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 people 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 Baechalín, 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), a group that no longer exists today. They originally convened as a task force charged with resolving ANA member issues, but realized those issues were intractable, and instead formed 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 team met in Shrewsbury, NJ, completed the new organization’s Articles of Incorporation and Bylaws, 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 organization in April, and held the first Narcolepsy Network Annual Meeting and election of officers in May. Approximately 75 members attended the first meeting. Since then, Narcolepsy Network has held Annual Conferences 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, Narcolepsy 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, which gained 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 ten years as an all-volunteer organization, Narcolepsy Network hired 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, diagnosis, 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 Narcolepsy Network and its goals into the future.
Dear Members and Supporters,

2018 was an exciting year for Narcolepsy Network. From our informative annual conference in Indianapolis, Indiana, to our meetings with regulatory groups, to our outreach programs, to our participation in numerous events, your organization has worked tirelessly to assist people with narcolepsy (PWNs). I am indebted to our staff, Board of Directors, volunteers, and friends in enabling us to accomplish so much.

Here are some highlights from 2018:

Conference attendees enjoyed the always friendly Midwest in early October. The local volunteer group was amazing and played a key role in making the event such a success. Speakers came to share their wisdom and experiences with the nearly 400 participants. We heard from Dr. Lois Krahn, of the Mayo Clinic, as she gave her keynote speech “Narcolepsy: Like It or Not, We Are All on a Learning Curve.” Other speakers presented data on the latest research findings, talked about how to deal with narcolepsy on a daily basis, and offered topics for people of all ages. Attendees, many there for the first time, left with an increased knowledge about narcolepsy, renewed hope, and the potential for life-long friendships.

Representatives from Narcolepsy Network met with officials from the Food and Drug Administration, educating them on the struggles PWNs face and the importance of new treatments to alleviate unmet needs. They were quite receptive, and changes have occurred subsequent to that meeting. Narcolepsy advocates once again traveled to Washington, DC for Rare Disease Week and met with legislators to advocate for PWNs.

Narcolepsy Network representatives participated in numerous activities, both nationally and internationally. Suddenly Sleepy Saturday saw proclamations from 27 US governors and 10 US mayors. fundraisers and awareness events ranged from across the United States to the rain-soaked streets of Dublin, Ireland and conference rooms in London, UK. Several Board members and staff met with some of our Medical Advisory Board at the International Sleep Conference in Baltimore, MD. Our Executive Director Dr. Eveline Honig and I attended the invitation-only 7th International Symposium on Narcolepsy, an event which brought together 100 of the world’s experts in the field of narcolepsy. Our Youth Ambassador program continued to train new advocates, several of whom have presented to educational leaders and groups on the effect narcolepsy has on the lives of students. Last, but not least, the amazing #TeamNarcolepsy ran in the TCS New York City Marathon, with all eight runners doing an incredible job.

2019 holds the promise of diverse changes, so I invite you to stay informed by continuing your membership with Narcolepsy Network. Please join us in Albuquerque, NM to build relationships, network with other PWNs, and gather essential information at our unique conference. If you have not previously attended, you will not be disappointed!
A Reason to Give: Sofia Andreocci

Thirteen is an age that can be exciting and confusing. Nancy Gibbs wrote an article for *Time* magazine about this tricky age. She asked, “What does it mean to be 13, backstage adults, watching on tiptoe, waiting to go onstage?” For Sofia, 13 brought her center stage with an invisible disorder.

This was a very hard time for Sofia. Her parents were in a motorcycle accident shortly before Christmas, which just so happened to be a few days before her birthday. Meanwhile, she received the news that her grandmother was diagnosed with breast cancer all while dealing with the normal hormonal shifts a young teen girl faces. Sofia turned to Google since she knew her symptoms weren’t just a part of growing up. She says, “I had such bad muscle weakness whenever I ended up laughing. I had to edit my personality – I was always super outgoing, but it was a downer that I had to brace myself every time someone told me a joke.” She adds, “The falling asleep and the constant urge to nap gave it away too.”

Her parents initially thought this was all part of puberty while her teachers thought Sofia just wasn’t sleeping enough at night. After several doctors came up empty handed with any answers, Sofia’s parents brought her to see a sleep specialist who ultimately confirmed her narcolepsy. The sleep doctor went through several medications to see which one would be the right fit. While she was on the right track for finding out which medication protocol worked for her, she was struggling in school. Sofia couldn’t stay awake for lessons or tests, and as a result, her grades suffered.

