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 Baechaline, 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 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 the first meeting. Since then, the Network 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. Network 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 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 the 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 very significantly from its original 79. As newly diagnosed younger people join our organization, they bring with them the energy and creativity to advance the Network and its goals for the next 25 years and beyond.
A Message from the President

Dear Members and Supporters,

2017 was a whirlwind year for Narcolepsy Network! From our amazing Annual Conference in Portland, Oregon, to our outreach programs, to our efforts to understand the impact of healthcare coverage changes, 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 is a brief overview of some of 2017’s highlights:

Conference attendees were able to enjoy the sights and sounds of a surprisingly dry Portland during our weekend in October. Speakers came from across the US to share their wisdom and experiences with the over 400 in attendance. The keynote speech was given by the world-renowned narcolepsy expert Dr. Emmanuel Mignot of Stanford University; he discussed genetics and immunology. We also had the honor to meet and hear from Harley Emery, Miss Oregon 2017. Harley is an amazingly accomplished young adult who has dealt with narcolepsy in her life. As a physician and as a parent of a daughter with narcolepsy and cataplexy, I always come away from the conference with a renewed realization of the importance that Narcolepsy Network plays in the lives of so many.

Participants in our Youth Ambassador (YA) program continue to be trained - they have been empowered to reach out and educate people in their communities. In addition to local presentations, YA members have advocated for PWNs at national conferences and have been featured in numerous publications. We plan to continue the YA program during 2018 and encourage interested youth to apply for next year.

The changes in healthcare coverage in 2017 had an impact on many people throughout the US, not just those with narcolepsy. The Network made several appeals to its membership to contact their local representatives to discuss how the changes impacted them as they dealt with a chronic medical condition. Personally, I would encourage our members to remain engaged at their local and state level as this process continues to evolve.

On March 11, 2017 governors from 17 states and mayors from 12 US cities issued official proclamations for Suddenly Sleepy Saturday, also known as Narcolepsy Awareness Day. Additional awareness events in 2017 included the Network’s participation in several national conferences, a fundraising walking in New York City and Seattle, Washington, marathon runners, a bed race, and others.

I invite you to join us in Indianapolis, Indiana October 5-7 for our 2018 conference. If you have not previously attended, you will not be disappointed. If you are returning, welcome! During 2018, please remain an active member of Narcolepsy Network, as we all have something to contribute.
On paper, the act of acceptance seems like an easy thing to do. The dictionary definition seems almost like an afterthought. To accept something, according to Merriam-Webster means “to endure without protest…to regard as…normal, or inevitable.” For Mike, even with the signs of narcolepsy staring at him in the face, he still struggled to accept narcolepsy as a part of his life. It was a challenging road for him, but now he wishes to help others on their journey.

In 2010, Mike was working a lot and no matter what he did, he felt tired. He thought his symptoms were due to him “running a thousand miles an hour.” He had a job working from 9:00 PM-5:00 AM and would try his best to stay awake, but ultimately, he was let go for falling asleep on the job. After he was terminated, he realized that instead of working, he was sleeping more and more. Other symptoms seemed to become more apparent as well, like hallucinations and vivid nightmares at night. Mike finally made an appointment with his doctor.

Mike recalls his primary care physician saying to him, “You drink a lot of caffeine, and you’re still tired. You’re taking vitamin B supplements, and you’re still tired. You’re sleeping 8-10 hours at night, and you’re still tired.” The doctor recommended a sleep study which determined his narcolepsy diagnosis.

Even with the knowledge of being diagnosed, Mike ignored it. He said, “I have this diagnosis, that’s all I need. I thought I probably just needed to nap more or have a better sleep hygiene – I didn’t take it seriously.” He ended up on Xyrem, but really wasn’t focusing on his health. After six months, his insurance ran out as did his prescription. His mindset went from “I have to figure out what’s wrong” to “I know what’s wrong” to “whatever, I just need to keep moving on.”

Rock bottom seemed to hit after getting together with some friends one evening. When he left his friend’s house, who lived about 45 minutes away, it took him two and a half hours to get home because he kept blacking out and would wake up in a new intersection and didn’t know where he was. Mike recalls, “I was just mindlessly driving through of the night. When I woke up, I hit a hydrant in front of my house.” His now wife said, “It’s time to do something.” After this, Mike finally took the steps to research his disorder to really understand how to treat it.

