Mission Statement

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 (PWNs), promoting and supporting narcolepsy and related research, and providing education and resources both to people living with narcolepsy and the public at large.

A Brief History of Narcolepsy Network

Narcolepsy Network emerged from the vision of 13 women from self-help groups across the United States — Mary Babcock (NE), Ruth Justice Nebus (NJ), Norma J. Potter (FL), Nicole L. Kephart (OR), Ann Matthes (MA), Eve Davis (NH), Sue Brockway Carella (CA), Niss H. Ryan (NY), Clair S. Sassin (DC), Jan Wright (CA), Violet Baumann, Blanche Baechalin, and Lorraine Baird (NJ).

In July 1984, most of these women met for the first time in Akron, Ohio. 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.

They elected Mary Babcock provisional President, decided on the name “Network,” and began outlining the new organization’s programs. Demonstrating the power of REM sleep, committee member Jan Wright awoke from a short nap inspired with the new group’s motto: “CARE,” standing for COMMUNICATION, ADVOCACY, RESEARCH, and EDUCATION.

In January 1986, the Task Team met at Chilton House in Shrewsbury, NJ, completed the Articles of Incorporation and Bylaws for the new organization, appointed Ruth Justice Nebus as its incorporator, and elected Niss H. Ryan, Sue Brockway Carella, Jan Wright, Norma J. Potter, and Ruth Justice Nebus as its founders. They incorporated the association in April, and held the first Narcolepsy Network Annual Meeting and election of officers in May in Shrevesport, NJ. Approximately 75 members attended that first meeting. Since then, NN has held annual meetings every year in various US cities.

From its first year, Narcolepsy Network opened communications with the National Institutes of Health, the few sleep disorders centers then in existence, and other key health and science leaders. Understanding and supporting relevant research, advocating for PWNs, and building the organization were foundational goals.

By 1988, the Network’s New York City conference drew 200 attendees. There, Dr. John Holloman received the first William C. Dement Research Award, and members staged a “Nap-In” in Central Park, gaining national attention and coverage on CNN. Members crisscrossed the country in the “Wake Up America” caravan as part of a concerted effort to raise both public and Congressional awareness about sleep disorders. This 12,000-mile journey bore fruit in 1993 when President Clinton signed The National Sleep Disorders Research Advisory Board into law.

By 1996, after 10 years as an all-volunteer organization, the growing Narcolepsy Network began hiring professional staff, including its first Executive Director. This allowed for further advocacy, organizational development, and physician outreach at such venues as the American Academy of Neurology and the National Science Foundation. Membership drives, health provider education, and fundraising efforts also became better coordinated.

What does the future hold for Narcolepsy Network? Since our founding, we have seen major advances in research and treatments. Technology has vastly increased access to information on symptoms, diagnoses, treatments, research, resources, and more. Our membership has grown significantly from its original 79. As newly diagnosed younger people join our organization, they bring with them the energy and creativity to advance NN and its goals into the future.
Dear Members and Supporters,

In 2016, Narcolepsy Network celebrated its 30th Anniversary - three amazing decades of advocating for those with this chronic condition. I personally want to thank all who have joined us and have dedicated their time, energy, talents, and resources to make NN the singular go-to organization for all things narcolepsy. From our annual conference, to our support groups, to our wide-ranging involvement in educational programs, we are a unique organization.

Here are some of the highlights of the past year:

The annual conference held in Orlando, Florida provided the opportunity for over 400 participants to interact with friends old and new, hear about the latest developments in the world of research and applied sciences, learn coping techniques to help in everyday life, and have the opportunity to be yourself. Every year, we hear from members that the conference is one of the major events in their year and 2016 was no different.

We awarded the Researcher of the Year award to Dr. Attila Szakacs for his ongoing work in the field of pediatric narcolepsy. Go to page 9 to read more about his research.

Additional Youth Ambassadors received training and have been successful in reaching out to their local communities, and using their personal stories to educate school and medical professionals about narcolepsy, thus effectively raising awareness.