By the time Sofia reached the 9th grade, she knew she needed to receive accommodations, though she was ashamed to admit it. She explains, “Freshman year was really rough because I didn’t want to tell anyone [that I have narcolepsy]. I was afraid that people were going to look at me as inferior or that I wasn’t smart enough to be in a certain class.” She had a meeting with her teachers and principal to explain that she needed accommodations in order to succeed in school. This meeting did not prove to be positive for Sofia. She did not receive the accommodations that she needed and felt that her voice wasn’t heard because her disorder happens to be an invisible one.

While Sofia’s school finally granted accommodations for her in her sophomore year, her teachers didn’t always follow through on them. She didn’t want to speak up because she felt like her teachers would hold it against her if she brought up the subject, so she stayed silent. Sofia went to the Narcolepsy Network conference in Orlando, Florida where she heard speakers giving advice on learning to advocate for oneself and that inspired her.

By the end of 10th grade, Sofia was able to find her voice. She says, “I told them, I need [the accommodations] in order for me to graduate. I also recognized that I could redeem myself. Sofia continues, “By junior year, I got myself organized, and could feel [when a sleep attack was coming on]. I learned to stand up or chew gum when this happened.” Sofia also started to accept that narcolepsy was a part of her life.

Sofia says that her experiences have made her realize that public schools don’t always handle kids with invisible disorders properly. She explains, “I learned through this process that there are so many kids who have to deal with it on their own. It would be amazing to have regular students advocate for kids with disabilities to help eliminate the stigma.” She added, “I also want to help students learn how to advocate for themselves. If I learned how to do that sooner, I probably would have received better grades.”

In 2017, Sofia decided to apply to become a Narcolepsy Network Youth Ambassador (YA). She wanted to feel the sense of community from others who know exactly what she is going through. As a YA, she learned to educate a wide variety of audiences about narcolepsy including teachers and doctors. She says, “I learned the only way to advocate for yourself is through telling your own story.” All of this inspired Sofia to start a program at her school where kids with disorders can be paired with a student who does not have a disability. Together, the students work on coping and time management skills, learn how to be an advocate, and educate their teachers on their individual needs that will make them successful. Sofia hopes that every school in her district will have this program in place in the future.

Sofia looks forward to graduating high school in the spring of 2019 and she wants to be “part of eliminating the stigma that falls around disabilities.” She echoes that statement when she says, “I just want to help students get the help that they need, no matter the situation.”
In her late 20s, Kimberly was having thyroid issues and would later be diagnosed with Grave's disease. During this time, she attributed her tiredness to her thyroid issues. Then in her mid-thirties, her thyroid levels were off again. Her doctor prescribed a beta-blocker to slow her heart rate down in hopes Kimberly could sleep at night. Kimberly developed an asthmatic reaction to this medication. Her doctor of internal medicine took her off that medication and prescribed Lunesta for her sleep issues. She would only take this new medication occasionally, but even when she did, Kimberly still didn't feel refreshed.

At the time, Kimberly worked at a dental clinic that primarily served children on Medicaid. She was responsible for checking in 80-120 patients every day. She explains, “I felt like I could have taken a pillow with a room full of crying children, with cartoons on the TV, and fallen asleep.” While she didn't realize it at the time, she was experiencing automatic behavior and making mistakes when creating the clinic's schedule – her symptoms were starting to impede on her work. Soon after, her doctor suggested narcolepsy and scheduled a sleep study to confirm the diagnosis. Kimberly added, “I was able to explain away what I was feeling. After I received my diagnosis and I learned more, when I look back on my life, I can trace [my narcolepsy] back to grade school/middle school. I was able to explain away that I was over committed. I was staying up too late. I had too many responsibilities as a teenager or in college. Nothing would lead me to connect the dots.” Growing up, Kimberly admits to not being a morning person, always felt tired, and says that she does not have a good memory. She also struggled with school assignments that involved a lot of reading. However, she never brought up how she was feeling and assumed that everything was just a part of growing up.