He was trying to deal with narcolepsy as best he could. He tried several medications in hopes that something would work. He was also able to find employment where he could work three days a week at home. “I was trying to find balance. I was afraid that I would become disabled. At this time, I fully respected the disorder, but I didn’t know if I would ever to have a normal job again.” On the positive side of things, it was during this time that he took better care of himself, making sure that he had a strict sleep schedule. However, he was self-conscious and did not want to talk about narcolepsy with anyone except for his roommate and wife.

It wasn’t until he met someone online with narcolepsy that he felt like the future wouldn’t be so bleak. He explains, “I didn’t think I could be happy. Every night was a stress-filled dream – it was a hallucination. It wasn’t until I found someone online [who had narcolepsy], who was going through the same thing, that I was able to see that it’s not just me. There was hope.”

It was around this time that #nchat on Twitter was created. At this time, Mike still felt a bit of shame with narcolepsy. He found himself venting about his disorder and started hashtagging narcolepsy. Over time, others started to catch on and they decided to create a question and answer session on Twitter. The sessions welcomed all comments about narcolepsy. Mike finally started to not feel alone with this disorder. He says, “I could finally talk to people about narcolepsy and see others do the same thing.” The Q&A sessions are still active on Twitter and usually happen on the first Saturday of the month at 5:00 PM ET – just follow #nchat to join the conversation.

At the 2017 conference, Mike accepted the Public Awareness Award on behalf of the Arizona Support Group. He got involved with that group because he wanted to meet someone face-to-face with narcolepsy. He was at first apprehensive about joining a support group because he thought he would be walking into a group meeting with “a group of sad people,” but he went anyway. The support group turned out to be a positive experience. Mike says, “We will share bad times, but we’ll also share happy times like new careers, weddings, babies – those make it special.” He also says that going to a support group made him finally realize that he could accept his disorder. He explains, “It’s one thing to read that [narcolepsy] is hard on someone. It’s another to watch it before your eyes. You’ll see someone who is feeling down and watch them smile for the first time in months wanting to talk about their experience. It made an impact.”

Mike’s interaction with both #nchat and his involvement with the support group gave him a drive to want to help others. He seems at peace with his diagnosis. He says, “Not only do I feel like I can accept help, but I can help others. I can pay it forward.”
Mackenzie is like any other teen. She's busy with school and sports and has her sights on college and dreams about the future. The difference is that she has narcolepsy. At the age of ten, Mackenzie came down with the flu. More specifically, she had a confirmed case of the H1N1 virus. A couple months later, she still didn't feel like herself. While she admits that she was always one who took a long time to recover from an illness, this time was different. She explains, “I would always nap when I was younger, but it wasn’t excessively.”

Her parents also noticed that something was wrong. While she was home schooled, Mackenzie’s mother would find her sleeping on books while trying to do her work – a characteristic that was unlike Mackenzie. She also started to show signs of cataplexy and would have difficulties walking from room-to-room. She went to doctor’s and found herself at the Children’s Hospital of San Diego who were stumped about what was going on. They thought her cataplexy was a sign of epilepsy.

While at the Children’s Hospital, Mackenzie’s mom asked for a sleep study. The study pointed to narcolepsy and was finally confirmed by Dr. Mignot, the renowned Director of the Stanford Center of Sleep Sciences and Medicine and the Center for Narcolepsy.

About fours years after diagnosis, Mackenzie enrolled at a public charter school. At the beginning, she says “I would push through. Every day during third period I would feel super tired at math.” Her parents let Mackenzie make the decision as to whether she wanted to tell her teachers about her narcolepsy. She didn't tell her teachers during her freshman year. She said that she still wasn't as accepting or open with her diagnosis just yet. Her mom did get accommodations for a room to rest in if she needed it, but Mackenzie as she says, “refused to use it.” During her sophomore year, she realized that she needed to have a 504 plan, which is a blueprint for how the school would provide support to a child with a disability, for if she needed extra time to rest before tests. Her school isn't opened on Mondays, so her plan also included coming in on those days for tests if she needed to. The plan helped her then going forward in her junior and senior years.

As Mackenzie worked her way through school, she began to not feel ashamed of her narcolepsy. She explains, “Most people have never heard of narcolepsy. I was glad to be the one to tell them about it. Hopefully, they will begin to understand [what narcolepsy is].”

In 2016, Mackenzie signed-up for Narcolepsy Network’s Youth Ambassador (YA) Program, a national program designed to train promising young members of Narcolepsy Network to advocate for people with narcolepsy. She says, “I wanted to get involved because I know how helpful it’s been to talk with teachers about narcolepsy. It’s useful [to talk with teachers] because there may be kids who have narcolepsy and don’t want to talk about it or may not even know that something is wrong.”

