



## OUR MISSION

inform, support, educate,  
fund research, and find a cure  
for Kennedy's Disease

As 2019 closes, please remember the KDA in your charitable giving. Our mission is to inform, support, educate, fund research and find a treatment/cure for Kennedy's Disease. We can't do this without you. The KDA is run entirely by volunteers, which means over 90% of the money you donate goes directly to doctors and researchers seeking a cure.



## KDA News

[Visit the new and improved KDA website!](#)



A huge thanks to all who attended and participated in the 2019 KDA Conference! It was a great time to see old friends, make new friends and

connect with the many doctors and researchers seeking a treatment and cure. Our first conference in Orlando was also our highest attendance ever for a KDA conference, so you'll see us in sunny Florida again sometime in the future.

## Research Updates (with links to the papers)

- **Identical Twins with KD:** A case study of two identical twins with KD shows very different onset of the symptoms of Kennedy's Disease. One twin started showing signs at age 31 whereas the other not until he was 56. There were also several other differences in how the KD impacted their lives. Read more about it here: [Monozygotic Twins Discordant for Kennedy Disease: A Case Report.](#)
- **Molecular Mechanisms and Therapeutics for KD:** In an attempt to develop new therapies for people with KD, a paper by Frederick J. Arnold and Diane E. Merry provides a comprehensive overview of the many ailments that people with KD encounter. [Molecular Mechanisms](#)

- **Heat Shock Protein as a possible treatment:** It is believed that the long CAG repeat length in the androgen receptor is a mechanism that causes the protein to fold incorrectly and thus get trapped in the cell nucleus. The ability of Hsp70 to facilitate degradation of misfolded proteins makes it an attractive therapeutic target in polyQ diseases, of which KD is one. [Targeting Hsp70 facilitated protein quality control for treatment of polyglutamine diseases](#)

## Mobility Aids

Many thanks to Jim Kissling, owner/operator of [Autofarm Mobility](#), who filled an entire room with mobility aids for people to try out during the 2019 KDA conference.

Jim states that there should be no stigma with the use of mobility aids.

"No one feels weird because they use a spoon or a hammer. They are just the right tool for the job. Like a spoon or a hammer, a scooter or wheelchair is just a tool we use to live life."



**RESNA**

Rehabilitation Engineering and Assistive  
Technology Society of North America

### ATP: The right professional for mobility needs

You wouldn't go to your primary care doctor to get your teeth cleaned as this is not what they are trained to do. You shouldn't go to them to help you with your mobility needs either.

Whatever your mobility needs might be, an ATP (Assistive Technology Professional) can help you find the right technology aid for your needs. Also, they can take care of navigating the complicated insurance forms that are often required.

If you don't have a personal recommendation, the best way to find an ATP in your location is to use the RESNA directory.

<https://www.resna.org/member-directory/individual>

Other resources available on the RESNA site include

- State Assistive Technology Act Programs
- Assistive Technology Financing Programs
- Protection & Advocacy Programs (PAAT)
- Position Papers and Provision Guides

<https://www.resna.org/about/consumer-and-public-information>

Do you have a message to share with us? Let me know it! [jameson411@gmail.com](mailto:jameson411@gmail.com)

### KDA Memorial Page

If you have a loved one with Kennedy's Disease who has passed away and would like to have them added to the KDA memorial page, let us know at [Contact the KDA](#) with the information and a picture.

Click here to see the [KDA Memorial Page](#)

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