In 2006, Kimberly was diagnosed with narcolepsy and started medication. Her neurologist also urged her to make some lifestyle changes. It took Kimberly another three years before she really understood what her diagnosis meant and how to accept it as a part of her life. She says, “When I was first diagnosed, I thought, give me my medication and I'll go on with my life.” In 2009, she hit a wall – spiritually, emotionally, mentally, physically – everything came crashing down.

She says, “I created coping skills on how to manage my tiredness. [During this time], those coping mechanisms weren't working. I could manage one thing that was out of control, but spiritually and emotionally, I just couldn't do it.” She decided to leave her job working at her church due to how the stress was affecting her health. She thought her bilingual skills would help her land another job soon after. Unfortunately, she was out of a job for about nine months. She did not have family that lived around her and was very close to having her home foreclosed on. That was the wake-up call that she needed. She says, “I knew I needed to manage my narcolepsy, otherwise, it'll manage me and I'll lose everything that I've ever wanted.”

In 2014, Kimberly connected with others through Narcolepsy Network’s closed Facebook support group page. She connected with another person from Indiana and from there, sparked the idea about forming a local support group. She says that first meeting of talking with someone else who shared similar experiences was transforming and validating. She added, “[After that meeting,] the battle in my head was over and now I could truly refocus.” Her support group, Naptown Narcoleptics, now meets once a month and encourages anyone in Indiana to join the casual group meeting.

Meeting others with narcolepsy is important for obtaining the much-needed support in order to take on this invisible disorder. Getting to share experiences with other PWNs is life-changing and indescribable. Kimberly added, “Sometimes you don’t even realize the struggles you deal with are connected with narcolepsy until you start to talk with others and realize, oh, you struggle with that too? It’s freeing and consoling that there’s someone else who understands. Connecting with other people and getting that validation, and seeing that there's life beyond the disorder, can help you realize that there are people who are making life happen.”

Kimberly is now living her best self. She offers this advice for anyone who is newly diagnosed or struggling.

“Give yourself permission to grieve. Allow yourself to experience the stages of grief. This is a healthy step towards managing life with narcolepsy as opposed to narcolepsy controlling your life.”

“Be kind to yourself and patient in the process. It will take time. Have open communication with your doctor to find the right combination of prescriptions, sleep hygiene, and behavioral and lifestyle changes that work best for your body.”

“Fight against social isolation by connecting with other PWNs. It’s easy to diminish the value of meeting another person living with narcolepsy.”

Finally, Kimberly says, “Empower yourself with knowledge and confidently advocate. Take advantage of online resources, organization websites, and books written by those living with narcolepsy.”

A Reason to Give: Kimberly Ratliff
2018 Highlights

Staff and Board Members Met with FDA Representatives

Narcolepsy Network’s President Dr. Mark Patterson, Executive Director Dr. Eveline Honig, and Board Members Keith Harper and Sharon O’Shaughnessy went to the Food and Drug Administration (FDA) to meet with officials responsible for drug evaluations. The meeting highlighted the struggles of living with narcolepsy from various perspectives, along with a discussion on how new treatments are needed.

Narcolepsy Advocates Went to Washington, DC for Rare Disease Week

In February, seven Narcolepsy Network advocates and board members joined 750 other advocates in Washington, DC to participate in Rare Disease Week. The event is an opportunity for patients, family, and rare disease advocates to connect with each other and meet with members of Congress. Meeting with lawmakers and their staff gave the opportunity to influence legislators and their staff. Our advocates shared their personal stories, experiences, and facts about narcolepsy. It was truly democracy in action!

Narcolepsy Bed Race Went International

The Narcolepsy Bed Race was a doubleheader in 2018. There were two races, one in Roanoke, VA and another in Dublin, Ireland. Members of two Irish narcolepsy groups, Narcolepsy in Ireland and SOUND (Sufferers of Unique Narcolepsy Disorder), joined in on this fun event. The race in Ireland took place at the Red Cow Moran hotel in Dublin. The hotel’s back parking lot was turned into a race course and a member of the Narcolepsy in Ireland group generously helped provide the beds. In addition to the two Irish narcolepsy organizations, and Narcolepsy Network, teams from Avadel Pharmaceuticals, and Narcolepsy UK also participated. The bed race took place in connection with the annual Irish narcolepsy meeting, so there were plenty of PWNs and supporters on hand to help decorate beds and cheer on the teams.

