**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 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), 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 that 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 join our organization, they bring with them the energy and creativity to advance Narcolepsy Network and its goals into the future.
A Message from the President

Dear Friends,

I want to start off by saying thank you.

Thank you to the board for giving me the opportunity to lead this organization alongside our very talented Executive Director Dr. Eveline Honig. Thank you to the staff for doing the hard work to run this organization's programs. Thank you to our members, donors, and supporters for making all of this possible through your volunteer efforts and financial contributions.

And above all, I want to say a heartfelt thank you to our advocates. These are the people who went above and beyond in 2019 to spread awareness about narcolepsy. These are the people who made a difference every single time they put themselves out there. These are the people who took a risk, and continue to do so, by advocating publicly for our entire community.

What is the risk that our advocates take?

They risk the misconceptions that permeate a public ill-informed about narcolepsy. They risk the negative stereotypes carelessly reinforced by Hollywood. They risk their careers by putting themselves on the line for a disorder that’s so often, and so easily, misunderstood.

If it wasn’t for their risk-taking, I wouldn’t be writing this letter. If it wasn’t for their efforts, you wouldn’t be reading it. Most of us would still be undiagnosed; subject to harsh judgment from our employers, friends, and sadly, even our own families.

What is advocacy? At its core, advocacy is simply telling your story. When you decide to do this, your words open people’s eyes to a reality that they never knew existed.

Without advocates taking these personal risks to tell their story, awareness about narcolepsy would stagnate. Instead, awareness is growing, as more and more individuals like our Youth Ambassadors (and their parents) share their personal stories.

Your advocacy will, in fact, change lives.

Advocacy is the single most important initiative at Narcolepsy Network. We believe that the most effective way to 1) reduce time to diagnosis and 2) increase the percentage of diagnosed patients is to train as many advocates as we possibly can. We started with our Youth Ambassador program, and plan to expand this effort significantly in the next few years.

In 2020 and in the years to come, I challenge you to become an advocate for the narcolepsy community by:

- Educating lawmakers on Capitol Hill during Rare Disease Week.
- Submitting a state proclamation for Suddenly Sleepy Saturday.
- Participating in #Nchat on Twitter.
- Volunteering at our Annual Conference in Philadelphia.
- Running the TCS New York City Marathon.
- Sharing your personal story during World Narcolepsy Day.

Thank you,

Keith Harper
President, Board of Directors
kharper@narcolepsynetwork.org
Angry, agitated, and withdrawn - these are three words that may describe any teenager. Those words may be followed up with "they'll grow out of it." But what if there is no "growing out of it?" The teenage years can be hard on anyone, but for Caroline, her lack of normal sleep caused her to go down a spiral that led to mental health issues.

Caroline says that she was always a "bad sleeper." By the time she was in 6th grade, she noticed she was gaining weight and later, she became, what she describes as, obese. Over the next two years, she would stay up at night, not because she wanted to, but because she couldn't fall asleep. Then during the day, there was nothing she could do to prevent her from falling asleep. She adds, "It was a frustrating cycle because no matter how much sleep I got, I never felt any better." By her freshman year of high school, she felt depressed and confused as to why she feeling this way.

By her freshman year of high school, she felt depressed and confused as to why she was feeling this way. She explains, "For many years, I thought I was a hypochondriac. I would pretend to be sick to stay home from school, when in reality, I was just exhausted. It got to the point where I thought something was really wrong with me – I was irrational." Once she found out it was narcolepsy, she says, "I was relieved because it wasn't just in my head and it wasn't terminal."

Caroline knew her mom went through "an angsty" phase in high school so maybe she, too, was entering one as well. Yet this was different. She pushed people away and was unpleasant to be around – feelings steamed from being sleep deprived most of the time. She adds, "I was a suicidal mess."

Caroline's mom got her a therapist and had a chance conversation with a friend whose own daughter had a sleep study. This led to an appointment with a neurologist. From there, Caroline was able to get a relatively quick diagnosis of narcolepsy.