Our members aided in spreading the word by having official Narcolepsy Awareness Day proclamations on March 12, 2016 in dozens of cities and states throughout the US, holding events such as a walk in New York City and a bed race in Virginia, and forming additional support groups. Many such groups have made use of NN's financial assistance in using the Meetup.com platform to help grow their memberships.

We had representation at several national conferences throughout the year, allowing us the opportunity to meet one-on-one with professionals who can have a significant impact on the lives of those with narcolepsy.

We will use 2017 to continue to grow the outreach of the organization. Staff members are staying current on the changing healthcare insurance laws with the anticipated restructuring of the Affordable Care Act and will keep the membership informed of these changes. Additionally, the annual conference moves back to the West Coast to the lovely city of Portland, Oregon.

Plan to join us in Portland, renew your membership, and be an active participant in your organization! Together we can do awesome things!

Mark Patterson, MD, PhD
President
Narcolepsy Network Board of Trustees
As far back as Jerry Stillkind could remember, he considered himself to be a night person – going to bed late and getting up late when his schedule allowed him to do so. In college, he avoided 8:00 AM classes and would nap if he felt it was necessary.

Jerry was a reporter and has worked for the Providence Journal, Associated Press in New York, and the Baltimore Sun, just to name a few. He said, “As a reporter, I was on a deadline and rushing around – you had to get the story in, that’s all that was to it. Period. It was probably a godsend! I was good at my job and it worked for me because I had to keep going to get the story done.” Jerry reflects on the time before his diagnosis and while certain things did not seem unusual, they could have been indicators that something else was going on. For instance, Jerry says, “I thought of myself as a great napper. If I needed to, I could nap on the top of a table or on the ground - anywhere!” During this time, Jerry worked nights. He would work until midnight or 2:00 AM and then was able to go home, sleep, do whatever chores he needed to do, take a nap if it was necessary, and then go back to work. “Problems began in the mid 1990s,” he goes on to say. “I started working during the day. I still had deadlines, but by late afternoon, I was beat. I was able to meet deadlines, but it was getting harder. That was one of the reasons why I went to see my original doctor. I knew something was going on.”

Jerry’s primary care physician did a battery of blood tests. His results showed up normal, but suggested that Jerry see a physiologist to see if there were underlying emotional or mental issues that were causing his fatigue. Jerry went to see his physiologist on a weekly basis and was prescribed antidepressant medications, but as Jerry put it, “none of them were any help.”

After Jerry retired in 2000, he was still suffering from excessive sleepiness. He stumbled across a sleep study done at the National Institute of Health in the Washington, DC area, where Jerry was from. He was accepted to the study, which was a series of polysomnographs. The study did not diagnose Jerry, but it was enough that he was referred to another doctor. From there, Jerry had another polysomnograph and it was during this time frame that he also had a multiple sleep latency test (MSLT) done. This time, the doctor indicated that Jerry could have narcolepsy, a disorder that Jerry did not know much about. His doctor referred him to yet another doctor for final diagnosis.

Jerry’s symptoms did seem to progress – he was feeling more tired, needing more naps, and not feeling refreshed after sleeping. His doctors prescribed stimulants to help with his excessive sleepiness. After a while, the stimulants did not seem to be effective. Jerry reflected, “I think I cycled through every medication that is on the market, even Xyrem. Xyrem really works wonders for some people, but I just couldn’t tolerate it.” Jerry said that getting older, too, doesn’t make the matters easier and brings on its own sleeping issues.

In 2005, Jerry attended his first NN conference in Boston. The first meeting was a real eye-opener. He met a lot of people with narcolepsy and saw firsthand what a person with cataplexy goes through, a narcolepsy symptom he never experienced. At the conference, Jerry heard coping mechanisms and the latest research. He added, “I enjoyed seeing and meeting other people with narcolepsy in one place. It’s also refreshing to hear that work is being done as far as research is concerned.” Since 2005, Jerry has attended every conference and enjoys meeting new people, reacquainting with old friends, and exploring a new part of the country he has never been to.