As a YA, Mackenzie enjoys giving presentations because so many know little about the disorder other than what they see from the entertainment industry. She presented to the faculty at her school, to some doctors at a hospital, talked with the coaches at her school, and attended the National Association for School Nurses convention. She even hosted a local event called “Knockout Narcolepsy” at a kick boxing club. As Mackenzie reaches more people, she says, “The most rewarding aspect of being a YA is bringing awareness to people. Most people are appreciative for the knowledge. They can then have understanding for students or even family members who may narcolepsy.”

Mackenzie has not let narcolepsy stop her. She has some advice for other young children who may be going through the diagnosis process. “At the time, your life seems shifted, but look at all those people with narcolepsy who are successful. You feel like there’s no light at the end of the tunnel, but there is. There’s hope for future for a cure, so stay positive. For the parents, it’s important to have a constant support system. The child isn’t choosing narcolepsy, so support is key.”

Mackenzie is hopeful for the future and wants to pursue a career as a physician assistant focusing on neurology. Her experience as a patient and talking with neurologists, and learning about how the brain functions has inspired her interest. Mackenzie can see herself helping others since she has first hand knowledge of her disorder.
2017 Highlights

5th Annual Narcolepsy Bed Race a Success
For the fifth year, we asked participants of the Narcolepsy Bed Race to stay in bed late, as long as it had wheels! This is one of a kind event raised money for Narcolepsy Network while having a great time racing beds around a parking lot. Awards were given for the fastest bed, most funds raised, and best design. A team called the Colonel Quacks won the event by three seconds. The team that ended in second lost not only one wheel but two, and carried their bed around the course to the finish line.

March 11, 2017 Declared as Suddenly Sleepy Saturday
Suddenly Sleepy Saturday, also known as Narcolepsy Awareness Day, was held on March 11, 2017. Suddenly Sleepy Saturday falls on the day before Americans turn their clocks ahead one hour for daylight savings time, a time when even those who do not have narcolepsy may experience sudden sleepiness or daytime drowsiness, just as people with narcolepsy do every day.

In 2017, supporters in 31 US states requested proclamations. Governors of 17 states approved the request and issued proclamations, so did mayors in 12 US cities.

Narcolepsy is Represented at In-District Advocacy Days for Rare Diseases
In August 2017, several board members and NN’s Executive Director Eveline Honig attended the in-district advocacy days for rare diseases in New York City. The rare disease advocates met with Brook Gesser from the office of US Senator Kirsten Gillibrand. The group talked about narcolepsy in detail and the importance of sponsoring the Open Act. The Open Act will allow the repurposing of medicines for rare diseases. It is critical to add co-sponsors to the Open Act to increase the number of FDA improved treatments for rare diseases.

Board Member Raises Funds While Running NYC Marathon
Keith Harper, VP of NN’s Board of Directors, ran the 2017 TCS New York City Marathon. He ran to raise narcolepsy awareness and funds for NN. Over $2,000 was raised!

We’re excited to announce that Narcolepsy Network has been selected as an Official Charity Partner for the 2018 TCS New York City Marathon. Narcolepsy Network joins more than 350 official charity partners in the biggest marathon in the world.
2017 Highlights

When Narcolepsy Lets Us Down, Understanding Lifts Us Up

In early fall, we kicked off the “LiftUsUp Campaign.” The goal of the campaign was to raise awareness of narcolepsy and how the impact of this disorder affects daily life. The campaign also helped the general population better understand what it’s like to live with narcolepsy.

We shared several videos on social media. Our goals with these videos was to raise awareness by having users like and share the video; ask patients to post their own story, and then increase the number of fans on social media so we can raise more awareness to more people. Keep sharing and liking these videos to spread more awareness! Post your own story on this website: https://narcolepsy-liftusup.com/.

Youth Ambassadors Represented NN at National Conferences

Savannah Hughes represented Narcolepsy Network at the American Thoracic Society’s International Conference held at the Walter E. Washington Convention Center in Washington DC. Savannah spent her time in the vendor hall at the NN booth interacting with anyone interested in learning about narcolepsy and the mission and resources of NN. She was able to utilize the Youth Ambassador slides and presentation board to explain the symptoms and treatment for narcolepsy and offered print materials to further assist physicians and their patients.