Once she received her diagnosis, Caroline says she felt relieved. She explains, "For many years, I thought I was a hypochondriac. I would pretend to be sick to stay home from school, when in reality, I was just exhausted. It got to the point where I thought something was really wrong with me – I was irrational." Once she found out it was narcolepsy, she says, "I was relieved because it wasn't just in my head and it wasn't terminal."

Caroline decided to share her condition with others and was not reserved about it. She was also able to start treatment. She started on a stimulant, and while that did help her during the day, it wasn't helping at night. Next, she tried Xyrem, which finally gave her some relief. She says, "I now have a normal sleep schedule and I feel rested when I wake up."

Along with the sleepiness, Caroline also says that her cataplexy was severe. "I would use a cane and wear kneepads around the house and had to babyproof the kitchen because I would fall and hit my head so often. If someone made me laugh, I could have 60 episodes in a half hour." She also says that her cataplexy altered how she lived her life. For instance, she wouldn't go in the ocean over the fear that she could drown. In her group of friends, she had an appointed "Caroline catcher" just in case anyone said anything funny. Caroline added that it got to the point that she was nervous to show her emotions over worry that she would get hurt.

Luckily, Caroline was able to go on an antidepressant that serves as a cataplexy suppressant. The antidepressant and Xyrem made what Caroline calls "a normal life" possible. Prior to her treatment, it was inconceivable that she would be able to drive, a right of passage for most teens. Now, Caroline is able to drive herself every day.

Since her diagnosis, Caroline has been an active member in the narcolepsy community. Her neurologist asked if she wanted to participate in videos for morethan71percent.com. Then in 2018, she became a Narcolepsy Network Youth Ambassador. She went to the annual conference held that year in Indianapolis, Indiana and was trained to tell her story and meet other youth with narcolepsy. She adds that one of the best experiences about meeting other Youth Ambassadors was "getting to meet people my age who have narcolepsy and meeting others who understand what I am going through."

Caroline has been a Youth Ambassador. She and her mom attended Rare Disease Week on Capitol Hill in 2019 and she joined Young Adult Representatives of Rare Disease Legislative Advocates, a program of the EveryLife Foundation that brings together 16-30-year olds to advocate for the rare disease community. Additionally, she has given presentations to the nurses in her county and was asked to give a presentation at a fundraiser that benefited Narcolepsy Network. Caroline was also asked to help with presentations and the planning for next year's class of Youth Ambassadors. All of this hard work led Board of Director's member Cynthia Zorn to nominate Caroline for an award from the Council for Exceptional Children. She won and was honored in the self-advocacy category in early February.

Caroline has a very bright future ahead of her! While she doesn't know where she'll go to college just yet, she knows she wants to study political science and neuroscience and says her dream job is to be a researcher at the National Institutes of Health or Food and Drug Administration. When asked if she had any advice for other youth who may just be starting on their narcolepsy journey she answered with, "Never settle. Are you feeling good? What can make you feel better?" For parents who may also be on a journey with their child, Caroline offers, "Be supportive, but trust your gut. Do additional research if you think that something is not quite right."
Narcolepsy can be a slow burn. It can wait on the back burner, showing symptoms overtime, little by little. For instance, we often hear from people who claim that they were just “always tired” over the course of their childhood or that they struggled staying awake in school. Eventually, those symptoms get worse, to the point of boiling over. That usually leads to a doctor’s visit, or maybe many doctor’s visits, and oftentimes, misdiagnosis, until narcolepsy is the clear answer.

This wasn’t the path that Alan’s diagnosis took him on. He doesn’t remember a particular symptom from his youth or doesn’t attribute his symptoms to a particular virus or sickness that could have triggered his disorder. His symptoms came to a peak when he came to a literal near crash.

Before his diagnosis, Alan was being treated for anxiety and depression; the treatments he was on were supposed to help with those issues and were also supposed to give him some added energy. It was around this time that his sleepiness started to be more apparent and his treating psychologist referred him to his primary care doctor for a sleep study. That particular doctor did not believe in sleep studies and did not honor the request to have the study done.

