

2024 CONFERENCE
NOVEMBER 2-4
Orlando, FL



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John and Debby Lauber

Anonymous



Saturday, 2 November

8:45 am Registration/Coffee, Pastries and Fruit

9:30 **Welcome**
KDA President

9:45 **KDA Keynote Address**
Ms. Susanne Waite, Founder and President Emerita

10:00 **The Ten Things I've Learned in My 25 Years with KD**
Ed Meyertholen, PhD

10:30 **The KD Family: Genetics, Testing, and the Implications**
Alice Schindler, Lead Genetics Counselor, NIH/NINDS

10:55 **Break**

11:15 **What We Are Learning About Carriers**
Abdullah AlQahtani, MD, MPH
Johns Hopkins University

11:40 **What's New in Mobility Devices?**
Jim Kissling, President, AutoFarm Mobility
Note: Mobility devices will be on display in Salon 4.

12:00 pm **Lunch**

1:30 **How to Increase the Impact of the KDA**
Terry Thompson, KDA President
Lew Myers, KDA Fundraising Advisor

1:45 **KDA Umbrella Organizations: Value to KD Patients**
Brian Lin, MDA,
Alli Ward, NORD

2:10 **An Emotional Roadmap for the Journey with Kennedy's Disease**
Dr. John Weaver, Psy.D.
Owner, Stress Management & Mental Health Clinics

3:00 **Break**

3:30 **Breakout Sessions** *(in-person only)*
KD Men – Moderator: Jameson Parker
KD Carriers – Moderator: Heather Montie
KD Spouses/Caregivers - Moderator: JoDee Coulter

5:00 **Conference Sessions End for the Day**

6:00 **Reception and Beginning of Silent Auction**

7:00 **Dinner** *(included with registration)*
Ballroom D

8:00 **Live auction and completion of silent auction**

Sunday, 3 November

Note: Time Change to Eastern Standard Time

7:30 am Breakfast Buffet

8:20 Welcome to Day 2 and Announcements
KDA President

8:30 Tips and Tricks for KD Men, with Q&A
Moderator: Jameson Parker, KDA Vice President
KDA Board Members

9:00 Tips from an Occupational Therapist
Kathleen Farrell, OTR/L, Occupational Therapist, NIH

9:25 NIH Natural History Study: Results and Implications
Chris Grunseich, MD, NIH/NINDS

9:50 Break

10:20 Advice from a KD Clinician, with Q&A
Tahseen Mozaffar, MD, University of California, Irvine
With NIH clinicians Angela Kokkinis, Chris Grunseich,
Abdullah AlQahtani

11:00 A Primer on KD Research
Ed Meyertholen, PhD

11:30 pm Lunch

1: 00 Keynote Address for Research
Kurt Fischbeck, MD, NIH (emeritus)
Al La Spada, MD, PhD, University of California, Irvine

1:20 Unexpected Prevalence of KD Gene Mutation
Matteo Zanovello, University College, London

1:40 Clinical Trials Update
Overview: Chris Grunseich, MD, NIH/NINDS
Vissia Viglietta, MD, PhD, Nido Biosciences –
Nido-361 Update
Gianni Soraru, MD, University of Padua –
Update on Clenbuterol trial
Milan Barnes, PT, NIH, Kruthika Doreswamy, MPH, NIH,
and Michael Sheehan, PT, NIH –
Use of wearable sensors in SBMA

2:30 Break

3:00

Reports from KDA Grant Recipients

Carlo Rinaldi, MA, MD, PhD, Oxford University –
Harnessing polyQ AR transcriptional activity to advance a gene therapy strategy in the SBMA clinic

Shinichiro Yamada, MD, PhD, Nagoya University –
Pathophysiology and development of symptomatic therapy for cold paresis in SBMA

Alyson Sujkowski, PhD, Wayne State University –
Using Drosophila exercise for therapeutic discovery in Kennedy's Disease

Kerri Schellenberg, MD, MMedEd, University of Saskatchewan –
Clinical characteristics and prevalence of KD in the indigenous populations of western Canada

Silvia Fenu, MD, Carlo Besta Institute, Milan –
Connecting SBMA international registries/databases: a retrospective study