During the Roanoke race, every second counted and for a little while it looked like the race would be a three-way tie. In the end, the “Rock-a-Bye Baby” team turned in the fastest time of 37.5 seconds, narrowly beating out the Colonel’s Quacks and the Dream Team by just .5 seconds!
2018 Highlights

March 10, 2018 was Declared as Suddenly Sleepy Saturday

We once again asked the narcolepsy community to celebrate Suddenly Sleepy Saturday, also known as Narcolepsy Awareness Day, by requesting a proclamation officially recognizing the day from a governor or mayor. In 2018, 27 proclamations were granted from US governors and 10 from US mayors.

Youth Ambassador Represented Narcolepsy Network at a National Conference

Executive Director Dr. Eveline Honig and Youth Ambassador Mackenzie Zorn ran an exposition booth on behalf of Narcolepsy Network at the annual Parent Teacher Association (PTA) conference. They educated and advocated about narcolepsy and Narcolepsy Network not only to PTA members but also to other booth exhibitors as well. The booth increased the awareness of narcolepsy and the importance of recognizing this invisible disorder. NN’s presence at this conference was fundamental in broadening the awareness for narcolepsy specifically in regards to primary and secondary education.

DREAM BIG! Walk Held in Several Cities

In May, walkers of every kind gathered for the sixth DREAM BIG! Walk. From power walkers to leisure walkers, dog walkers to little ones just learning to walk, this was a fun-filled event for everyone. For the second year, the DREAM BIG! Walk took place all across the country! We had two official locations: New York City and Seattle, Washington. We also had several groups in various states that walked in their hometown.

We also asked our supporters to form Dream Teams. Dream Team Captains created fundraising pages and encouraged their friends, family, and co-workers to join their team and contribute. In 2018, 17 Dream Teams were created and they raised over $6,000! Several teams not only met their fundraising goal, but surpassed it.
2018 Highlights

Narcolepsy Network Represented at the International Narcolepsy Symposium

President Dr. Mark Patterson and Executive Director Dr. Eveline Honig were invited to participate at the International Narcolepsy meeting in Boston. Dr. Patterson presented a poster on cataplexy and they also gave a presentation on Narcolepsy Network’s activities.

“Get to Know Narcolepsy” Presented at the Annual SLEEP Meeting

Narcolepsy Network staff and board members met with some of NN’s Medical Advisory Board including Dr. Todd Swick, Dr. Thomas Scammell, and Dr. Lois Krahn. They met before the Annual SLEEP meeting, a joint venture of the American Academy of Sleep Medicine and the Sleep Research Society. At the meeting, Dr. Michael Thorpy, Dr. Bogan, and Executive Director Dr. Eveline Honig presented “Get to Know Narcolepsy.”

#TeamNarcolepsy Ran the 2018 TCS New York City Marathon

Narcolepsy Network was named as an official charity partner of the 2018 TCS New York City Marathon. The race provided a unique platform for the #TeamNarcolepsy runners to pursue their goals, while raising awareness for a cause close to their hearts - narcolepsy. We were excited to support them on their journey to the iconic finish line, as they raised important funds to benefit programs that support the narcolepsy community.

We are so proud of the eight gritty runners who finished 26.2 miles in our organization’s name. It is no small feat to finish a race of this length! Thank you again to our runners: Emily Jillette, Xenly Ancheta, David Younts, Jason Ruff, Christian Novello, Ijeoma Chimezie, Keith Harper, and Mee Warren.

In 2018, we raised over $36,000 and were in the top third of all fundraising charities. We also had a Cheer Zone in New York City as the runners raced towards the finish line.
2018 Highlights

2018 Conference: Accelerating Narcolepsy Awareness

Narcolepsy Network headed to the Midwest for our 33rd Annual Conference. On October 5-7, PWNs, supporters, friends, and family arrived in Indianapolis, Indiana.

The conference kicked off Friday evening with a welcome reception, mingling, and a chance to catch up with new and old friends. Saturday morning started with breakfast and the keynote speaker of Dr. Lois E. Krahn.