Currently, Jerry’s symptoms seem to be getting worse, though he admitted that age probably plays into this. He seems more tired each day and needs up to three naps to get by. He says that he does keep active in a theater discussion group, book clubs, lectures, and he goes to the movies often. Jerry added, “Sometimes, I may feel tired when I do these things, but I keep on going, and advise anyone to find an interest and keep at it for as long as you can.”
When Emily Baker was diagnosed with narcolepsy as a teen, she struggled to cope. Looking back, she thinks her symptoms started when she was around 11, although she was not diagnosed until high school. At first, she felt hopeless, struggling with depression and sleepiness. Emily explained, “I couldn’t see how I could ever succeed.” Medications helped a little, but it was hard for her to imagine a successful future when she was working so hard just to keep her head above water.

Trying Xyrem was a turning point for Emily. She found that the new medication helped a lot and it became easier to manage her symptoms. Once she was able to look beyond simply surviving, Emily took her first steps into raising awareness and educating people about narcolepsy. For a project during her senior year, Emily distributed educational materials about narcolepsy to school nurses in her area to help undiagnosed PWNs like her find help sooner.

Although finding the right medications helped, Emily still couldn’t drive and did not go to college. Between this and her remaining narcolepsy symptoms, she struggled to figure out how to make a living. Selling Mary Kay cosmetic products turned out to be a good fit since it gave her flexible hours and the ability to set her own work schedule. Emily also spread narcolepsy awareness through her connections with her clients, and for the past three years, she has used her Mary Kay business to raise money for narcolepsy.

As Emily started feeling better and became more empowered through her work with Mary Kay and raising narcolepsy awareness, she also got more involved in the narcolepsy community. In addition to working on local education and awareness efforts, she also went to a FDA meeting several years ago to share her experiences and joined the Flamel patient advisory meetings where she gave doctors and researchers feedback on what it is like to live with narcolepsy.

While she felt empowered by her narcolepsy advocacy and enjoyed the community connections she made through Mary Kay, Emily says she was still struggling with some of the more overlooked aspects of narcolepsy.

Like many PWNs, Emily had trouble with sleep eating and weight gain. She knew that the extra weight and her eating habits were not helping her narcolepsy or overall health, so about two years ago she started working with a health coach.

Changing habits can be tough, but through Emily’s determination and perseverance, she succeeded in losing 70 pounds all with the help and support of her coach. Her health coach helped her establish healthier habits like cutting back on carbs and sugars. While eating better and becoming more active was key to her success, Emily also says “having support from a coach has been really important.” She has maintained her weight for over a year and is excited by how much better she feels.

Emily’s new passion for health has also given her a new path to success and another opportunity to help the narcolepsy community. Her experience working with a health coach opened her eyes, not just to the importance of healthy eating, but also to the vital role health coaches can play in helping people make daunting lifestyle changes.

Advocating to others about the importance of healthy habits and eating better led her to become certified as a health coach herself.

For Emily, being a health coach is the perfect job. “Whatever I do,” she says, “awareness is at the core.” As a health coach, she can share her story and help other people with health issues, including other PWNs. She can work remotely over the phone, so there is a lot of flexibility and her narcolepsy isn’t a major issue. Most of all, she loves “having the ability to give back to the community and make a living doing it.”

Thinking back on her journey with narcolepsy, from her diagnosis and struggles with depression, to now working as a health coach and acting as a role model for newly diagnosed PWNs, Emily says that narcolepsy has really been a blessing in disguise. She commented, “I don’t know who I would have been without it. It made me a strong and determined person.”
2016 Highlights

Inaugural Youth Ambassadors Spread Narcolepsy Awareness

Several of our Youth Ambassadors (YAs) spoke to different groups, including a
group of educators, a boy scout troop, and medical doctors. All of the present-
tations were positively received and each of the YA teams reported that their
audiences had many questions.

