

|             |  |
|-------------|--|
| 10:00 AM    | <b>Introduction to Day 2</b>   |
| 10:05       | <b>Managing Symptoms of SBMA: A Live Q&amp;A</b> <ul style="list-style-type: none"><li>- Carlo Rinaldi, Chris Grunseich, Angela Kokkinis, Luca Zampedri, Beth Solomon, and Tahseen Mozaffar, M.D. <i>Professor of Neurology and Pathology &amp; Lab Medicine, Director, Division of Neuromuscular Disorders, University of California, Irvine</i></li></ul>  |
| 10:55       | <b>Approaches to Treating Kennedy's Disease and Update on Clinical Trials –</b><br><b>Moderator:</b> Kurt Fischbeck, M.D. <i>Distinguished Investigator, NIH/NINDS</i> <ul style="list-style-type: none"><li>• Michael Chan, PhD <i>Vice President, AnnJi Pharmaceutical</i></li><li>• Lauren Elman, M.D. <i>Associate Professor of Neurology, Perlman School of Medicine, University of Pennsylvania</i></li><li>• Katy Meilleur, PhD <i>Principal Clinical Scientist, Biogen</i></li><li>• Jeremy Springhorn, PhD <i>Chief Executive Officer, Nido Biosciences</i></li></ul>   |
| 12:05 PM    | <b>BREAK</b>   |
| 12:30       | <b>Highlights from October 2021 SBMA Research Conference –</b> <ul style="list-style-type: none"><li>- Diane Merry, PhD <i>Professor, Department of Biochemistry and Molecular Biology, Thomas Jefferson University</i></li></ul>  |
| 12:50       | <b>Reports from 2019 KDA Grant Recipients –</b> <ul style="list-style-type: none"><li>• Heather Montie, PhD <i>Philadelphia College of Osteopathic Medicine</i></li><li>• Catheryn Wooi Fang Lim, PhD <i>University of Oxford, UK</i></li><li>• Kentaro Sahashi, M.D., PhD <i>Nagoya University Graduate School of Medicine</i></li><li>• Emanuela Zuccaro, PhD <i>University of Padova, Italy</i></li><li>• Bilal Malik, PhD <i>University College London</i></li></ul>   |
| 1:30        | <b>Researcher Roundtable and Q&amp;A –</b><br><b>Moderator:</b> Dr. Fischbeck <ul style="list-style-type: none"><li>• Pietro Fratta, PhD <i>Clinician Scientist, University College London Institute of Neurology</i></li><li>• Cindy Jordan, PhD <i>Michigan State University</i></li><li>• Masahisa Katsuno, M.D. <i>Professor, Nagoya University</i></li><li>• Albert LaSpada, M.D., PhD <i>Distinguished Professor, Associate Dean for Research, Director Institute for Neurotherapeutics, U of California Irvine School of Medicine</i></li><li>• Andrew Lieberman M.D., PhD, <i>Professor of Pathology, University of Michigan</i></li><li>• Maria Pennuto, PhD <i>Associate Professor, Department of Biomedical Sciences, University of Padua</i></li><li>• Diane Merry</li><li>• Carlo Rinaldi</li></ul> |
| 2:20 – 2:30 | <b>Day 2 Wrap-up</b>   |