



2018 KDA Conference and Educational Symposium

# Solving the KD Puzzle

San Diego, California | October 31–November 2



## 2018 KDA CONFERENCE - PRELIMINARY AGENDA

Tuesday, October 30	
6:00 pm	<b>Meet in hotel lobby for optional Welcome Dinner</b>
6:15 pm	<b>Informal dinner at local restaurant</b> (cost not included in registration)
Wednesday, October 31	
7:30 am	<b>Registration/Sign-in</b>
8:15 am	<b>Welcome from KDA President</b> Andrew Cassar
8:30 am	<b>Introductions Around the Room</b> Members and Guests
9:15 am	<b>Family Planning with Kennedy's Disease: The PGD IVF Process</b> Dr. Heather Montie, <i>Philadelphia College of Osteopathic Medicine</i>
9:45 am	<b>Effect of Androgen Receptor on Digit Growth</b> Dr. Marc Breedlove, Rosenberg Professor of Neuroscience, <i>Michigan State University</i>
9:55 am	<b>Break</b>
10:30 am	<b>The UK National Kennedy's Disease Clinic: An Update on Biomarker Research Two Years On</b> Dr. Pietro Fratta, Clinician Scientist, <i>University College London Institute of Neurology</i>
11:00 am	<b>Mobility Devices: Something New to Consider</b> Ron Goldberg, CEO, <i>Isowalk, Inc.</i>
11:30 am	<b>How the Muscular Dystrophy Association Supports the KDA</b> Blaine McFadden, LCSW, CMC Care & Clinical Services Director, LA Territory, <i>MDA</i>
12:00 pm	<b>Lunch</b>
1:30 pm	<b>Don't Forget About the Women: Qualitative Study of Carrier Issues</b> Jill Wickham, SHFEA MSc MCSP (Physiotherapy Academic, UK)
2:00 pm	<b>Tips and Tricks for Managing Kennedy's Disease, featuring Tips from a Speech Therapist</b> Informal Discussion led by Jameson Parker, KDA Vice President, with Angela Kokkinis, RN, BSN, Clinical Research Nurse, <i>NIH Neurogenetics Branch</i>
3:00 pm	<b>Break</b>
3:30 pm	<b>Men's, Women's, Carriers' Breakout Sessions</b>
5:00 pm	<b>Conference ends for the day. Dinner on your own.</b>

Thursday, November 1

8:15 am	<b>Conference Updates and Directions for the Day</b> Andrew Cassar
8:30 am	<b>Exercise Intervention in KD Patients</b> Joanne Compo, <i>NIH/NINDS</i>
8:40 am	<b>Exercise to Improve Functional Mobility in Kennedy's Disease, Part 2</b> Joseph A. Shrader, PT, C, Ped Senior Clinical and Research Physical Therapist, <i>NIH</i>
9:55 am	<b>Break</b>
10:25 am	<b>Beginning with the KD Patient: An Empathic Multimedia Approach in Educating Healthcare Professionals</b> Jill Wickham, SHFEA MSc MCSP (Physiotherapy Academic, UK)
10:50 am	<b>KD-101 //and// How the KDA Makes Its Funding Decisions</b> Ed Meyertholen, PhD, Assistant Dean, <i>Georgetown University</i>
12:05 pm	<b>Lunch</b>
1:35 pm	<b>Research Undertaken at UCL Institute of Neurology in London</b> Prof. Linda Greensmith, <i>Graham Watts Laboratories for Research into Motor Neuron Disorders, University College, London</i>
2:00 pm	<b>Two Birds, One Stone: Growth Hormone Therapy in SBMA/NASH Patients</b> Yahya Wada, Research Technician, <i>NIH/NINDS</i>
2:10 pm	<b>Fishing for a Cure for Kennedy's Disease</b> Dr. Heather Montie, <i>Philadelphia College of Osteopathic Medicine</i>
2:30 pm	<b>Targeting the Cell Cycle Machinery to Modulate Androgen Receptor Phosphorylation in SBMA</b> Diana Piol, PhD, Post-doctoral Fellow, <i>Department of Biomedical Sciences, University of Padova</i>
2:45 pm	<b>Break</b>
3:15 pm	<b>State of the Art in Therapeutic Modalities</b> Christopher Grunseich, M.D. Staff Clinician, <i>NINDS/NIH</i>
3:40 pm	<b>Roundtable Discussion of the Global Effort Against Kennedy's Disease</b> Moderator: Dr. Kenneth Fischbeck Distinguished Investigator, <i>NIH/NINDS</i>
4:45 pm	<b>Set-up for Silent Auction and Dinner</b>
6:00 pm	<b>Early Reception – Cocktails and Beverages</b> <b>Silent Auction</b>
7:00 pm	<b>Dinner</b> (included with conference registration)
8:00 pm	<b>Live Auction and Silent Auction Completion</b> <i>Mingling with old and new friends</i>

## Friday, November 2

8:15 am	<b>Conference Updates and Directions for the Day</b> Andrew Cassar
8:30 am	<b>Developing Kennedy's Disease-related Assays Using iPSC-derived Motor Neurons</b> Thomas Durcan, PhD, Assistant Professor, <i>Montreal Neurological Institute, McGill University</i>
8:50 am	<b>Modulation of the Androgen Receptor AF2 Domain as a Strategy for SBMA Therapy</b> Ane Korff, PhD, <i>Taylor Lab, St. Jude Children's Research Hospital</i>
9:15 am	<b>Regulation of Androgen Receptor Expression level and Function in SBMA Pathology</b> Dr. Janghoo Lim, Associate Professor, <i>Yale School of Medicine</i>
9:30 am	<b>One Gene, Many Proteins: Investigating the Role of AR Isoform 2 as a Therapeutic Target for SBMA</b> Carlo Rinaldi, M.D., PhD, Associate Professor, <i>Department of Physiology, Anatomy and Genetics, University of Oxford</i>
9:45 am	<b>Transcellular Regulation of Protein Homeostasis in KD</b> Laura Bott, PhD, Postdoctoral Fellow, <i>Molecular Biosciences, Northwestern University</i>
10:00 am	<b>Break</b>
10:30 am	<b>Research Updates from the Merry Lab</b> Diane E. Merry, PhD, Professor, <i>Department of Biochemistry and Molecular Biology, Thomas Jefferson University</i>
10:50 am	<b>The Function of Deubiquitinating Enzyme USP7 in SBMA</b> Anna Pluciennik, PhD, <i>Department of Biochemistry and Molecular Biology, Thomas Jefferson University</i>
11:05 am	<b>Updates from the Lieberman Lab</b> Andrew Lieberman, M.D., PhD, Professor of Pathology, <i>University of Michigan</i>
11:25 am	<b>LaSpada Lab Updates</b> Anastasia Gromova, Phd Student, <i>La Spada Lab, Duke University</i>
	<b>Early Preclinical Symptoms of SBMA May Be Independent of Androgens</b> Dr. Cindy Jordan, <i>Michigan State University</i>
12:05 pm	<b>RNA-seq of Human iPSC Derived Motor Neurons Implicates Mitochondrial Dysfunction in SBMA</b> Naemeh Pourshafie, Phd Student, <i>NIH/NINDS</i>
12:15 pm	<b>Wrap-up – End of conference for all but researchers</b>
12:30 pm	<b>Researchers' luncheon and discussions</b>