2017 KDA Conference Final Agenda

	Tuesday, November 7
6 PM	For those who signed up for dinner, gather in hotel lobby.
6:15 PM	Optional dinner at a la Lucia

	Wednesday, November 8		
7:30-8:15	Registration/Sign-in		
8:15-8:30	Welcome from KDA President Andrew Cassar		
8:30-9:15	Introductions Around the Room Members and Guests		
9:15-10:00	Genetics and Family Planning Alice Schindler, MS, CGC Genetic Counselor/Research Coordinator, <i>NIH</i> , <i>With</i> Heather Montie, PhD Assistant Professor, <i>Philadelphia College of Osteopathic Medicine</i>		
10:00-10:30	Break		
10:30-11:45	Using Exercise and Other Physical Therapy Interventions to Optimize Functional Mobility Joseph A Shrader, PT, C. Ped, Senior Clinical and Research Physical Therapist, <i>with</i> Vincent Shieh, BA, Post-Baccalaureate IRTA Fellow <i>Clinical Research Center, NIH</i>		
11:45-12:15	Maximizing Functional Independence: Modifying Tasks and Using Adaptive Equipment/Mobility Aids Kathy Farrell, MS, OTR/L, Clinical and Research Occupational Therapist <i>NIH</i>		
12:15-1:45	Lunch		
1:45-2:05	Quality of Life in Kennedy's Disease Robert Guber, M.D. Candidate, Special Volunteer <i>NIH/NINDS</i>		
2:05-2:50	Update on Nutrition in Kennedy's Disease Angela Kokkinis, RN, BSN Clinical Research Nurse, NIH Neurogenetics Branch		
2:50-3:20	Break		
3:20-4:50	Men's, Women's, Carriers' Breakout Sessions		

	Thursday, November 9
8:15-8:30	Conference Updates and Directions for the Day
8:30-10:00	KD-101 and
	How a Drug Gets Approved
	Ed Meyertholen, PhD
	Assistant Dean, Georgetown University
10:00-10:30	Break
10:30-10:50	Silencing of Mutant AR Co-activators as a Therapeutic Approach
	Manuela Basso, Assistant Professor
	University of Trento, Centre for Integrative Biology
10:50-11:05	Study to Identify Genetic Modifiers a/w SBMA Disease Progression
	Maher Budron, B.S., IRTA Fellow
11.05.15.15	NIH/NINDS
11:05-12:15	Speech and Swallowing from Soup to Nuts
	Dr. Neil Porter
10.15.1.20	Assistant Professor of Neurology, University of Maryland
12:15-1:30	Lunch
1:30-2:20	Respiratory Issues in Kennedy's Disease
	Noah Lechtzin, M.D., M.H.S.
2:20-2:50	Johns Hopkins University School of Medicine
2:20-2:30	Gene Targeting Strategies in SBMA: CRISPR and Antisense Oligonucleotides Christopher Grunseich, M.D.
	Staff Clinician, NINDS/NIH
2:50-3:10	Discussion of CRISPR and Gene Targeting Strategies
2.30-3.10	Chris Grunseich et al
3:10-3:40	Break
3:40-3:55	PolyQ Length-specific Engineering of a hiPSC Model of SBMA
	Xia Feng, Postdoctoral Fellow
	NIH/NINDS
3:55-4:05	The iPSC/CRISPR Platform at the Montreal Neurological Institute
	Lenore Beitel, PhD, Program Manager
	Montreal Neurological Institute-McGill University
4:05-4:35	Metabolic Alterations in SBMA
	Andrew Lieberman, M.D., PhD
	Professor of Pathology, University of Michigan Medical School
4:35-6:00	Set-up for Silent Auction and Dinner
6:00-7:00	Early Reception – Cocktails and beverages; Silent Auction
7:00-8:00	Dinner (Included with conference registration)
8:00-8:15	Success of the 2017 KDA Golf Scramble
	Guest Speaker - Charley Goforth
8:15-10:00	Live Auction and Silent Auction Completion; mingling with new and old friends.
	Auctioneer: Jameson Parker

8:30-9:00 9:00-9:15 9:15-9:30	Conference Updates and Directions for the DayResearch Updates from the Merry LabDiane E. Merry, PhD, ProfessorDepartment of Biochemistry and Molecular Biology,Thomas Jefferson UniversityRole of USP7 in SBMADr. Anna Pluciennik, PhDResearch Instructor, Thomas Jefferson UniversityThe Role of Deficient AR Nuclear Export in SBMA PathogenesisFrederick (Eric) Arnold, PhD StudentMerry Lab, Thomas Jefferson UniversityResearch UpdatesAndrew Lieberman, M.D., PhDProfessor of Pathology, University of Michigan Medical School
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9:15-9:30	Dr. Anna Pluciennik, PhD <u>Research Instructor, Thomas Jefferson University</u> The Role of Deficient AR Nuclear Export in SBMA Pathogenesis Frederick (Eric) Arnold, PhD Student <u>Merry Lab, Thomas Jefferson University</u> Research Updates Andrew Lieberman, M.D., PhD
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Ì	Andrew Lieberman, M.D., PhD
	Professor of Pathology, University of Michigan Medical School
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	Motor Neuron Diseases Using Worms as a Model System
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Ì	Molecular Biosciences, Northwestern University
	Break
10:30-11:05	Human Stem Cell Modeling of Kennedy's Disease
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	UCSD
11:05-11:25	SBMA iPSC Muscle Model and La Spada Lab Updates
	Anastasia Gromova, PhD Student
	La Spada Lab, UCSD
	Non-coding RNAs in SBMA
I	Naemeh Pourshafie, PhD Student
	NIH/NINDS
11:40-11:55	Links Between Kennedy's Disease and Autophagy
	Ryan Prestil, PhD Student
	NIH/NINDS
	Developing a Treatment for Kennedy's Disease
	Dr. Kenneth Fischbeck
	Distinguished Investigator, NIH/NINDS
12:20-12:30	Wrap-up