Mission Statement

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

A Brief History of Narcolepsy Network

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

In July 1984, most of these women met for the first time in Akron, Ohio. All were members of the American Narcolepsy Association (ANA), which no longer exists today. Originally convened as a task force charged with resolving ANA member issues, this group soon realized those issues were intractable, and instead began forming a new organization. They elected Mary Babcock provisional President, decided on the name “Network,” and began outlining the new organization’s programs. Demonstrating the power of REM sleep, committee member Jan Wright awoke from a short nap inspired with the new group’s motto: “CARE,” standing for COMMUNICATION, ADVOCACY, RESEARCH, and EDUCATION.

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

The Network’s activities reached a new level in 1992, as 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.
Dear Members and Supporters,

2014 was a tremendous year for Narcolepsy Network, filled with many successful events and programs that raised narcolepsy awareness, educated a variety of audiences, and empowered people with narcolepsy.

Here is a quick look at some of the ways NN CARES about the narcolepsy community:

**C — Communication:** NN continued to be a social media powerhouse by bringing narcolepsy news and information to people around the world via its Facebook and Twitter pages, with more than 6,000 followers, and an active Facebook support group with nearly 5,000 members. These and other social media outlets were an important part of our advocacy and awareness efforts this year.

**A — Advocacy:** Narcolepsy patient advocates rallied together to apply for and receive official proclamations declaring March 8, 2014 to be Suddenly Sleepy Saturday/ Narcolepsy Awareness Day in 25 states and cities, an all-time record high. The narcolepsy community worked together to stop a TV commercial from Honda that inaccurately portrayed people with narcolepsy, and instead created a public service announcement (PSA) advocating for people with narcolepsy.

**R — Research:** Two international researchers received our 2014 Researcher of the Year awards. NN granted awards to Dr. Masaki Nakamura and Dr. Olivier Andlauer for their seminal and clinically relevant narcolepsy research studies. Read more about both these researchers on pages 10 and 11. And, as a result of the newly developed Research Committee, there were more research-oriented articles in *The Network* newsletter than ever before.

**E — Education:** Two medical professional education initiatives were spearheaded by board member Mark Patterson: a QR-coded wristband for patients to wear that links emergency personnel to an informative website; and two poster presentations at the annual SLEEP meeting regarding the wristbands’ development and details of NN's efforts to mobilize the narcolepsy community to participate in the FDA’s narcolepsy patient-focused drug development meeting in 2013.

**S — Support:** NN’s staff expanded this year with the addition of Outreach Coordinator Melissa Patterson. For the second year in a row, there was double-digit growth in our support groups, with 12 new groups added this year. See page 5 for more about our support groups.

As NN’s Board President, I am dedicated to ensuring that the NN CARES vision permeates throughout the narcolepsy community. I encourage all people with narcolepsy, their families, and supporters to become members of this growing community. NN relies on memberships, donations, and grants to further our mission.

Sara Kowalczyk, MA, MPH
President, Board of Trustees
In a household with two sleepy people (Brianna has idiopathic hypersomnia [IH] and Romeo has narcolepsy), and three energetic boys, life can be interesting. Thankfully Brianna and Romeo España seem to thrive on a life of change and chaos. This is a skill both of them have brought to their involvement with Narcolepsy Network.

Brianna and Romeo met in 2004, became engaged two weeks later, and got married in 2005. The first of their three sons, now 9, was born that same year. Since then they have added two more sons, now ages 7 and 3, to their family.

Between 2004 and 2009, Romeo served in the Navy, and Brianna served as a volunteer Ombudsman for Romeo’s command. Brianna has put the skills she learned as a military volunteer to good use for NN. In 2013 and 2014, she organized volunteers at the annual conference. Her ombudsman experience also led her to help design NN’s new Resource Program to connect members with expert help when they need it. When the Resource Program launches in 2015, she will serve as its first Community Representative, a vital link between members in need and the experts who can help them.

Narcolepsy entered the Españas’ lives in 2008 when Brianna received a strange phone call from her husband. Romeo said that the Navy thought he had killed himself. One of his shipmates (a Navy term for co-worker) had come by the house to see why Romeo didn’t show up for work. “He had 5 alarms going off when his shipmate found him face down in bed,” she recalls.