4:00

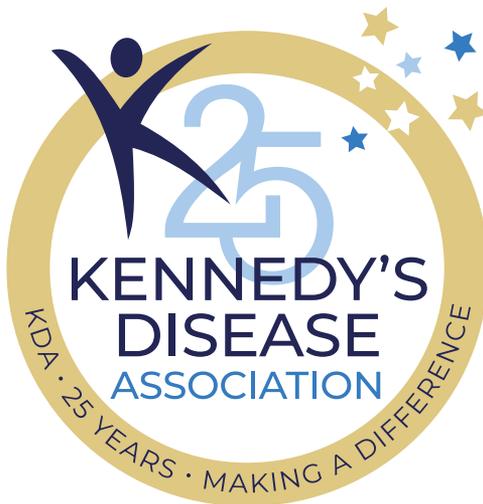
Research Summary and Q&A,

with senior researchers and lab heads

Moderator: **Diane Merry**, PhD, Thomas Jefferson University

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**
*Moderator: **Andy Lieberman**, MD, PhD, University of Michigan*
Janghoo Lim, PhD, Yale University –
Protein Homeostasis in the Pathogenesis of SBMA
David Luong, La Spada Lab, UC Irvine –
Delineating novel pathways of motor neuron demise in SBMA
Diane Merry, PhD, Thomas Jefferson University,
Tissue-specific repeat instability in SBMA
Caroline Rodrigues, PhD, Miranda Lab, Case Western
Reserve University – *Stem cell modeling of SBMA*
Heather Montie, PhD, Philadelphia College of Osteopathic
Medicine – *Does CD38 disrupt skeletal muscle function
in KD?*
Laura Bott, PhD, Northwestern University –
*Interindividual variation in protein misfolding disease:
Lessons from the model organism C. elegans*

10:00 **Break**



**Kennedy's
Disease
Association**

**2000
KDA
formed**



St. Louis, MO

**2002
1st KDA
Conference**

Baltimore, MD

New Orleans, LA

San Diego, CA

Atlanta, GA

Las Vegas, NV

Baltimore, MD

**2010
KDA's 10th
Anniversary**

San Diego, CA

Conferences

1968

1991

2000

'02

'04

'06

'08

2010

SBMA paper
Kennedy, Alter
& Sung

La Spada et al.
find expanded
CAG repeat in
AR gene in KD

Research
models



10:30

Panel 2: Translational Targets

Moderator: Diane Merry, PhD, Thomas Jefferson University
Gianni Soraru, MD, University of Padua – *Hearing function in KD: a case control study from a tertiary referral center*

Caterina Marchioretto, PhD, University of Padua – *From molecular pathogenesis to pharmacological intervention targeting skeletal muscle*

Riccardo Cristofani, PhD, University of Milan – *Proteostasis of androgen receptor*

Ramesh Narayanan, PhD, University of Tennessee – *Update on the preclinical development of AR N-Terminus domain binding degrader ONCT-505 for the treatment of KD*

Agamjot Sangotra and Andy Lieberman, University of Michigan – *Harnessing protein quality control to degrade polyglutamine AR in SBMA*

Ambra Speciale, DPhil candidate, Oxford University – *RNA editing dysregulation in SBMA: molecular mechanisms and therapeutic implications*

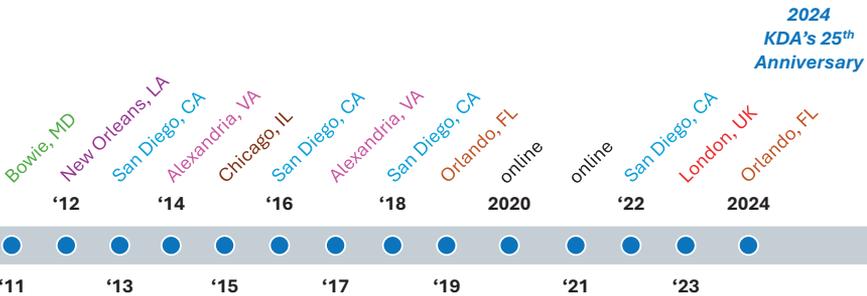
Brad Turner, PhD, and Jibao Yuan, University of Melbourne, Florey Institute – *Developing a brain-penetrating antisense treatment approach for SBMA*

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 KDA 2024 Conference**





THE KDA TEAM

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Jameson Parker, Vice President
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Kathy Thompson, Secretary
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Diane Merry, PhD
Pietro Fratta, PhD
Charlotte Sumner, MD
Alexander McCampbell, PhD
Christopher Grunseich, MD

Retired Board members who continue to assist:

Ed Meyertholen, Patient Advocate to the Scientific Review Board



The Kennedy's Disease Association

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