Then it was time for the breakout sessions. There was something for everyone! Some of the popular sessions included “An Integrative Health Approach to Narcolepsy” with Dr. Rubin Naiman, “Sleep Disorders in the Workplace” with a representative from the Job Accommodation Network (JAN), and there were sessions and support groups for a range of ages and needs.

On Saturday, we also handed out several awards to members who were active in their communities. We congratulate the following:

- The Ruth Justus Nebus Volunteer of the Year Award Winners: Kimberly Ratliff and Jessica Franklin
- Public Awareness Award Winners: Youth Ambassador Daria Hamilton, Youth Ambassador Sofia Andreocci, and Youth Ambassador Merritt Artim.
- Support Group of the Year Award Winners: Northwest Narcolepsy Support Group (Seattle, Washington) and Foothills Narcolepsy Support Group (North Carolina).

Sunday brought another day of breakout sessions. Before the conference came to a close, attendees gathered around to share their conference experience. Many came for the first time. Some were there for a loved one. Others were there meeting another person with narcolepsy for the first time. Everyone was grateful to be in a room where they were truly understood.

Narcolepsy Network would like to thank the staff of the Westin Indianapolis, the event planners of City Girl Events, all speakers and presenters, volunteers, vendors, and our sponsors of Jazz Pharmaceuticals, Avadel Pharmaceuticals, Harmony Biosciences, LLC, donors Dianne and Sam Kernell, and Takeda Pharmaceutical Company for making the 2018 conference a great success.

We hope you will save-the-date for the 2019 conference which will be held on October 25-27 in Albuquerque, New Mexico.
Q&As with Todd J. Swick, MD

Todd J. Swick, MD is board certified in neurology and sleep medicine (American Board of Sleep Medicine and the American Board of Psychiatry and Neurology with a sub-specialty in Sleep Medicine). He is Assistant Clinical Professor of Neurology at The University of Texas School of Medicine-Houston and is Senior Medical Director of Neurology and Sleep Medical Consultants of Houston. He has recently been hired as an International Sleep Medicine Consultant for the Medipert Sleep Medicine Center in Beijing, China. He is the Medical Director of the North Cypress Medical Center Sleep Disorders Center and Apxix Sleep Diagnostic Centers in Houston, Texas. He has been practicing in Houston, Texas for the past 34 years and has spent the last fifteen years doing sleep medicine on an exclusive basis. His practice is one of the largest in Texas.

In October 2014, Narcolepsy Network awarded him the Robert Clark, MD, Clinician of the Year Award. He serves as a national speaker on sleep medicine and neurology for national and international pharmaceutical companies such as Merck, Jazz Pharmaceuticals, XenoPort Pharmaceuticals, UCB Pharma, and Vanda Pharmaceuticals. In his role as an International Sleep Medicine Consultant, he has been asked to help to advise and develop the first private Sleep Medicine Center in The People’s Republic of China, Beijing.

Q. How did you become interested in narcolepsy?

A. As a neurologist, the neural control of sleep was an easy step into the field of narcolepsy and all disorders of excessive daytime hypersomnia. This, after all, was the prototypical sleep disorder emanating from the brain which was hypnotized in 1929 and proven in 1998.

Q. According to the biography on your website, you have been active in the field of sleep medicine since the 1980s. Since that time, how has sleep medicine/narcolepsy changed from when you first started?

A. We have learned more about sleep in the 30+ years I have been involved in sleep medicine than we have learned in the past 200 years. The discovery of orexin/hypocretin and the continuing research on the neural control of wake and sleep mechanisms is enormous.

Q. Do you feel that the perception of narcolepsy has changed since you first started in sleep medicine?

A. When I first started in sleep medicine, in the early 1980s, all patients with excessive daytime sleepiness were called “narcoleptic.” I remember seeing patients with obvious sleep apnea who would fall asleep in cars, while sitting, and even while working. They were classified as narcoleptic and were told “there is nothing we can do about that.”

Q. At our conference, we try to have as many youth tracks as possible and we continue to have more and more young people attend our conference. Do you think patients are getting diagnosed earlier? It is due to better awareness?

A. Narcolepsy typically starts in the teenage years. The pharmaceutical industry has started an outreach to better educate primary care practitioners, family medicine doctors, and pediatricians on how to evaluate patients with symptoms of excessive daytime sleepiness, cataplexy, and sleep disorders in general. The numbers of patients being diagnosed at an earlier age are increasing, but we still have a great deal more to do! One of the problems is that sleep medicine, even today, is given very short shrift in terms of education in the majority of US medical schools!

