

# **OUR MISSION**

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

## 2019 Conference Announced - Nov. 13-15

This year's Kennedy's Disease Association conference is in sunny Orlando, Florida! Wed. November 13 to Fri. November 15.

Traditionally we have followed the location of the Society for Neuroscience conference with the aim that researchers who specialize in KD would come early to our conference. It turns out that we have a large, dedicated group of doctors and researchers many of whom have told us they will go where we go.

So this year, we decided to attend a warmer climate location to make the KDA conference

as accessible and available for as many KD families as possible. You will see hotel information and the ability to register in the near future. Hope to see you there!

#### **Dim Sum Give Some**

Monday, March 18th is the 3rd annual Dim Sum Give Some event.

"The Dim Sum Give Some Gala brings together fourteen renowned chefs from across the country in support of Kennedy Disease. Join Daniel Jacobs and friends, as they bring a new culinary experience to the Midwest."

We at the KDA are so very thankful to chef Daniel Jacobs and friends who organize this amazing culinary event. We wish you a smashing success this year.

To find out more about this event in <u>The</u> <u>Italian Community Center, 631 East</u> <u>Chicago Street, Milwaukee, WI - click on the link</u>



### **Exciting Discovery Published in Neurology Journal**

A multi-year study on KD patients from London, United Kingdom and Padova, Italy recently concluded. The title and link to the results are <u>"Muscle and not</u> <u>neuronal biomarkers correlate with</u> <u>severity in spinal and bulbar</u> <u>muscular atrophy"</u>

Here is a description about this paper from one of the researchers, Pietro Fratta, who informed the KDA about this important result.



"This work uses blood samples from 93 Kennedy's patients, alongside controls and samples from models of disease, to look for traces of neuron and muscle damage in Kennedy's disease. It finds that muscle damage is prominent, whilst neuron damage is below detection levels. This work highlights the role of muscle damage in Kennedy's disease, which is extremely important for how therapies are designed. Further, this study supports the use of a specific biomarker, creatinine, for Kennedy's disease clinical trials.

This study was possible only thanks to the incredibly strong participation to research of patients attending the Kennedy's Clinic at the National Hospital in London and the University of Padova."

This result opens new pathways to measure the effectiveness of possible treatments. The results are peer-reviewed and the paper is Open Access at this link: http://n.neurology.org/content/early/2019/02/20/WNL.0000000000007097

#### **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 <u>Contact the KDA</u> with the information and a picture.

KDA Memorial Page

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