



OUR MISSION

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

KDA News

2019 Conference - Orlando FL - November 13-15

Response to sign-up for the 2019 KDA Conference has been overwhelming! For the first time ever we are forced to put a cap on the number of registrations because the conference facility is already nearly at capacity. If you would like to grab one of the last few slots, it's important to register as soon as possible.

[Information](#)
[Registration](#)
[Agenda](#)



Maria Montie is the KDA Interim President

A valuable part of the KDA board for several years, Maria is taking the presidency of the KDA this year. We are so happy to have you in the role Maria! [Click here to read her Bio](#) on the KDA website.

Andrew, we the board and the greater KDA community thank you for your dedicated leadership and service and hope to see you return to the board.

The KDA has connected with a group in Japan who supports people with SBMA. [Click here to see their website](#).

Research Updates

- **MDA Awards \$6.6M to 25 Scientists Working in Neuromuscular Diseases** - This grant includes research in CRISPR and Kennedy's Disease! [Click here for the MDA News](#)
- **Src kinase inhibitors (SKI) are candidate therapeutics for SBMA.** [Click here to read a](#) heavy-duty article in Nature about some positive results in SBMA mice studies.
- **Efficacy and safety of leuprorelin acetate for subjects with Kennedy's Disease.** Two separate studies suggested that leuprorelin acetate may be effective and safe treatment for KD. To learn more, click [here](#).

- **Muscle and not neuronal biomarkers correlate with severity in spinal and bulbar muscular atrophy.** This study suggests that Kennedy's Disease appears to impact the muscles more than the motor neurons. To learn more, click [here](#).
- **Kennedy's Disease Patients are More Likely to be Affected by Metabolic Disorders, Heart and Liver Disease.** *This is information you should share with your doctor.* [Click here to read more in SMA News.](#) You can also read the original [journal article clicking here](#).

Fund Raising News



Texas Golf Tourney held on Sept 28th, this years event was as successful as past years. It is likely just under \$30,000, the exact numbers will be shared at the KDA conference.



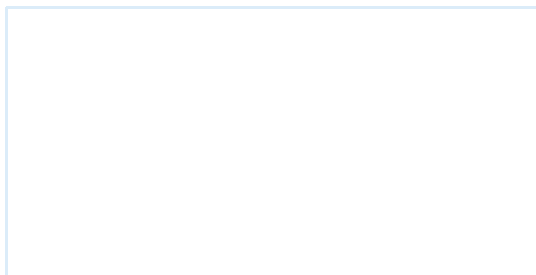
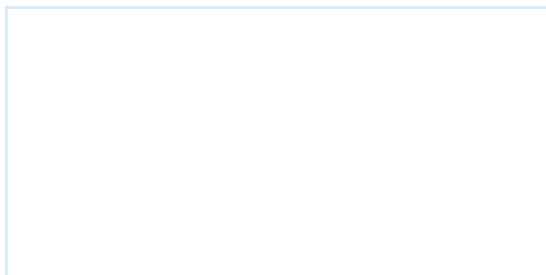
The Ed Montie 5K raised a record \$28,600 for Kennedy's Disease Association this year- Thank you Montie family, ShindelRock who donated half the amount as a match and thank you to the many many people who participated!

At this years conference, we will auction off a beautiful Slow Lane Guitar donated by Bill and Lou Tudor. Bidding will begin *before* the conference starts, more information in a few weeks!



Mobility Aids

Mobility aids are posted here because we think they may be of use or will give you an idea of ways to continue to live an active life. Unless otherwise stated, we have not tried these products and we do not recommend these items over similar products. We do not receive any payment to post items here.





The "Transformer" Scooter

Compact and light weight, electric folding mobility scooter - by Solex. 54 lbs with battery and carry a passenger up to 300 lb.

Advertised price: \$2,295

[See it in action here.](#)



EZ Lite Cruiser Wheelchair

Folds and fits in the trunk. 44 pounds (without battery), capable of handling passengers weighing up to 264 pounds.

Several models available. Advertised price: \$2,195 - \$2,625

[EZ Lite website](#)

Final Thoughts - Accept but don't surrender!

I have wondered "what I would have done differently if I had known about KD earlier in life?"

I was diagnosed in my late 50's. Long before I started to feel like I was trapped in an old man's body, I now realize that there were signs that I should have known were not from just a lack of exercise and being out of shape. My pride and stubborn nature pushed me to just keep working harder. I hope that had I known about KD I would have decided to work smarter and find a way to live well with KD.

For example, I hope that I would have accepted the need to hire others to do some work around the house that I was having trouble doing. In my 30s and 40s I fell off of a ladder cleaning the gutters often enough for my wife and daughter to fear for my safety every time they heard me getting out the ladder. Fortunately I have strong bones and a hard head. My worst injuries were scrapes, bruises, and sprained joints. However, those falls could easily have resulted in a broken limb or a fractured skull.

My limitations are now obvious, even to me; however it remains difficult to accept that there are more tasks that I can no longer do safely. It does not help knowing that when I see my wife mowing the lawn or handling the luggage when we travel. I still think "*I should be doing that!*" Acceptance is the hard work that KD gives us. But it is NOT the same thing as giving up. For me it meant finding and then taking joy in other routine tasks of life that I can do safely. For example I can prepare simple meals and then clean-up the kitchen.

My hope and prayer is that all of us living with KD work hard to take joy in what we can do and avoid what we cannot do safely.

- David Yelton, KDA Board Member, secretary and conference photographer.

Do you have a message to share with us? Let me know it! 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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