Q. Switching gears, you are serving as an International Sleep Medicine Consultant assisting in setting up sleep medicine centers in China. What is the perception of narcolepsy in that country versus here and how will these centers help?

A. China has a very high prevalence of narcolepsy as does most of Asia (Japan has the highest), but physicians and health care practitioners are limited in treatment options. China, like the US and most Western countries, does not readily recognize the myriad of symptoms of narcolepsy and puts them together to form an accurate diagnosis.

Q. Finally, you are always so gracious to speak at our conference. What motivates you to attend year after year and why is it important for doctors and patients to attend our conference?

A. I have always said, I learn more attending the Narcolepsy Network meeting by listening to patients with narcolepsy than any textbook, paper, or lecture. I get to hear the real trials and tribulations of PWNs and get to hear what works and what doesn’t work when it comes to their treatment. It is an honor for me to listen and learn from them.
Thank You 2018 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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Board of Directors conference calls were held on:
January 21, 2018
February 25, 2018
March 25, 2018
April 15, 2018
May 20, 2018
June 24, 2018
July 22, 2018
August 26, 2018
September 16, 2018
November 18, 2018
December 16, 2018

The Board of Directors met in person on:
October 8, 2018

*Sarah DiDavide left the Board of Directors in October 2018. Rajeev Sachdeva started serving on the Board in October 2018.
Narcolepsy Network continues to be grateful to our supporters and donors who enable us to reach more PWNs and expand our programs. One of our goals is to increase public awareness of narcolepsy and advocate for all those living with this invisible disorder. In 2019, we were able to do this in several ways. At the beginning of the year, we had the honor of speaking to representatives at the FDA to encourage the development of new medications. We were also able to be active at several large conferences to talk with those who are directly involved with the lives of children with narcolepsy. In the fall, we held our successful annual conference and we had eight runners participate in the New York City Marathon.

As we look forward, we will continue our mission of improving the lives of people with narcolepsy in 2019 and beyond.

Warm Regards,

Louise O’Connell, MS
Treasurer
Narcolepsy Network Board of Directors

Statement of Financial Position - As of December 31

<table>
<thead>
<tr>
<th>Assets</th>
<th>2018</th>
<th>2017</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cash and cash equivalents</td>
<td>$264,066</td>
<td>$101,324</td>
</tr>
<tr>
<td>Pledge receivable</td>
<td>---</td>
<td>10,000</td>
</tr>
<tr>
<td>Prepaid expenses and other</td>
<td>24,112</td>
<td>12,056</td>
</tr>
<tr>
<td>Investments</td>
<td>72,975</td>
<td>182,073</td>
</tr>
<tr>
<td><strong>Total Assets</strong></td>
<td><strong>$361,153</strong></td>
<td><strong>$305,453</strong></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Liabilities</th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Accounts payable and accrued expenses</td>
<td>$2,843</td>
<td>$29,070</td>
</tr>
<tr>
<td>Accrued payroll and related</td>
<td>2,952</td>
<td>2,952</td>
</tr>
<tr>
<td>Deferred membership dues</td>
<td>12,578</td>
<td>11,657</td>
</tr>
<tr>
<td><strong>Total Liabilities</strong></td>
<td><strong>$18,013</strong></td>
<td><strong>$43,679</strong></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Net Assets</th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Unrestricted</td>
<td>$305,714</td>
<td>$236,428</td>
</tr>
<tr>
<td>Temporarily restricted</td>
<td>36,426</td>
<td>25,346</td>
</tr>
<tr>
<td><strong>Total net assets</strong></td>
<td><strong>$342,140</strong></td>
<td><strong>$261,764</strong></td>
</tr>
</tbody>
</table>