Later that fall, Romeo was diagnosed with narcolepsy and had to medically retire from the Navy. This was not part of their plan, but, Brianna says, “This explained so much. At the same time it terrified me. Narcolepsy is very misunderstood. Most people think narcoleptics are lazy. Well, yep! That’s Romeo! Brilliant but lazy!”

Besides, of course, Romeo is not lazy — he has a neurological disorder. Trying to explain this to people who are not intimately acquainted with narcolepsy was frustrating for Brianna, especially at first. Fortunately, their kids were very young at that time, so narcolepsy has always been a normal part of their life.

“They don’t know any other life so they don’t really think how we live is strange. They enjoy the responsibility and the independence they have and have always been praised for their maturity level.” Brianna says.

She adds that being parents with narcolepsy and IH is just like normal parenthood, “Very challenging but very rewarding. Having a sleep disorder didn’t really make it more challenging, it just made it different. We are able to teach our children that life will throw you some nasty curve balls, but it doesn’t mean you can just give up. You get back on your feet stronger than before.”

Life threw the Españas another curve ball in 2013 when Brianna was diagnosed with idiopathic hypersomnia. She says that her involvement with NN as a supporter for Romeo was a big help for her after her own diagnosis, since she already knew the kind of life she could have with IH and her family was already set up for it.

After leaving the military, Romeo spent several years as an engineering consultant for the petroleum industry and provided industrial prototypes for a variety of local companies. Around the same time, he started building unmanned aerial vehicles, or drones, for civilian applications.

Since people with narcolepsy are not allowed to get a full pilot’s license, drone technology gives PWNs like Romeo a unique alternative to being in an airplane cockpit. “With things like ‘First Person View,’ a PWN could wear glasses while the drone is in flight to see what it sees,” he explains.

In 2013, Romeo’s drone building experience helped him find his dream job as a hardware engineer at a Dallas technology company. He also volunteers at the Dallas Makerspace where he channels his engineering talents into “inspiring future generations of mad scientists.”

Romeo and Brianna are living proof that people with narcolepsy and idiopathic hypersomnia can raise families, follow their passions and give back to their communities. Narcolepsy Network is fortunate to count this inspiring and dedicated couple among its members and supporters.
As part of its mission to provide support to people with narcolepsy, Narcolepsy Network encourages the formation of support groups. In 2014 that network of groups increased dramatically with 12 new groups starting up in cities across the country. There are now more than 30 active in-person groups in the U.S.

The purpose of these groups is to provide people with narcolepsy and their supporters a safe and welcoming environment where they can share experiences, voice frustrations, and enjoy spending time with others who understand what it’s like to live with narcolepsy.

NN also offers online groups via our website and Facebook to make support available day and night to anyone in the world.

If you are interested in starting a support group in your community visit narcolepsynetwork.org to learn how to begin.
Narcolepsy community turns a punch line into an opportunity for awareness

Narcolepsy Network and the entire narcolepsy community have long worked to dispel myths and misunderstandings about narcolepsy. When Honda Motor Company released a TV commercial using narcolepsy as a punch line, NN board members immediately contacted Honda and began rallying supporters. The community quickly and effectively lobbied to have the ad pulled from the airways and the internet. In addition, Honda was persuaded to make several PSAs about narcolepsy and air them on national TV.

We are pleased that we could work with others in the narcolepsy community to seize the opportunity to increase awareness about narcolepsy with both a major international corporation and among the general public.

Outreach to healthcare providers and educators continues in 2014

NN continued its efforts to increase the understanding of narcolepsy among healthcare professionals by attending the American Sleep and Breathing Academy’s Sleep and Wellness meeting, and SLEEP 2014, a joint meeting of the American Academy of Sleep Medicine and the Sleep Research Society. At both meetings NN staff and board members distributed information about narcolepsy and NN to attendees.

Outreach to educators continued with NN president Sara Kowalczyk and board member Dr. Rahul Kakkar attending the American School Counselor Association national meeting. Kowalczyk and Kakkar were warmly received by the more than 2,000 school counselors in attendance.