The program continues to be a success. For instance, in April, the YA team
from Oconomovac, MI set up at a health fair that was attended by over 300
people. In June, the YA Team from Colorado worked at the NN booth at the
Annual Sleep Conference providing the sleep community with more informa-
tion regarding the YA program and information on what it’s like to be a youth
with narcolepsy.

NN is Represented on Rare Disease Day

In March, Eveline Honig, Executive Director for NN, and Board Mem-
ber Keith Harper traveled to Washington, DC and Albany, New York
to represent NN on Rare Disease Day. This is a day that hopes to raise
awareness for the 7,000 rare diseases and disorders, including narco-
lepsy, that affect nearly 30 million Americans. In the US, any disease or
disorder affecting fewer than 200,000 people is considered a rare dis-
ease.

In Albany, Keith met New York State Senator Kemp Hannon (R-Nassau
County) and also sat in the Senate chamber for the reading of the Rare
Disease Day proclamation.

In Washington, DC, Eveline participated in the Rare Disease Legislative
Advocates Conference and Lobby Day on Capitol Hill. The conference
focused on several bills and laws, especially the OPEN ACT (Orphan
Products Extension Now), which contains legislation that holds the potential to double the number of treatments
available to rare disease patients. Eveline was able to meet with the staff of Senator Chuck Schumer, Senator
Kirsten Gillibrand, and Representative Carolyn Maloney.

Annual Bed Race Once Again Provides a Unique Way to Spread Narcolepsy Awareness

Five teams of enthusiastic narcolepsy supporters constructed, dec-
orated, and raced beds around a parking lot to raise awareness and
money for Narcolepsy Network at the fourth annual Bed Race in
Roanoke, Virginia. Creating unusual and interesting events like the
bed race is key to breaking through the noise of everyday life and
generating more awareness.
2016 Highlights

Partnership Expands Online Information and In-Person Meetings

Narcolepsy Network, Global Genes, a leading rare disease patient advocacy organization, and Wake Up Narcolepsy (WUN) have partnered up on two endeavors that aim to spread information and awareness to the narcolepsy community and to the general public.

The first project is the online Narcolepsy Toolbox. The toolbox grew because both NN and WUN felt like there was a great deal of information for narcolepsy, but there was a need for a place to keep all materials. This project was designed for both newly diagnosed and for PWNs who want to go back to the site for reference. The Toolbox contains resources to help patients on their journey and tools for schools, employers, and the public.

The second project was the 2016 Narcolepsy Meetup Tour. The Meetup Tour brought together PWNs and their supporters in Seattle, Washington; Chicago, Illinois; Cambridge, Massachusetts, and Houston, Texas.

Support Groups Grow with the Help of an Online Tool

Narcolepsy Network is sponsoring support groups all across the country with a centralized map located at www.meetup.com/pro/NarcolepsyNtwrk.

What is Meetup.com? It is software built specifically to connect people online and get them together in the real world. It is a great tool to help you run a successful support group.
**2016 Highlights**

**Poster Presented at the SLEEP Meeting in Denver**

Dr. Mark Patterson presented a poster of the first wave results from the Nexus Narcolepsy Registry at the 2016 SLEEP meeting, the annual scientific and clinical meeting for sleep medicine physicians and sleep and circadian researchers. Showcasing the registry data at this and other conferences will help make sleep specialists aware of this valuable information, spurring them to conduct further evaluations and research in the field of narcolepsy.

From the over 500 PWNs who have completed the first questionnaire, this is just some of the information that has been obtained:

- Symptom onset was 19 years.
- Diagnosis was at 31 years old, for a delay in diagnosis of 12 years.
- 64% acknowledge narcolepsy-attributable impairment in non-work daily activities.
- 74% of patients report current use of medications for narcolepsy.