| Total liabilities and net assets            | $360,153  | $305,453  |

Statement of Activities - Years ended December 31

<table>
<thead>
<tr>
<th>Income</th>
<th>2018</th>
<th>2017</th>
</tr>
</thead>
<tbody>
<tr>
<td>Corporate Grants</td>
<td>$72,000</td>
<td>$50,000</td>
</tr>
<tr>
<td>National Conference*</td>
<td>216,824</td>
<td>214,702</td>
</tr>
<tr>
<td>Contributions</td>
<td>145,418</td>
<td>95,360</td>
</tr>
<tr>
<td>Membership Dues</td>
<td>27,396</td>
<td>28,868</td>
</tr>
<tr>
<td>Other</td>
<td>3,600</td>
<td>7,563</td>
</tr>
<tr>
<td><strong>Total Income</strong></td>
<td><strong>$465,238</strong></td>
<td><strong>$396,493</strong></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Expenses</th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>National Conference</td>
<td>$165,328</td>
<td>$175,055</td>
</tr>
<tr>
<td>Public Information</td>
<td>78,223</td>
<td>97,236</td>
</tr>
<tr>
<td>Membership</td>
<td>56,747</td>
<td>68,580</td>
</tr>
<tr>
<td><strong>Total Program Expense</strong></td>
<td><strong>$300,298</strong></td>
<td><strong>$340,871</strong></td>
</tr>
<tr>
<td>General and administrative</td>
<td>64,841</td>
<td>65,463</td>
</tr>
<tr>
<td>Fundraising</td>
<td>19,733</td>
<td>16,712</td>
</tr>
<tr>
<td><strong>Total Expenses</strong></td>
<td><strong>$384,872</strong></td>
<td><strong>$423,046</strong></td>
</tr>
</tbody>
</table>

Net increase (decrease) in net assets

<table>
<thead>
<tr>
<th>2018 Revenue Categories</th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>National Conference</td>
<td>$150,000</td>
<td>$135,000</td>
</tr>
<tr>
<td>Contributions</td>
<td>$33,000</td>
<td>$40,000</td>
</tr>
<tr>
<td>Corporate Grants</td>
<td>$18,000</td>
<td>$28,000</td>
</tr>
<tr>
<td>Membership Dues</td>
<td>$16,000</td>
<td>$13,000</td>
</tr>
<tr>
<td><strong>Total Revenue</strong></td>
<td><strong>$187,000</strong></td>
<td><strong>$188,000</strong></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>2018 Expense Categories</th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>National Conference</td>
<td>$75,000</td>
<td>$73,000</td>
</tr>
<tr>
<td>Public Information</td>
<td>$27,000</td>
<td>$29,000</td>
</tr>
<tr>
<td>Corporate Grants</td>
<td>$24,000</td>
<td>$25,000</td>
</tr>
<tr>
<td>Membership</td>
<td>$15,000</td>
<td>$14,000</td>
</tr>
<tr>
<td>General &amp; Administrative</td>
<td>$10,000</td>
<td>$12,000</td>
</tr>
<tr>
<td>Fundraising</td>
<td>$5,000</td>
<td>$6,000</td>
</tr>
<tr>
<td><strong>Total Expense</strong></td>
<td><strong>$144,000</strong></td>
<td><strong>$145,000</strong></td>
</tr>
</tbody>
</table>
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. Consult your tax advisor for details.

Other Ways to Support Us

Shop Til You Drop While Raising Funds!

If you do a lot of your shopping online, you can shop and help out Narcolepsy Network at the same time. Just remember to go to www.smile.amazon.com for your online shopping. 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 Narcolepsy Network. It’s just like shopping on the regular Amazon site, but we benefit. 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 Narcolepsy Network by going to Your Account and selecting Change Your Charity.

Another way to help out Narcolepsy Network while doing your online shopping is using iGive.com. 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 us. To use iGive, register through their website or download the app, then follow their list of links to stores and websites to shop online like you normally would.

Create a Fundraising Campaign on Facebook

Are you thinking about doing something special for your birthday or other special event? How about create a fundraising campaign on Facebook where you can ask your friends to support your cause? To start a fundraiser, click Fundraisers in the left menu of your News Feed, then click Raise Money. Select Narcolepsy Network as your charitable organization, choose a cover photo, and fill in the details. Then click Create. That’s it!

Narcolepsy Network Staff

Eveline Honig, MD, MPH
Executive Director

Michelle Doherty
Accounting Manager

Kristin Fisher
Communications Coordinator

Christine Hackenbruck*
Executive Assistant

Joyce A. Scannell
Office Manager

*Started as Executive Assistant on April 1, 2019.