NN representatives also attended several events in Washington, DC. Member Dr. Allison Greenstein, from Roanoke, VA, was one of seven panelists to speak at the Rare Disease Congressional Caucus Briefing on September 17. In addition, NN’s Outreach Coordinator Melissa Patterson and Sara Kowalczyk attended another Congressional Caucus Briefing and the Community Congress breakfast sponsored by the EveryLife Foundation for Rare Diseases. In October, Kowalczyk also attended The Rare Diseases and Orphan Products Breakthrough Summit sponsored by National Organization for Rare Diseases (NORD).
Suddenly Sleepy Saturday brings narcolepsy awareness to every corner of the country

Through the efforts of NN members and supporters, 25 states and several cities officially proclaimed March 8 as Suddenly Sleepy Saturday. People in an additional 18 states requested proclamations from their governor’s office, but did not receive them.

Also on Suddenly Sleepy Saturday, the Second Annual Narcolepsy Bed Race, organized by Dr. Mark Patterson, took place in Roanoke, VA. Building on the success of the 2013 race, teams came together for a lot of fun, creativity and a little friendly competition.

Each of the four teams completed two laps around the course, with four team members pushing or pulling their bed and the fifth team member riding in style. After completing the first lap, the rider had to swap places and an item of clothing with one of the runners before taking off on their final leg. Prizes were given for the team with the fastest time, the most creative theme, and the most funds raised.

About 70 spectators attended, and the race was covered by both the Roanoke Times newspaper and the Roanoke-area CBS affiliate. In addition the winning team continued to raise awareness by entering their racing bed in the Roanoke St. Patrick’s Day parade. Appearing in these two community events, the race’s message of narcolepsy awareness reached more than 60,000 in southwest Virginia.

New York City’s DREAM BIGGER! Narcolepsy Walkathon a huge success!

Braving a forecast of rain, more than 145 walkers gathered at Pier 46 in New York City’s scenic Hudson River Park on April 26, 2014 to raise narcolepsy awareness as well as funds for Narcolepsy Network’s support, research and other programs. The day started out cloudy and cool but, by registration time, skies were clearing. In addition to supporters from the tri-state area, the walk drew participants from across North America, including Colorado, Georgia, North Carolina, and Canada.

New to the walk in 2014 were fundraising “Dream Teams.” Fourteen captains volunteered to create online fundraising campaigns. The addition of these teams helped the walk raised over $18,000, which is more than double the previous year’s fundraising total.
FDA releases Voice of the Patient Report

In June 2014, the U.S. Food and Drug Administration (FDA) released its final report on a public meeting on narcolepsy. “The Voice of the Patient” summarizes comments and themes that PWNs and their supporters offered at the Sept. 24, 2013 public meeting and via the public docket, which was open for comment for several months in the fall of 2013. The meeting and the report are part of the FDA’s Patient-Focused Drug Development Initiative.

The patient perspectives gathered at the meeting and in the docket have strengthened the FDA’s understanding of the burden that narcolepsy has on patients, as well as the methods PWNs use to manage their symptoms, and any side effects they may experience as a result of those treatments. The FDA staff will consider these findings when they are evaluating new therapies. The full report is available on the FDA’s website.

Two posters presented at SLEEP 2014 meeting

Narcolepsy Network made two poster presentations at the SLEEP 2014 meeting in Minneapolis. Both posters were authored by Mark Patterson, MD, PhD, co-vice president of NN’s Board of Trustees. Approximately 5,000 sleep professionals from around the world attended the meeting, held May 31 — June 4, 2014.

One poster presentation, “Narcolepsy Community’s Response to the FDA Patient-Focused Drug Development Initiative” provided an overview of Narcolepsy Network’s role in generating interest and participation in the FDA’s public meeting on narcolepsy drug development. FDA officials have described the narcolepsy community’s response to the meeting as “unprecedented.”