**NN Adds New Member to its Medical Advisory Board**

Narcolepsy Network is grateful for the members of the medical advisory board. They are a dedicated group of professionals who are working towards a better understanding of narcolepsy and how narcolepsy impacts everyday life. Our newest medical advisory board member is Dr. Jason Ong, Associate Professor of Neurology at Northwestern University Feinberg School of Medicine. Dr. Ong received his PhD in clinical psychology from Virginia Commonwealth University and completed a fellowship in Behavioral Sleep Medicine at Stanford University Medical Center.

He began his interest in narcolepsy at Rush Medical Center in Chicago, Illinois after a neurologist approached him to see if he could apply his knowledge of behavioral sleep medicine to a PWN. At that time, there wasn’t an established protocol to help patients cope with narcolepsy, besides managing daytime sleepiness with naps and sleep hygiene at night. Dr. Ong realized that he can apply his knowledge of how he treated other patients with other pain disorders to PWNs.

He is now hopeful that further studies can be done in this area and that there will be a role for behavioral sleep medicine. He envisions sleep clinics that not only have doctors who are knowledgeable in sleep disorders, but professionals who are able to educate PWNs on how narcolepsy affects psychosocial functioning. These professionals will help a PWN explain what narcolepsy is to other people, how to achieve life goals when symptoms may feel overwhelming, and other issues that may arise.

Dr. Ong hopes to bring his knowledge of behavioral sleep medicine to NN’s medical advisory board. He said, “We need more treatments and a cure [for narcolepsy], but in the meantime, we need to pay attention to the psychosocial aspect – what patients are going through, what are their needs, and how we address those needs. My perspective will hopefully reach not only NN, but the narcolepsy field.”

*Photo courtesy of Northwestern Medicine*
On October 21-23, PWNs, supporters, friends, and family descended on the B Resort and Spa in Orlando, Florida for the 31st Annual Conference. The conference kicked off Friday evening with a welcome reception and a surprise visit by a princess with a very fitting moniker. Princess Aurora, also known as Sleeping Beauty, was on hand to add a touch of Disney to the conference.

Saturday morning kicked off with breakfast and a presentation from keynote speaker Dr. Judith Owens MD, MPH, Director of Sleep Medicine at Boston Children’s Hospital in Boston, Massachusetts. Dr. Owens described potential behavioral treatment in patients with hypersomnia disorders, reviewed the evidence supporting behavioral treatment strategies in narcolepsy, and outlined potential approaches in incorporating behavioral interventions into treatment plans for patients.

Then it was time for the breakout sessions. There was something for everyone! In addition to the breakout sessions, there also was a membership meeting that highlighted two people who were honored for their work for spreading narcolepsy awareness.

Wanjiru Wa Nduati received the Public Awareness Award. This award is given to an individual who has made a significant or unique contribution to treating people with narcolepsy or a related sleep disorder. Wanjiru received this award for her work in her home country of Kenya and with her organization, the Narcolepsy Africa Foundation. The Researcher of the Year award was also given. This year, it was presented to Attila Szakacs, MD. He was honored for his exemplary record of professionalism and significant contribution of time, talents, and service to the narcolepsy community.

Sunday brought another day of breakout sessions. Before the conference came to a close, everyone gathered in the Grand Ballroom for a bit of reflection. This might have been the most inspirational part of the entire conference - one attendee after another spoke with sincere gratitude to finally be in a room where they were heard and understood.

We are already busy planning the 2017 conference which will be held on October 27-29 at the Marriott Portland Downtown Waterfront in Portland. We hope you will join us!
How did you become interested in narcolepsy?

In the late fall of 2009, an increasing number of patients with narcolepsy were identified at our clinics in Halmstad, Sweden and the Queen Silvia’s Children’s Hospital in Gothenburg. The patients appeared to have experienced a sudden onset of the disorder that came within months after vaccination against the H1N1 influenza virus. Intrigued by these patients, a research project was set up to study whether there was a possible causal relationship between the vaccination and the onset of narcolepsy. We also wanted to determine whether we could find any associated impact on mental health or cognition and how narcolepsy affected the children in their daily lives.

