

2019 KDA CONFERENCE *PRELIMINARY* AGENDA

Orlando, Florida – 13-15 November



Please Note: This agenda is still in development and subject to change.

Tuesday, November 12	
6 pm	Meet in hotel lobby for optional Welcome Dinner
6:15 pm	Informal dinner at local restaurant (cost not included in registration)
Wednesday, November 13	
7:30 am	Registration/Sign-in
8:15 am	Welcome from KDA President Andrew Cassar
8:30 am	Introductions Around the Room Maria Montie, KDA Treasurer, with Members and Guests
9:15 am	Update on KD-UK and Planned Fundraising Initiatives Kim Slowe, Trustee <i>KD-UK</i>
9:35 am	Participation in Research: Good Will, Time and Hard Work: How to Strike a Balance Luca Zampedri, KD Research Nurse <i>UK National Kennedy's Disease Clinic and UCL Queen Square Institute of Neurology</i>
9:50 am	Break
10:20 am	Fatty Liver Disease and KD: What Does It Mean and What Should You Do About It? Karen Corbin, PhD, RD <i>Investigator, AdventHealth Translational Research Institute</i>
11:10 am	See More, Do More, Live More – Get Mobile! Jim Kissling <i>President, AutoFarm Mobility</i>
12:00 pm	Lunch
1:30 pm	Do's and Don'ts for KD'ers: What You Need to Know Jameson Parker KDA Vice President
2:00 pm	Managing the Emotional Roller Coaster of Kennedy's Disease JoDee Coulter, MT-BC, CT, CPT, and KD spouse.
2:45 pm	Break
3:15 pm	KD Patients, Partners and Carriers' Breakout Sessions
5:00 pm	Conference ends for the day. Dinner on your own.

Thursday, November 14	
8:15 am	Conference Updates and Directions for the Day
8:30 am	Exercise to Improve Functional Mobility in Kennedy's Disease Joseph A. Shrader, PT, C, Ped Senior Clinical and Research Physical Therapist, <i>NIH</i> <i>with</i> Jamel Joseph, MS, <i>NIH</i>
9:45 am	Break
10:15 am	KD-101: A Primer on Kennedy's Disease for Non-Scientists Ed Meyertholen, PhD
11:25 am	Who's Doing KD Research Around the Globe? Christopher Grunseich, M.D. Staff Clinician, <i>NINDS/NIH</i>
11:45 am	Development of a Selective Modulator of the Androgen Receptor AF2 Domain as a Potential New Treatment for Kennedy's Disease Elliot Ehrich, M.D., Chief Medical Officer, <i>Nido Biosciences</i>
12:00 pm	Lunch
1:30 pm	A Breakthrough in Treating Neurodegenerative Disease: SMA Dr. Richard Finkel, Chief of Neurology, <i>Nemours Children's Hospital</i>
2:20 pm	Moving Forward with SBMA Biomarkers Dr. Pietro Fratta, Clinician Scientist <i>University College London Institute of Neurology</i>
2:40 pm	Visualizing Proteostasis Decline in Aging and in Misfolding Diseases Laura Bott, PhD, Postdoctoral Fellow, <i>Molecular Biosciences, Northwestern University</i>
2:50 pm	Rescuing Neuromuscular Function in KD: Why One Therapeutic Agent May Not Be Enough Dr. Cindy Jordan, <i>Michigan State University</i>
3:10 pm	Break
3:40 pm	Round Table Discussion of Potential Treatments for Kennedy's Disease Moderator: Dr. Kenneth Fischbeck Distinguished Investigator, <i>NIH/NINDS</i>
5:00 pm	Set-up for Silent Auction and Dinner
6:00 pm	Early Reception – Cocktails and Beverages Silent Auction
7:00 pm	Dinner (included with conference registration) Announcement of 2019 KDA Grants Fundraising for the KDA – Louise Goforth, KDA Board Member
8:00 pm	Live Auction and Silent Auction Completion <i>Mingling with old and new friends</i>
Friday, November 15	
8:15 am	Conference Updates and Directions for the Day Andrew Cassar
	<i>The following four talks are by recipients of 2018 KDA grants.</i>
8:20 am	Excitation-Contraction Coupling Machinery in SBMA Muscle Marco Pirazzini, PhD, <i>Department of Biomedical Sciences, University of Padova</i>

8:35 am	Analysis of Androgen Receptor Phosphorylation Using a Multidisciplinary Approach Laura Tosatto, PhD, <i>Institute of Biophysics, National Council of Research, Italy</i>
8:50 am	Using Patient-derived Stem Cells to Model SBMA Helen Miranda, Assistant Professor, <i>Department of Genetics and Genome Sciences, Case Western Reserve University</i>
9:05 am	Selective Translation of Androgen Receptor Isoform A to Prevent PolyQ Mediated Toxicity Riccardo Cristofani, PhD, <i>Department of Pharmacological and Biomolecular Sciences, University of Milan</i>
9:20 am	Evaluation of the Effects of a Combined Treatment to Reduce the Adverse Effects of ARpolyQ in Cell and Animal Models of SBMA Angelo Poletti, Professor, <i>Department of Pharmacological and Biomolecular Sciences, University of Milan</i>
9:35 am	Updates from the Merry Lab Diane E. Merry, PhD, Professor, <i>Department of Biochemistry and Molecular Biology, Thomas Jefferson University</i>
9:55 am	Mechanism of Mitochondrial Dysfunction in Spinal and Bulbar Muscular Atrophy Naemeh Pourshafie, PhD Student, <i>NIH/NINDS</i>
10:05 am	Break
10:35 am	Src Signaling Is a Novel Therapeutic Target for KD Masahisa Katsuno, M.D., Professor, <i>Nagoya University</i>
10:55 am	Utilizing Zebrafish to Help Find a Treatment for Kennedy's Disease Dr. Heather Montie, <i>Philadelphia College of Osteopathic Medicine</i>
11:15 am	Research Update //Title forthcoming// Dr. Maria Pennuto, <i>University of Padova, Italy</i>
11:35 am	Investigating Mechanisms of Muscle Atrophy in Kennedy's Disease Samir Nath, M.D./PhD Student, <i>Lieberman Lab, University of Michigan</i>
11:55 am	Decoding AR Variants: Key to Outsmart SBMA? Carlo Rinaldi, M.D., PhD, Associate Professor <i>Department of Paediatrics, University of Oxford</i>
12:15 pm	Modeling SBMA Disease Pathogenesis: Toward Mechanism and Therapy Dr. Albert R. LaSpada, Professor, <i>Departments of Neurology, Neurobiology, and Cell Biology, Duke University School of Medicine</i>
12:35 pm	Wrap-up End of conference for all but researchers
12:50 pm	Researchers' luncheon and discussions