



THE GLOBAL KD FAMILY: TOGETHER AGAIN 2022 KDA CONFERENCE

Virtual and In-Person
San Diego, California | November 9-11, 2022

For more information go to: kennedysdisease.org



2022 KDA CONFERENCE AGENDA

Wednesday, November 9	
From 7:15 am	Registration/Sign-in/Continental Breakfast
8:15 am	Welcome and Overview of Patient Focused Drug Development Meeting (PFDD) Terry Thompson, KDA President
8:30 am	Patient Focused Drug Development (PFDD) Meeting Introduction <ul style="list-style-type: none"> • KDA Welcome (KDA President) • FDA Welcome and Opening Remarks (FDA TBA) • Overview Clinical of Kennedy's Disease (Dr. Chris Grunseich, NIH) Panel 1: Health Effects and Daily Impacts of KD, responding to these questions: <ul style="list-style-type: none"> • Kennedy's Disease Association - PFDD 2022 (kdapfdd.net)// Moderator/Discussant: Brian Ahangar/Ed Meyertholen
10:30 am	Break
11:00 am	PFDD Meeting (continued) Panel 2: Patient Perspectives on Potential Treatments, responding to these questions: <ul style="list-style-type: none"> • Kennedy's Disease Association - PFDD 2022 (kdapfdd.net) Moderator/Discussant: Brian Ahangar/Ed Meyertholen
12:30	Lunch
2:00	NIH Quality of Life Study (Dr. Abdullah Al Qahtani, NIH)
2:15 pm	Conference Participant Introductions and General Discussion
2:45	Caregivers: The Unsung Heroes of KD Jason Resendez, President and CEO, National Alliance for Caregiving
3:00 pm	Breakout sessions for KD men, women carriers, and spouses/caregivers <ul style="list-style-type: none"> • Note: Breakout sessions will be for in-person attendees only
Thursday, November 10	
8:15	Conference Updates and Directions for the Day Terry Thompson
8:30	Update on the Biology of KD Ed Meyertholen, PhD

9:10	Exercises to Improve Speech and Swallowing Beth Solomon, Senior Lead, Speech Pathology Section, <i>NIH</i>
9:40	Exercise and Your KD (tentative) Joe Shrader, Senior Clinical and Research Physical Therapist, NIH
10:00	Break
10:30	The French National Protocol for Kennedy's Disease Dr. Pierre-François Pradat Sorbonne University Department of Neurology
11:00	Managing KD: A roundtable with Clinicians, with Q&A Chair: Dr. Chris Grunseich, NIH, Dr. John Ravits, Dr. Tahseen Mozaffar, Dr. Brian Ahangar, Dr. Carlo Rinaldi Topics (Examples): Management of symptoms, regular visits to neurologists and other healthcare professionals, exercise, nutrition, psychological support, ...
12:00 pm	Lunch
1:30	Intro to Research Talks and KD Registry: Update and Analytics Terry Thompson
1:45	Presentations by 2020 KDA Grant Recipients Gerry Pfeffer (University of Calgary), Antonella Falconeri (University of Padova), Manuela Basso (University of Trento), Mariarita Galbiatti (University of Milan)
2:30	Break
3:00	Summary of Trends in KD Research: Roundtable with lab directors Chair: Dr. Kurt Fischbeck and TBD
4:00	Research Q&A
4:30	Announcement of 2022 KDA Grants and Waite-Griffin Fellowship Award
4:45	Set-up for Silent Auction and Dinner
6:00	Early Reception – Cocktails and Beverages Silent Auction
7:00 pm	Dinner (included with conference registration)
8:00 pm	Live Auction and Silent Auction Completion <i>Mingling with old and new friends</i>
Friday, November 11	
8:15 am	Conference Updates and Directions for the Day Terry Thompson
8:30 am	Panel: Disease Mechanisms* Chair: SRB Member
9:30 am	Panel: Emerging Therapeutic Targets* Chair: SRB Member
10:30 am	Break
11:00	Panel: Clinical Trials and Trends* Chair: SRB Member
12:00 pm	Wrap-up – Dr. Kenneth Fischbeck, Terry Thompson End of conference for all but researchers

Afternoon	Researchers' luncheon and discussions
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*Researchers will be placed in one of the panels based on their proposed presentations. They will be given a three-slide format to use, with one slide describing their study/project, a second describing their process in layman's terms, and third describing why their study/project is important for KD. Pharmaceutical representatives will be allotted 1-3 slides, if desired, to briefly describe/update their plans for any clinical trials.

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