What impact do you think this research will have on our understanding of narcolepsy and/or its treatment?

In this population-based study with a well-described cohort of children and adolescents with narcolepsy both with and without association to the H1N1 influenza vaccination*, we found a 25 times higher incidence in the period after vaccination against H1N1 influenza compared with the period before. The children with Pandemrix-associated narcolepsy had a lower age at onset and a more sudden and pronounced onset than is generally seen. H1N1 influenza vaccination with Pandemrix is a precipitating factor for narcolepsy in children in combination with HLA-DQB1 *0602. Further genetic and immunological studies are needed to identify the exact mechanism behind H1N1 influenza vaccine-induced narcolepsy. We identified psychiatric comorbidity in 43% of the children with Pandemrix-associated narcolepsy and increased difficulties within verbal performance and working memory. This highlights the importance of a careful psychiatric and neuropsychological follow-up of all children and adolescents with narcolepsy. A narcolepsy-specific HrQoL instrument called the NARQoL was developed. HrQoL was tested with both the NARQoL and a generic QoL questionnaire and was found to be more globally affected when tested with the NARQoL. No previous studies have investigated the adaptive behavior of children with narcolepsy associated with the H1N1 influenza vaccination. Adaptive skills were tested using the ABAS-II questionnaire that focuses on basic adaptive skills with an everyday behavior approach. The parents of children in the PHV group rated significantly lower mean indices for the general adaptive composite, conceptual and social composites compared with the general population. These findings are strengthened by the decreased social confidence and a decrease in the school/concentration domain in the disease-specific HrQoL questionnaire, the NARQoL. The parents report on impaired adaptive behavior in their children and high parenting stress indicates a considerable impact on daily life. Psychiatric comorbidity showed a further impact on cognitive functions, HrQoL, adaptive behavior and parenting stress. Findings in this thesis highlight the complexity of narcolepsy and the need of a multiprofessional healthcare.

Where will your research take you in the future?

I consider that a long-term follow up of the children is very important to learn more about how narcolepsy develops during 10-15 years, especially during adolescence and young adult lifetime. For these, we need to expand our cohort of patients and repertoire of instruments to measure severity of narcolepsy. My research team is also interested in further cooperation with other teams investigating the genetic and immunologic aspects of the disorder.

You received the Researcher of the Year award at our conference this year. What does the award mean to you?

I felt very honored to receive this award and must say that I was extremely pleased to know that Narcolepsy Network appreciates the research that I carry out together with my research group. Our intention has always been to share the results that can improve patient care and lead, thereby, to a better life. We all strive to create a happy life for our families and our children, and for a hopeful future. Patients with narcolepsy must also have the opportunity to achieve all of these goals! The award will be used for this purpose and will have an immediate impact on our ability to perform ongoing research projects with focus on psychosocial health and quality of life of children and adolescents with narcolepsy.

*This study focuses on children and adolescents who received the Pandemrix H1N1 influenza vaccine that was given in Europe in 2009.
Thank You 2016 Donors!

Narcolepsy Network thanks the following donors, whose generous gifts made it possible for us to provide information and support to thousands of people living with narcolepsy and their families. We also thank those not listed who volunteered their time and energy to help further Narcolepsy Network’s mission.

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<tr>
<td>Rochelle Zoula, PhD</td>
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</table>
SLEEP CENTER MEMBERS
Carilion Clinic Sleep Center
Teresa A. Carroll
Roanoke, VA
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Board of Trustees conference calls were held on:
January 13, 2016
February 21, 2016
March 20, 2016
April 20, 2016
May 15, 2016
June 26, 2016
July 17, 2016
August 21, 2016
September 18, 2016
October 23, 2016 *
November 20, 2016
December 18, 2016

*The Board of Trustees met in person in October at the Annual Conference in Orlando.
Narcolepsy Network is fortunate to have supporters and donors who enable us to expand our programs and reach more people with narcolepsy and their loved ones. Each year, we strive to spread more awareness through campaigns such as Suddenly Sleepy Saturday, which asks governors and mayors across the United States to proclaim one day in March as a day for narcolepsy awareness. We have also been to several national conferences which brought us face-to-face with those who may work, teach, or interact with those with narcolepsy. Hopefully, the more we educate these professionals, the more we can change the misunderstanding and stereotypes of this disorder.