Two years went by and his excessive daytime sleepiness was at its worst. Alan says, “It got to the point where I was falling asleep driving to and from work. [Once] I was driving on a split highway with two lanes and when I woke up, I was overtaking an SUV.” Alan decided to bypass his primary care doctor and found himself a sleep specialist who was able to order the sleep study. The study showed that Alan has mild sleep apnea and the hope was that by treating the sleep apnea, his symptoms would dissipate. Those treatments, including a CPAP, did not help. His doctor decided to focus on narcolepsy in order get some relief.

Alan’s initial reaction to his diagnosis was optimistic. He added, “[At that time] I had no idea what narcolepsy was. I had a diagnosis and [the doctors] knew what it was. I thought that they would put me on stimulants and everything will go back to normal. I’d have my life back. Everything would be brilliant!” Unfortunately, for Alan, his journey with narcolepsy would be ongoing. While he was able to get medication to treat his symptoms, he was still feeling very sleepy. Like many other narcolepsy patients, he cycled through medications at varying milligrams in hopes to find the right combination. While some seemed to work for a while, he thinks his tolerance for others grew too much and just stopped working. For now, he is taking modafinil and Xyrem and is hopeful that the new medications that will hit the market soon may make a difference.

Around the time of Alan’s diagnosis, he was being considered for a new job. He was honest and forthright about his narcolepsy and the new company offered him the position. For a while, things seemed to be going well. Alan was able to receive his necessary accommodations but eventually, things started to sour. The company arranged to have a cot set up, but that eventually was placed underneath a conference room table. Alan explained, “I would have to walk by co-workers [to use the cot], so I stopped using it.” After about a year with the company, Alan says that his narcolepsy was starting to be used against him. He adds, “I had different rules from everyone else. [For example,] everyone had flexi-time, except me. If I was a minute late, I’d be fired. If I worked a minute longer, I’d be fired. If I worked from home, I’d be fired. It was like my boss kept on forgetting my invisible disability.” He ended up using FMLA for time missed at work and went into an intensive outpatient program for depression. Not too long after, he was let go. After a long fight, he was able to go on disability.

This time of his life was very stressful. He said that at the time, he did not know another person with narcolepsy and there were no support groups to share his feelings or frustrations. He felt that he was going at this disorder alone. It was also around this time that he went to his first Narcolepsy Network conference. By pure coincidence, he shared a taxi from the airport with Louise O’Connell (current Treasurer for Narcolepsy Network’s Board of Directors) and her daughter, Katie, who has narcolepsy. Whether it was pure happenstance or some sort of karmic intervention, after their chance encounter, Louise and Katie took Alan under their wing at the conference. He says with a slight crack in his voice, “That was incredibly life changing! It was a massive safety-net for me. I had severe depression and anxiety and for the first time, it was gone.”

After the conference, Alan also decided to start going to an active support group where he was living in San Diego, California. With the group, he was able to organize Suddenly Sleepy Saturday events, received a proclamation for the day from the mayor, did some outreach to local doctors, and participated in social events. He adds, “Comparing my life with narcolepsy before a support group and later with a support group, it’s night and day! You can get help on Facebook, but you gain a lot from talking face-to-face with people. You can ask follow-up questions. You learn from others.”

Alan is currently back in his home country of Ireland. He plans to continue his narcolepsy advocacy there as well. The support group he is currently involved with, Narcolepsy Ireland, is working with another group, Sufferers Of Unique Narcolepsy Disorder (SOUND), and the Irish Disability Caucus to convince the Irish government to write into law legislature regarding protection for people with disabilities, something that is absent from Irish law right now.
2019 Highlights

Narcolepsy Advocates Went to Washington, DC for Rare Disease Week

We sent 20 advocates to Rare Disease Week on February 24-28. This is a week-long event that is coordinated by the EveryLife Foundation and is designed to bring together the rare disease community. The week kicked off with a reception and a documentary screening. The next day was devoted to an entire day of training. Presenters included a welcome from Darlene Shelton, founder and President of Danny’s Dose, whose mission is to change current emergency protocols for those with special medical needs. Then it was time to hear from a panel that was led by a White House legislative staff member, the Senior Policy Advisor for the Office of Nancy Pelosi, and a health policy director. The panel explained how Congress can have an impact on healthcare policies.

