



Draft Agenda (15 July 2024)

Saturday, 2 November	
9:00 am	Coffee in Foyer
9:45	Welcome KDA President
10:00	KDA Keynote Address Ms. Susanne Waite Founder and President Emeritus
10:15	The Ten Things You Need to Know About KD Ed Meyertholen, PhD
10:45	The KD Family: Genetics, Testing, and the Implications Alice Shindler, Lead Genetics Counselor, NIH/NINDS
11:10	Break
11:30	What We Are Learning About Carriers Abdullah AlQahtani, MD, MPH Johns Hopkins University
11:50	What's New in Mobility Devices? Jim Kissling, President, AutoFarm Mobility Note: Mobility devices will be on display in Room 3.
12:20 pm	Lunch
1:50	Tips from an Occupational Therapist Kathleen Farrell, OTR/L Occupational Therapist, NIH
2:20	An Emotional Roadmap for the Journey with Kennedy's Disease Dr. John Weaver, Psy.D. Owner, Stress Management & Mental Health Clinics
3:10	Break
3:30	Breakout Sessions KD Men, Carriers, Spouses/Caregivers (In-person only)
5:00	Conference Sessions End for the Day
6:00	Reception and Beginning of Silent Auction
7:00	Dinner (included with registration) Ballroom
8:00	Live auction and completion of silent auction Mingling with old and new friends

Sunday, 3 November

- 7:45 am Breakfast Buffet**
(Foyer)
- 8:45 Welcome to Day 2 and Announcements**
KDA President
- 9:00 Tips and Tricks for KD Men, with Q&A**
Moderator: Jameson Parker, KDA Vice President
KDA Board Members
- 9:45 KDA Umbrella Organizations: Value to KD Patients**
MDA, NORD, LONDC representatives
- 10:15 Break**
- 10:45 Advice from a KD Clinician, with Q&A**
Tahseen Mozaffar, MD
University of California, Irvine
- 11:25 NIH Natural History Study: Results and Implications**
Chris Grunseich, MD
NIH/NINDS
- 11:45 A Primer on KD Research**
Ed Meyertholen, PhD
- 12:20 pm Lunch**
- 1:50 Keynote Address for Research**
Kurt Fischbeck, MD, NIH (emeritus)
Al La Spada, MD, PhD, University of California, Irvine
- 2:10 Unexpected Prevalence of KD Gene Mutation**
Matteo Zanovello (*invited*)
University College, London
- 2:25 Clinical Trials Update**
Chris Grunseich, MD, NIH/NINDS
Biotech and Pharmaceutical Representatives
- 3:00 Break**
- 3:30 Reports from KDA Grant Recipients**
Carlo Rinaldi, MA, MD, PhD, Oxford University
Shinichiro Yamada, MD, Nagoya University
Alyson Sujkowski, PhD, Wayne State University
- 4:00 Researcher Roundtable**
Moderator: TBD
- 5:00 Conference Ends for the Day**

Monday, 4 November

7:30 am	Breakfast Buffet Foyer
8:20	Conference Updates and Introduction of Research Panels KDA President Panel Coordinator: Andy Lieberman, MD, PhD, University of Michigan
8:30	Panel 1: Disease Mechanisms and Characteristics Moderator: TBD
9:20	Panel 2: Therapeutic Targets Moderator: TBD
10:00	Break
10:30	Panel 3: Moving Into the Clinic Moderator: TBD
11:20	Research Summary TBD
12:15 pm	Conference Wrap-up KDA President
12:30	Conference Ends for All but Researchers
1:00	Researcher Luncheon and Discussion
3:00	End of <i>KDA 2024</i> Conference