As we look forward, we will continue our mission of improving the lives of people with narcolepsy. We will continue to serve as a beacon of friendship in 2017 and beyond.

Warm Regards,

Louise O’Connell
Treasurer
Narcolepsy Network Board of Trustees

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**Narcolepsy Network, Inc. Financial Report**

**Statement of Financial Position - As of December 31**

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<td><strong>Assets</strong></td>
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<td>Cash and cash equivalents</td>
<td>$133,094</td>
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<td>Pledge receivable</td>
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<td>Prepaid expenses and other</td>
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<td>Investments</td>
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<td>166,296</td>
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<td><strong>Total Assets</strong></td>
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<td><strong>Liabilities</strong></td>
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<tr>
<td>Accounts payable and accrued expenses</td>
<td>$21,928</td>
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<td>Accrued payroll and related</td>
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<td>Deferred membership dues</td>
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<td>11,772</td>
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<td><strong>Total Liabilities</strong></td>
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<td><strong>Net Assets</strong></td>
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<td>Unrestricted</td>
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<td>Temporarily restricted</td>
<td>20,264</td>
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<td><strong>Total net assets</strong></td>
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<td><strong>Total liabilities and net assets</strong></td>
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**Statement of Activities - Years ended December 31**

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<td>Income</td>
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<td>Corporate Grants</td>
<td>$55,000</td>
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<td>National Conference*</td>
<td>139,675</td>
<td>158,067</td>
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<td>Contributions</td>
<td>96,959</td>
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<td>Membership Dues</td>
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<td>Other</td>
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<td><strong>Total Income</strong></td>
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<td>Membership</td>
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<td>Total Program Expense</td>
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<td><strong>Total Expenses</strong></td>
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<td>$410,526</td>
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Net increase (decrease) in net assets $(94,060) $(40,843)

*Conference Income includes corporate grants - $80,000 in 2016; $98,000 in 2015.

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**Five Year Revenue & Expense Comparison**


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**2016 Revenue Categories**

- National Conference 44%
- Contributions 30%
- Corporate Grants 17%
- Membership Dues 9%

**2016 Expense Categories**

- Public Information 36%
- National Conference 33%
- Membership 14%
- General & Administrative 12%
- Fundraising 5%
Donating to Narcolepsy Network

We express our sincere appreciation to all those who support Narcolepsy Network’s efforts. To make a donation, visit www.narcolepsynetwork.org. Please consult your lawyer for additional information on planned giving through a will, trust, or estate. Narcolepsy Network is a tax-exempt 501(c)(3) nonprofit organization. Your contributions are tax-deductible to the extent permitted by law. Please consult your tax advisor for details.

Other Ways to Support Us

If you do a lot of your shopping online, you can shop till you drop and help out NN at the same time. Just remember to go to www.smile.amazon.com for your online shopping, and switch any Amazon bookmarks to the corresponding Amazon Smile page. When a purchase is made through the Amazon Smile website, the company donates a portion of the purchase price of items you buy to an organization of your choice, like NN. It’s just like shopping on the regular Amazon site, but NN benefits. If you are new to Amazon Smile, the website will ask you to pick an organization when you first create your account and you can select “Narcolepsy Network” at that point. For returning users, you can select NN by going to Your Account and selecting Change Your Charity.

Another way to help out NN while doing your online shopping is using igive.com. Over 1,700 online stores participate with the igive.com program. Best of all, igive will often have special offers or coupons exclusively offered through their site, so you can benefit from these deals while also helping NN. To use igive, register with the website or download the app, then follow their list of links to stores and websites to shop online like you normally would.

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