The next part of the morning included learning about specific “asks” that are important to the rare disease community. The panel focused on supporting newborn screening reauthorization, increasing funding for the National Institutes of Health (NIH) and the Food and Drug Administration (FDA), and the importance of the Rare Disease Caucus. Each advocate was asked to bring one of these topics to their member of Congress. After a day of training, the advocates were armed with knowledge on how to present their case to their legislators. Our narcolepsy advocates met with legislators and their staff from states from New York to California.

March 9, 2019 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 2019, 25 proclamations were granted from US governors and 12 from US mayors.

Comedy Show Raised Funds for Narcolepsy Network

The comedy show entitled “Terrible People Sometimes Do Okay Things” was held at the Comic Strip Live in New York City on May 15. A huge thank you to Greg Radin and all of the comics for hosting the benefit show. They raised $350 to continue Narcolepsy Network’s mission of supporting people with narcolepsy.
2019 Highlights

Executive Director Attended the European Narcolepsy Network’s Narcolepsy Day

Executive Director Dr. Eveline Honig went to the European Narcolepsy Network’s Narcolepsy Day in Bern, Switzerland on May 18-19. We were the only patient support group from the US in attendance. This gathering provided the opportunity for scientists, patients, physicians, and healthcare professionals to receive updates and exchange ideas. The program included clinical and scientific updates, presentations on current research projects, and a session that brought together patient organizations to discuss how narcolepsy affects quality of life.

Narcolepsy Network was Represented at the Annual SLEEP Meeting & World Sleep Meeting

Staff members Christine Hackenbruck, Dr. Eveline Honig, and Board of Directors member Dr. Luis Ortiz, were on hand for the annual SLEEP meeting in June in San Antonio, Texas. Board member Dr. Luis Ortiz, and staff members Dr. Eveline Honig and Michelle Doherty traveled to Vancouver, Canada for the World Sleep Meeting in September. We were able to share our mission with sleep professionals who were happy to hear about our continued support for patients with narcolepsy.

We Celebrated the First World Narcolepsy Day

Narcolepsy Network partnered with 22 national and international organizations to establish World Narcolepsy Day. On September 22, the narcolepsy community, including support groups, medical professionals, advocates, and others, had the opportunity to come together. We asked the narcolepsy community to share their stories so we could then share on social media. We received so many submissions that we were able to share on our social media channels all day long!

New Class of Youth Ambassadors Trained to be Advocates

Fourteen youth from around the nation participated in the Youth Ambassador Program training on October 25. This annual training provided an opportunity for youth ages 14-22 who have been diagnosed with narcolepsy to meet other youth while learning the nuances of advocacy, as well as, learning to tell their story to the general public. The one-day training session included: learning how to present the slide presentation designed and written by Narcolepsy Network, learning how to write and convey an Elevator Speech, how to start a support group, and brain storming how to use social media for advocacy. Parents joined the Youth Ambassadors to learn about fundraising, press releases, and advocacy opportunities at the local and national level.
Narcolepsy Network headed to the Southwest for the 34th Annual Conference. On October 25-27, PWNs, supporters, friends, and family descended upon Albuquerque, New Mexico.

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 address given by Dr. Chad Ruoff. Dr. Ruoff’s presentation was entitled “Advances in Narcolepsy from Pathogenesis to Treatment” and discussed the current and recent advances in the diagnosis and management of this invisible disorder, novel ways of analyzing sleep studies, and new treatment options.

Then it was time for the breakout sessions. Some of the popular sessions included “Pediatric Narcolepsy: Diagnosis and Management” with Dr. Kiran Maski and “Narcolepsy as We Age” with Dr. Todd J. Swick. There were also support groups for a range of ages and needs.