Savannah also had the pleasure and honor of attending the American School Counselors Association in Denver, Colorado. While there was not nearly as much interest in narcolepsy as with the previous medically focused conference, NN’s presence there had an important impact.

Mackenzie Zorn was able to assist at a national conference during the National Association for School Nurses (NASN) meeting in San Diego, CA. Mackenzie not only got to inform school nurses on narcolepsy and how it affects students, but also how she actively advocates as a Youth Ambassador for Narcolepsy Network. Through this experience, Mackenzie was able to educate countless school nurses who work with and accommodate narcoleptic students. It was encouraging to hear that the majority of these nurses were familiar with narcolepsy and were eager to learn more.
2017 Highlights

Annual DREAM BIG! Walk Expands to the West Coast
Despise a rain delay, walkers of every kind gathered for the fifth annual DREAM BIG! Walk on May 14, 2017 in New York City. From power walkers to leisure walkers, dog walkers to little ones just learning to walk, it was a fun-filled event for everyone. New for 2017, the walk also took place in Seattle, Washington. Both groups successful raised narcolepsy awareness and funds for Narcolepsy Network.

We Made a Quilt!
A special thanks for those who submitted a quilt square to our quilt project! We were able to complete a quilt that highlights narcolepsy and showcases the creativity from PWNs. We hope to take the completed quilt to meetings or conferences around the country to help spark the conversation to learn more about this disorder. There’s still time to submit your square for the 2018 quilt. Contact us so we can send you a pre-cut square with guidelines for decorating it.

Board President Presents Posters at Conferences
We are so proud of our President Dr. Mark Patterson for presenting a poster he coauthored at the SLEEP Meeting in Boston. This meeting hosted international sleep researchers, clinicians, technicians, and others interested in the “sleep business.” Dr. Patterson also presented a poster on narcolepsy at the Carilion Clinic annual pediatric conference. It was a sold-out event, with over 250 pediatric healthcare providers from throughout southwest Virginia in attendance.

Giving Tuesday Was a Success!
Thanks to everyone who participated in Giving Tuesday on November 28, 2017. Giving Tuesday is the Tuesday after Thanksgiving that is designed to be a day of global giving to celebrate generosity and kindness.

We set a goal of raising $2,000 to represent the 1 in 2,000 who are diagnosed with narcolepsy in the US. Through your generosity, we were able to not only reach that goal, but surpass it! Through our Facebook page, we were able to raise $5,585.00.
2017 Highlights

2017 Conference: Creating a Path to Understanding

Narcolepsy Network headed back to the west coast for the 32nd Annual Conference. On October 27-29, nearly 400 PWNs, supporters, friends, and family descended upon Portland, Oregon.

The conference kicked off on 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 Dr. Emmanuel J. Mignot of Stanford University. Dr. Mignot’s presentation covered the genetics and immunology of narcolepsy. He also mentioned that his sleep lab did not receive much federal funding, so it’s even more important for us to lend our collective voices to make sure those in Congress understand how important it is to keep this important work going.

Then it was time for the breakout sessions. There was something for everyone! There were presentations on new medications, starting a support group, narcolepsy and aging, and there were several support groups in a range of ages and needs. This year’s optional activity was a food tour that took attendees around the city to taste what Portland had to offer.

We also gave out three awards at our conference. First, we awarded one of the public awareness awards to Mackenzie Zorn for her tremendous outreach work (read her story on page 4). We also awarded the Arizona support group for their awareness activities. The group was very active in receiving proclamations for their state and several cities for Suddenly Sleepy Saturday. We also awarded Dr. Lois Krahn the Physician of the Year Award (flip to page 9 to learn about Dr. Krahn’s interest in narcolepsy and her research projects).

We would like to thank the staff at the Marriott Portland Downtown Waterfront, the event planners of City Girl Events, all speakers and presenters, volunteers, vendors, and our 2017 sponsors of Jazz Pharmaceuticals, Avadel Pharmaceuticals, Harmony Biosciences, LLC, and donors Dianne and Sam Kernell for making the 2017 conference a great success.

We are busy planning the 2018 conference in Indianapolis, Indiana. We hope to see you on October 5-7, 2018!
Q&As with Physician of the Year Dr. Lois E. Krahn

Q: How did you become interested in narcolepsy?
A: I did my residency at the Mayo Clinic, which is an institution with many decades of experience in helping people with narcolepsy. I had the opportunity to meet patients living with narcolepsy and that really sparked my interest in becoming more skilled in assisting them.

