

# DYSAUTONOMIA INTERNATIONAL



AWARENESS



ADVOCACY



ADVANCEMENT

Dysautonomia International  
P.O. Box 596  
East Moriches, NY 11940

December 2019

Dear Patients & Caregivers,

Thank you for your interest in participating on the Dysautonomia International Patient & Caregiver Advisory Board (PCAB). PCAB members help Dysautonomia International focus on topics of importance to the patient community we serve, and serve as an ambassador for Dysautonomia International in the broader community.

We have prepared an application form to help us select PCAB members that represent the broad diversity of the dysautonomia patient population and have the diverse skills needed to help us achieve our mission of improving the lives of people living with autonomic nervous system disorders. Please complete the application at this link by December 15, 2019: [bit.ly/PCABapp](http://bit.ly/PCABapp).

PCAB members serve two-year terms. A PCAB member can be re-appointed by the Board of Directors when their term is up if the Board and PCAB member would like to continue the relationship.

Serving on the PCAB requires a serious ongoing time commitment, more than a regular volunteer. Here's an overview of PCAB expectations and responsibilities:

- volunteering at least 10 hours per month throughout the year
- attending PCAB meetings by telephone every other month (usually held on a weeknight evening)
- regularly corresponding with fellow volunteers and staff via email
- taking the lead on one or more volunteer projects
- assisting with fundraising, with a goal of raising \$1000 or more per year
- sharing medically accurate information on autonomic disorders
- attending Dysautonomia International events in your area and the annual conference if possible
- serving as an ambassador for Dysautonomia International in the online and in-person community
- complying with all Dysautonomia International policies regarding conflicts of interest, ethics, non-discrimination, financial policies, etc.

Examples of volunteer projects PCAB members may take the lead on:

- writing articles for, or editing and publishing the Dysautonomia Dispatch blog,
- curating and scheduling social media content,
- obtaining, summarizing and organizing medical journal articles on autonomic disorders,
- creating and editing educational videos,
- supervising the translation of educational content to foreign languages,
- performing an annual review and updating the Dysautonomia International physician list,
- organizing online or in-person fundraising events,
- responding to email and telephone inquiries from patients and caregivers seeking guidance,
- and many other projects that need your skills!

Examples of volunteer projects PCAB members may assist with:

- recruiting and training new volunteers
- assisting researchers with study design and beta-testing
- providing interviews to the media
- developing content for Dysautonomia International's website
- annual conference planning
- regional event planning
- fundraising

Thanks again for your interest in serving the dysautonomia community. We look forward to reviewing your application and will be in touch after all applications have been reviewed.

Sincerely,

Lauren Stiles, JD  
Founder & President