After learning about the latest developments, attendees were invited back to the hotel on Saturday evening for some fun. The festivities included a Halloween costume party and we had the pleasure to welcome comedian Jill Kimmel. Jill performed an all-ages comedy set and proved that laughter truly is the best medicine!

Sunday brought another day of breakout sessions. Before the conference came to a close, attendees gathered in the main ballroom to share their conference experience.

We hope you will save-the-date for the 2020 conference which will be held on October 16-18 in Philadelphia, PA.
2019 Highlights

First One-Day Narcolepsy Seminar a Success

We held our first one-day narcolepsy seminar on November 2 in New York City. The response was amazing and it exceeded our expectations!

Our keynote speaker was Dr. Michael Thorpy. He gave a presentation on the update on the diagnosis and treatment of narcolepsy. There was also a presentation on the psychosocial management of narcolepsy by Dr. Eric Zhou. We hope to have these one-day seminars in different cities across the nation.

#TeamNarcolepsy Completed the 2019 TCS New York City Marathon

#TeamNarcolepsy once again ran in the TCS New York City Marathon on November 3. Thanks to everyone who contributed to their fundraising efforts. With your support, we were able to raise $59,146. That's 60% more than in 2018 with over 100 more donors!

Special thanks to our returning runners: Keith Harper, Emily Jillette, David Younts, and Jason Ruff. A big thank you goes to our new runners: Kitty Balerna, Tatijana Conley, Piper Paul, Mariana Figuera, Peter Sexton, Angelo Rega, and James Messina.

Board of Director’s Vice President Spent the Day on Capitol Hill

Sharon O’Shaughnessy joined patient support advocacy organizations and societies for a day on Capitol Hill on November 19. Their hope was to urge members of Congress to support federal funding of critical sleep research and awareness. The power of their unified voices was much in evidence and their preparedness encouraged their members of Congress and their staff to take their recommendations with them as they craft national legislation.

Special thanks to Brandi Hill (@brandihillcom) for photographing the Annual Conference in Albuquerque, New York City Marathon, and One-Day Seminar in NYC.
Thank You 2019 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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We thank all of our donors for your support! While we cannot list all of our contributors, please know that your generosity helps us to expand our reach into the future.
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Board of Directors conference calls were held on:

- January 20, 2019
- February 20, 2019
- March 17, 2019
- April 14, 2019
- May 19, 2019
- June 30, 2019
- July 21, 2019
- August 18, 2019
- September 29, 2019
- November 19, 2019
- December 19, 2019

The Board of Directors met in person on:

- October 28, 2019

*Mark Patterson left the Board of Directors in February 2019; stepping up as the new Narcolepsy Network Board of Director's President was Keith Harper. Sharon O'Shaughnessy was appointed Vice President. Carol Arnette started serving on the Board in October 2019.
Narcolepsy Network, Inc. Financial Report

Narcolepsy Network had a tremendous year! We couldn’t have done it without our supporters and donors who allow us to grow our programs and reach more people with narcolepsy.

In 2019, we saw a rise in Facebook donations – an increase of over 50%! We’ve been fortunate to have 2.5 times more employer charity program donations and we had an increase of over 60% of marathon donations! With your help, we will be able to send more advocates to Washington, DC to meet their legislators during Rare Disease Week, select more runners to participate in the TCS New York City Marathon, and reach more people who are living with narcolepsy.

We hope you will continue to remember us in your giving! As we look forward, we hope to continue on this path of growth and reach more PWNs.

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>2019</th>
<th>2018</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cash and cash equivalents</td>
<td>$435,729</td>
<td>$264,066</td>
</tr>
<tr>
<td>Pledge receivable</td>
<td>145</td>
<td>---</td>
</tr>
<tr>
<td>Prepaid expenses and other</td>
<td>14,173</td>
<td>24,112</td>
</tr>
<tr>
<td>Investments</td>
<td>84,896</td>
<td>72,975</td>
</tr>
<tr>
<td><strong>Total Assets</strong></td>
<td><strong>$534,943</strong></td>
<td><strong>361,153</strong></td>
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</tbody>
</table>