Q: Since your residency in the early 1990’s, how has sleep medicine changed from when you first started?
A: In that era, neither modafinil, armodafinil, or sodium oxybate were available so we had few tools to treat narcolepsy. We were trying our best with the available medications to help patients be as functional as possible. Over the course of the last 20 plus years, we have learned much more about how the brain changes in association with narcolepsy and new treatment tools have become available.

Q: Do you feel like the perception of narcolepsy has changed at all in the last two decades?
A: Although the level of awareness within the general public is still lacking, I do think narcolepsy is better understood in that patients who live with narcolepsy feel better accepted than 25 years ago. Some of the recent scientific work about orexin and some of the direct to consumer advertising produced as a byproduct of medication marketing have allowed people to recognize that this really isn’t a rare disease – 1 out of 2,000 people have narcolepsy. So, it’s not some exotic [disease] that affects so little.

Q: Generally speaking, if someone started with a medication 15 years ago, is that medication still effective today?
A: In general, if an effective treatment was found that medication should remain effective over many years. The exception would be if a person developed multiple conditions. For example, if a person now has sleep apnea and narcolepsy. Sometimes, that original treatment is no longer sufficient or as a person ages, they can develop side effects or have changes to medications, or they may experience adverse effects. Then sometimes, we do have to revisit [the treatment plan]. In my experience, narcolepsy is a very treatable condition and many patients see a huge improvement in their ability to function on treatments.

Q: We heard from a long-time conference goer who said he was surprised to see so many young people at the conference from when he started attending. Do you think that patients are getting diagnosed earlier and is that due to better awareness?
A: Without any doubt, there’s more awareness and patients are diagnosed at an earlier age. That is terrific because it allows them to participate with an advocacy organization like Narcolepsy Network and they can realize that there’s a community of people who live with the same medical condition.

Q: You received our Physician of the Year Award at our 2017 conference, what does the award mean to you?
A: That award meant a great deal to me because I’d like to think that I have helped patients with narcolepsy live better, but to have a patient group recognize that, it is very meaningful to me. It validates that even though patients with narcolepsy are a subset of my patients with sleep disorders, they need specialized treatment and professionals who are committed to understanding their specific needs.

Q: Switching gears, do you have any research projects that are coming up that you can talk about and how will these impact sleep medicine or narcolepsy?
A: One thing that I do in a fairly continuous way is try to be a part of the clinical trial effort. The only way that data will be available to the FDA and the only way new medications will be reviewed and hopefully approved is if there are sites spread throughout the country that are able to recruit eligible patients. I personally feel that that is an important opportunity for patients to access treatments.

I also have interest in sleep walking. Some people with narcolepsy have experience with sleep walking either in the absence of treatment or in the presence of some treatments. The study is ongoing so I don’t have any results [yet], but we will be looking at those who sleep walk, some of whom may have narcolepsy and some who may be on medications that make sleep walking worse.

Q: What about some of your past projects?
A: I’ve been interested in why patients with narcolepsy use nicotine. Also, what self-management techniques people rely on to augment their response from medications. I’ve also done testing of cerebral spinal fluid measuring orexin and I hope this will help increase the efforts to have a commercially available CSF orexin test become accessible. We also did a community-based study of narcolepsy including those patients without cataplexy – it was a significant study. The study confirmed that narcolepsy occurs in about 1 out of 2,000 patients and it recognized that narcolepsy without cataplexy is more common than has been previously understood.

Q: 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 to attend our conference?
A: I learn an awful lot from patients and from their family members. Secondarily, the other physicians who come to the conference are focused on understanding the needs of patients with narcolepsy, so I learn from my colleagues who attend. Every year, I learn new ideas that I am able to consider implementing in my practice. For instance, how to help a person who is on sodium oxybate and how to manage the different side effects so they can continue to be on the medication.
Thank You 2017 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 15, 2017
- February 26, 2017
- March 19, 2017
- April 19, 2017
- May 21, 2017
- June 25, 2017
- July 16, 2017
- August 27, 2017
- September 17, 2017
- November 19, 2017
- December 17, 2017

The Board of Directors met in person on:

- October 30, 2017
Narcolepsy Network is grateful to the supporters and donors who enabled us to expand our programs and reach more people. Each year, we hope to spread more understanding of this disorder and 2017 was no exception. In the spring, we expanded the DREAM BIG! Walk to include New York City and Seattle, Washington. We also hosted a very unique event – the Annual Bed Race in Roanoke, Virginia. Participants decorated and raced beds around a parking lot in order to spread more awareness. During the past year, we also attended several national conferences to reach professionals who may interact with narcolepsy patients. Our hope is that we can change the misunderstanding, misdiagnoses, 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 be a valuable source of information and will serve as a beacon of friendship in 2018 and beyond.

