## **2019 KDA CONFERENCE AGENDA**

Orlando, Florida – 13-15 November



Tuesday, November 12  5:45 pm Optional Meet & Greet, with KDA Board Members, Rosen Hotel's Poolside Bar & Grill 6:15 pm Dinner on your own  Wednesday, November 13  7:30 am Registration/Sign-in 8:15 am Welcome from KDA President Maria Montie 8:30 am Introductions Around the Room Maria Montie, with Members and Guests 9:15 am Update on KD-UK and Planned Fundraising Initiatives Kim Slowe, Trustee KD-UK 9:35 am Participation in Research: Good Will, Time and Hard Work: How to Strike a Balance Luca Zampedri, KD Research Nurse UK National Kennedy's Disease Clinic and UCL Queen Square Institute of Neurology 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 Investigator, AdventHealth Translational Research Institute 11:10 am See More, Do More, Live More – Get Mobile! Jim Kissling President, AutoFarm Mobility 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 Break 3:15 pm Breakout Sessions KD Patients (with Jameson Parker); KD Partners (with JoDee Coulter); KD Carriers (with Lou Tudor, past KDA President) 5:00 pm Conference ends for the day. Dinner on your own.		
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Thursday, November 14	
8:15 am	Conference Updates and Directions for the Day
8:20 am	KD-101: A Primer on Kennedy's Disease for Non-Scientists
	Ed Meyertholen, PhD
9:30 am	Who's Doing KD Research Around the Globe?
	Christopher Grunseich, M.D.
	Staff Clinician, NINDS/NIH
9:50 am	Break
10:20 am	Exercise to Improve Functional Mobility in Kennedy's Disease
	Joseph A. Shrader, PT, C, Ped
	Senior Clinical and Research Physical Therapist, NIH
	with Jamell Joseph, MS, NIH
11:30 am	Development of a Selective Modulator of the Androgen Receptor BF3 Domain as a
	Potential New Treatment for Kennedy's Disease
	Elliot Ehrich, M.D., Chief Medical Officer, Nido Biosciences
11:45 am	Utilizing Zebrafish to Help Find a Treatment for Kennedy's Disease
	Heather Montie, PhD, Philadelphia College of Osteopathic Medicine
12:00 pm	Lunch
1:30 pm	Targeted Therapy for Spinal Muscular Atrophy: Rescuing a Fatal Neurodegenerative
	Disease
	Richard S. Finkel, MD, Chief, Division of Pediatric of Neurology, Nemours Children's
	Hospital; Professor of Neurology, University of Central Florida College of Medicine
2:20 pm	Moving Forward with SBMA Biomarkers
	Dr. Pietro Fratta, Clinician Scientist
2.40	University College London Institute of Neurology
2:40 pm	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, Department of Pharmacological and Biomolecular Sciences,
	University of Milan
2:55 pm	Rescuing Neuromuscular Function in KD: Why One Therapeutic Agent May Not Be
2.55 piii	Enough
	Dr. Cindy Jordan, Michigan State University
3:15 pm	Break
3:45 pm	Round Table Discussion of Potential Treatments for Kennedy's Disease
	Moderator: Dr. Kenneth Fischbeck
	Distinguished Investigator, NIH/NINDS
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
	Mingling with old and new friends

Friday, November 15		
8:15 am	Conference Updates and Directions for the Day Maria Montie	
8:20 am	Mitochondrial Abnormality in SBMA iPSC-derived Motor Neuron-like Cells Xia Feng, PhD, Johns Hopkins University	
8:35 am	Analysis of Androgen Receptor Phosphorylation Using a Multidisciplinary Approach Laura Tosatto, PhD, Institute of Biophysics, National Council of Research, Italy	
8:50 am	Using Patient-derived Stem Cells to Model SBMA  Helen Miranda, Assistant Professor, Department of Genetics and Genome Sciences, Case Western Reserve University	
9:05 am	Selective Translation of Androgen Receptor Isoform A to Prevent PolyQ Mediated Toxicity Riccardo Cristofani, PhD, Department of Pharmacological and Biomolecular Sciences, University of Milan	
9:20 am	Peripheral Tissues in KD: Role of Skeletal Muscle, Metabolism, Mitochondrial Pathology Dr. Maria Pennuto, University of Padova, Italy	
9:40 am	Excitation-Contraction Coupling Disruption in SBMA Muscle Marco Pirazzini, PhD, Department of Biomedical Sciences, University of Padova	
9:55 am	Mechanism of Mitochondrial Dysfunction in Spinal and Bulbar Muscular Atrophy Naemeh Pourshafie, PhD Student, NIH/NINDS	
10:05 am	Break	
10:35 am	Modeling SBMA Disease Pathogenesis: Toward Mechanism and Therapy Dr. Albert R. LaSpada, Professor, Departments of Neurology, Neurobiology, and Cell Biology, Duke University School of Medicine	
10:55 am	Investigating the Role of AR Post-translational Modifications in SBMA Pathogenesis Diane E. Merry, PhD, Professor, Department of Biochemistry and Molecular Biology, Thomas Jefferson University Functional Role of USP7 in the Pathogenicity of SBMA Anna Pluciennik, PhD, Department of Biochemistry and Molecular Biology, Thomas Jefferson University	
11:25 am	Src Signaling Is a Novel Therapeutic Target for KD  Masahisa Katsuno, M.D., Professor, Nagoya University	
11:45 am	Decoding AR Variants: Key to Outsmart SBMA? Carlo Rinaldi, M.D., PhD, Associate Professor Department of Paediatrics, University of Oxford	
12:05 pm	Visualizing Proteostasis Decline in Aging and in Misfolding Diseases  Laura Bott, PhD, Postdoctoral Fellow, Molecular Biosciences, Northwestern University	
12:20 pm	Investigating Mechanisms of Muscle Atrophy in Kennedy's Disease Samir Nath, M.D./PhD Student, Lieberman Lab, University of Michigan	
12:40 pm	Wrap-up End of conference for all but researchers	
1:00 pm	Researchers' luncheon and discussions	