<table>
<thead>
<tr>
<th>Liabilities</th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Accounts payable and accrued expenses</td>
<td>$11,265</td>
<td>$2,843</td>
</tr>
<tr>
<td>Accrued payroll and related</td>
<td>4,353</td>
<td>2,592</td>
</tr>
<tr>
<td>Deferred membership dues</td>
<td>19,681</td>
<td>12,578</td>
</tr>
<tr>
<td><strong>Total Liabilities</strong></td>
<td><strong>$35,299</strong></td>
<td><strong>18,013</strong></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Net Assets</th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Unrestricted</td>
<td>$402,135</td>
<td>$305,714</td>
</tr>
<tr>
<td>Temporarily restricted</td>
<td>97,509</td>
<td>36,426</td>
</tr>
<tr>
<td><strong>Total net assets</strong></td>
<td><strong>$499,644</strong></td>
<td><strong>342,140</strong></td>
</tr>
<tr>
<td><strong>Total liabilities and net assets</strong></td>
<td><strong>$534,943</strong></td>
<td><strong>$360,153</strong></td>
</tr>
</tbody>
</table>

Statement of Activities - Years ended December 31

<table>
<thead>
<tr>
<th>Income</th>
<th>2019</th>
<th>2018</th>
</tr>
</thead>
<tbody>
<tr>
<td>Corporate Grants</td>
<td>$69,300</td>
<td>$72,000</td>
</tr>
<tr>
<td>Conference and Seminars*</td>
<td>307,908</td>
<td>234,349</td>
</tr>
<tr>
<td>Contributions</td>
<td>170,322</td>
<td>145,418</td>
</tr>
<tr>
<td>Membership Dues</td>
<td>36,734</td>
<td>27,396</td>
</tr>
<tr>
<td>Other</td>
<td>19,266</td>
<td>3,600</td>
</tr>
<tr>
<td><strong>Total Income</strong></td>
<td><strong>$482,763</strong></td>
<td><strong>446,026</strong></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>Conference and Seminars</td>
<td>$204,464</td>
<td>$182,853</td>
</tr>
<tr>
<td>Public Information</td>
<td>80,432</td>
<td>78,223</td>
</tr>
<tr>
<td>Membership</td>
<td>63,130</td>
<td>56,747</td>
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<tr>
<td><strong>Total Program Expense</strong></td>
<td>$348,026</td>
<td>$317,823</td>
</tr>
<tr>
<td>General and administrative</td>
<td>65,082</td>
<td>64,841</td>
</tr>
<tr>
<td>Fundraising</td>
<td>32,918</td>
<td>19,733</td>
</tr>
<tr>
<td><strong>Total Expenses</strong></td>
<td><strong>446,026</strong></td>
<td><strong>402,397</strong></td>
</tr>
</tbody>
</table>

Net increase (decrease) in net assets: **$157,504** **$80,366**

*Conference Income includes corporate grants - $235,000 in 2019; $150,000 in 2018.

Five Year Revenue & Expense Comparison

<table>
<thead>
<tr>
<th>Year</th>
<th>Revenue</th>
<th>Expense</th>
</tr>
</thead>
<tbody>
<tr>
<td>2015</td>
<td>$369,683</td>
<td></td>
</tr>
<tr>
<td>2016</td>
<td>$410,536</td>
<td>$323,075</td>
</tr>
<tr>
<td>2017</td>
<td>$471,135</td>
<td>$423,046</td>
</tr>
<tr>
<td>2018</td>
<td>$482,763</td>
<td>$402,397</td>
</tr>
<tr>
<td>2019</td>
<td>$503,530</td>
<td></td>
</tr>
</tbody>
</table>

2019 Revenue Categories
- National Conference 53%
- Contributions 29%
- Corporate Grants 12%
- Membership Dues 6%

2019 Expense Categories
- Conference & Seminars 46%
- Public Information 18%
- Membership 14%
- General & Administrative 15%
- Fundraising 7%
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.

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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Michelle Doherty
Accounting Manager

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Communications Coordinator

Christine Hackenbruck
Executive Assistant