Warm Regards,

Louise O’Connell
Treasurer
Narcolepsy Network Board of Trustees

Narcolepsy Network, Inc. Financial Report

Statement of Financial Position - As of December 31

<table>
<thead>
<tr>
<th>Assets</th>
<th>2017</th>
<th>2016</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cash and cash equivalents</td>
<td>$101,324</td>
<td>$113,094</td>
</tr>
<tr>
<td>Pledge receivable</td>
<td>10,000</td>
<td>3,690</td>
</tr>
<tr>
<td>Prepaid expenses and other</td>
<td>12,056</td>
<td>12,354</td>
</tr>
<tr>
<td>Investments</td>
<td>182,073</td>
<td>177,196</td>
</tr>
<tr>
<td><strong>Total Assets</strong></td>
<td>$305,453</td>
<td>$326,334</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>$29,070</td>
<td>$21,928</td>
</tr>
<tr>
<td>Accrued payroll and related</td>
<td>2,952</td>
<td>3,208</td>
</tr>
<tr>
<td>Deferred membership dues</td>
<td>11,657</td>
<td>12,871</td>
</tr>
<tr>
<td><strong>Total Liabilities</strong></td>
<td>$43,679</td>
<td>$38,007</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Net Assets</th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Unrestricted</td>
<td>$236,428</td>
<td>$268,063</td>
</tr>
<tr>
<td>Temporarily restricted</td>
<td>25,346</td>
<td>20,264</td>
</tr>
<tr>
<td><strong>Total net assets</strong></td>
<td>$261,774</td>
<td>$288,327</td>
</tr>
</tbody>
</table>

| **Total liabilities and net assets** | $305,453| $326,334|

Statement of Activities - Years ended December 31

<table>
<thead>
<tr>
<th>Income</th>
<th>2017</th>
<th>2016</th>
</tr>
</thead>
<tbody>
<tr>
<td>Corporate Grants</td>
<td>$50,000</td>
<td>$55,000</td>
</tr>
<tr>
<td>National Conference*</td>
<td>214,702</td>
<td>139,675</td>
</tr>
<tr>
<td>Contributions</td>
<td>95,360</td>
<td>96,959</td>
</tr>
<tr>
<td>Membership Dues</td>
<td>28,868</td>
<td>28,292</td>
</tr>
<tr>
<td>Other</td>
<td>7,563</td>
<td>3,149</td>
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<tr>
<td><strong>Total Income</strong></td>
<td>$336,493</td>
<td>$323,075</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Expenses</th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Programs</td>
<td></td>
<td></td>
</tr>
<tr>
<td>National Conference</td>
<td>$175,055</td>
<td>$136,681</td>
</tr>
<tr>
<td>Public Information</td>
<td>97,236</td>
<td>152,169</td>
</tr>
<tr>
<td>Membership</td>
<td>68,580</td>
<td>58,922</td>
</tr>
<tr>
<td><strong>Total Program Expense</strong></td>
<td>$340,871</td>
<td>$347,772</td>
</tr>
<tr>
<td>General and administrative</td>
<td>65,463</td>
<td>49,507</td>
</tr>
<tr>
<td>Fundraising</td>
<td>16,712</td>
<td>19,856</td>
</tr>
<tr>
<td><strong>Total Expenses</strong></td>
<td>$423,046</td>
<td>$417,135</td>
</tr>
</tbody>
</table>

Net increase (decrease) in net assets

<table>
<thead>
<tr>
<th></th>
<th>2017</th>
<th>2016</th>
</tr>
</thead>
<tbody>
<tr>
<td>($26,553)</td>
<td>(94,060)</td>
<td></td>
</tr>
</tbody>
</table>

*Conference Income includes corporate grants - $135,000 in 2017, $80,000 in 2016.

Five Year Revenue & Expense Comparison

2017 Revenue Categories

2017 Expense Categories

| National Conference 55% | National Conference 41% |
| Contributions 25%       | Public Information 23%   |
| Corporate Grants 13%    | Membership 16%           |
| Membership Dues 7%      | General & Administrative 16% |
| Fundraising 4%          |                           |
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 NN 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 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. 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.

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!

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