

Narcolepsy Patient Organization



Our History

Emerged from the vision of 13 women from self-help groups across the US. In 1984, most of these women met for the first time. All were members of the American Narcolepsy Association (ANA), which no longer exists today. Originally convened as a task force charged with resolving ANA member issues, this group soon realized those issues were intractable, and instead began forming a new organization.

In 1986, the Task Team completed the Articles of Incorporation and Bylaws for the new organization.

In 1996, NN hired its first employee – a part-time office manager. In 1998, the first Executive Director was brought on. NN now employs six staff members and is governed by 11 Board of Trustees with various backgrounds.



Our Mission

Narcolepsy Network is dedicated to improving the lives of men, women, and children with narcolepsy. The organization's goals include increasing public awareness to foster early diagnoses; advocating for all persons with narcolepsy; promoting and supporting narcolepsy and related research; and providing education and resources both to people living with narcolepsy and the public at large.

After NN's first president was installed in 1986, it was decided that our motto would be: "CARE," standing for COMMUNICATION, ADVOCACY, RESEARCH, and EDUCATION.



Our Programs

Annual Conference: Approximately 75 members attended the first meeting. In 2016, we had over 400 attendees at our conference in Orlando, Florida. We meet at various cities through the US, usually in October, and offer a range of topics for PWNs and their supporters. Our next conference will take place on October 27-29 in Portland, Oregon.

Youth Ambassador Program: NN kicked off the Youth Ambassador (YA) Program, an outreach program for young PWNs, in 2015. The goal of the YA program is to educate and raise awareness about narcolepsy in classrooms and the community through presentations to teachers, nurses, community leaders, etc. The program decreases the stigma associated with narcolepsy, raises awareness about the condition among teenagers and adults who work with them, and presents accurate information about the condition to counter stereotypes.

Suddenly Sleepy Saturday: Every year, NN asks the narcolepsy community to submit a proclamation to their state governor or local mayor declaring Suddenly Sleepy Saturday, a day for narcolepsy awareness. In 2016, supporters in 37 US states requested proclamations. Governors of 18 states approved the request and issued proclamations, so did mayors in six US cities.



Our Programs (Continued)

Nexus Narcolepsy Registry: NN partnered with the Nexus Narcolepsy Registry, a collaboration of patient advocacy organizations including NN, leading narcolepsy researchers, and industry representatives. The goal of the registry is to track a large number of people with narcolepsy over several years. Volunteers were asked to complete a series of questions every six months - the questions asked about symptoms, diagnosis, treatments, and the ways narcolepsy affects day-to-day life. Findings from the registry will be published and shared at medical meetings with the hope of stimulating new research and discoveries that will improve diagnosis rates and treatments.

DREAM BIG! Walk: The DREAM BIG! Walk is a 2.5 mile that takes place in New York City along the Hudson River. Almost 80 people from across the country participated in the 2016 walk.

Bed Race: Five teams of enthusiastic narcolepsy supporters constructed, decorated, and raced beds around a parking lot to raise awareness and funds for Narcolepsy Network at the fourth annual Bed Race in Roanoke, Virginia.



The Role of the Executive Director

The Executive Director does the following:

- Manages and coordinates programs
- Attends various meetings
- Fundraises
- Manages staff and finances
- Advocates for PWNs (i.e. at the FDA)
- Keeps up with members
- Coordinates with medical professionals and is in contact with NN's Medical Advisory Board
- Represents NN

NN also employs an Office Manager, an Accounting Manager, an Outreach Coordinator, a Communications Coordinator, and an Office Assistant.

Faces of Narcolepsy Network



Members proudly showcase their proclamations received for Sudden Sleepy Saturday.



Attendees of the DREAM BIG! Walk pose for a photo.



In one of the most spirited fundraisers, participants of the Annual Bed Race try to out decorate and out run their opponents.

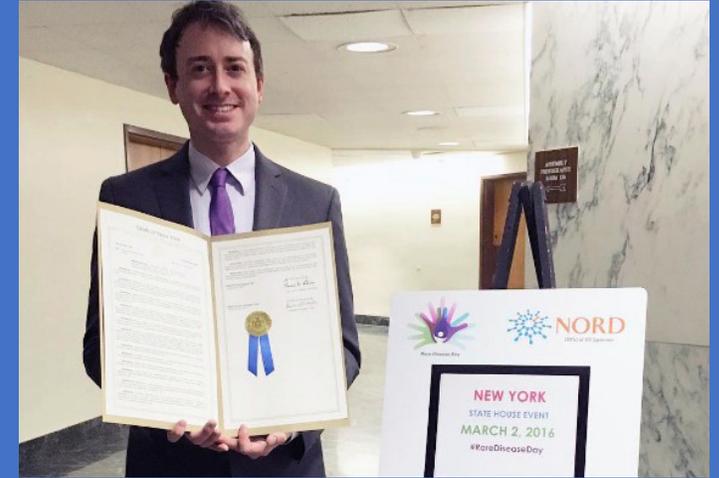
Faces of Narcolepsy Network



Dr. Michael Thorpy, MD, Dr. Judith Owens, MD, MPH, and r. Phyllis C. Zee, MD, PhD lead the Medication Panel Breakout Session at the 2016 Annual Conference.



Merrit Artim, a 2016 YA, stands in front of a presentation, ready to tell her community what narcolepsy is and how it affects daily life.



Board Member Keith Harper traveled to Albany, NY to meet with his local representative for Rare Disease Day.