The other poster, “Scannable QR Coded Medical Alert Wristbands for Patients with Narcolepsy,” focused on Narcolepsy Network’s development of a medical alert wristband and corresponding informational web page.
Our youth programming was greatly expanded this year, with separate sessions and activities for elementary-age kids and teenagers. Topics included driving, dating, advocacy, and transitioning to college, along with activities such as journaling, games to explain narcolepsy and a pizza party. More than 50 students ages 21 and younger attended the conference this year.

Saturday kicked off with breakfast and the keynote address by Dr. Todd Swick. Dr. Swick looked at the history of narcolepsy from its first description in medical literature in 1877 to the most recent discoveries about symptoms, causes and treatments. Breakout sessions followed the keynote address, with attendees choosing to attend sessions ranging from exercise, to dreaming, to beating stress and more.

Saturday night featured Ultimate Game Night, with a ballroom full of games including Bingo, giant Jenga, and giant Twister. Airbrush tattoos were also available and people of all ages got in on the temporary body art!

Sunday brought another day of breakout sessions covering a variety of topics including current narcolepsy research, health insurance, advice for living with narcolepsy and new sleep technology. As sessions wound down, people started saying goodbye and making plans to stay in touch and to meet up at our 2015 conference in Minneapolis.
Tell us a little about your research

My research focuses on improving the diagnostic criteria of narcolepsy. It is based on using the Stanford database of narcoleptic patients to perform statistical analyses to assess potential new criteria for the disease, but also revisits the quality of old diagnostic tests.

More specifically, we have shown that an unusually short REM latency (REM sleep is the stage of sleep where people dream, and that patients with narcolepsy have in excess) during a nocturnal sleep study is strongly associated with narcolepsy, but not with other common sleep disorders.

Another significant result is that in narcolepsy without cataplexy (a specific subtype of narcolepsy), patients who have a deficit in hypocretin (a chemical of the brain) present more severe results in sleep studies than patients without hypocretin deficiency, whereas it is very difficult to see a difference between these patients by only examining them.

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

Dr. Mignot, who directed this research, is always focused on improving understanding and treatment of patients with narcolepsy. It led to implementing a new criteria in the diagnosis of narcolepsy (short REM sleep latency at the night sleep study), meaning that patients can be diagnosed more easily and with less investigations.

It also led to a better understanding of narcolepsy without cataplexy, showing that it was important to establish what subtype patients were suffering from (with or without hypocretin deficiency), as the treatment might be slightly different, even though it is not established yet.

Where will your research go from here?

The next steps will be to see if patients with narcolepsy without cataplexy with hypocretin-deficiency should receive different treatment from those without hypocretin-deficiency.

How was your experience attending the NN conference this year?

The conference in Denver was an amazing experience. I particularly enjoyed meeting with people attending the conference. I had the opportunity to meet with many patients in a setting different from the hospital, and listening to their experience was inspiring. Eminent researchers were also present, and lots of new ideas were generated during the conference.
Dr. Nakamura is a researcher at the Japan Somnology Center at the Neuropsychiatric Research Institute in Tokyo, the director of Yoyogi Sleep Disorder Center, and a lecturer in the department of somnology at Tokyo Medical University. His primary research topic is neuroimaging studies of sleep disorders. His study “Differences in brain morphological findings between narcolepsy with and without cataplexy” used MRIs to discover several microstructural changes in the brains of people with narcolepsy with cataplexy. It was published in the journal *PLoS One* in November 2013.

Tell us a little about your research and how it affects our understanding of narcolepsy.

I found the brain microstructural differences between narcolepsy with cataplexy and narcolepsy without cataplexy by using a new MRI technique, DTI (Diffusion Tensor Imaging).

I think that these two types of narcolepsy (narcolepsy with cataplexy and narcolepsy without cataplexy) have different pathological mechanisms, and the symptomatic differences between these two types of narcolepsy might come from differences in the degree of deficiency of orexin neuronal projection.

I reported that narcolepsy with cataplexy showed moderate abnormality in the left amygdala and left inferior frontal area, whereas narcolepsy without cataplexy didn’t. Thus, I would say that cataplexy might be seen as a result of the abnormality of interactions among the emotion system (amygdala) and the motor control system (inferior frontal area) mediated by orexin projection.

Where will your research take you in the future?

The goal of my research on narcolepsy is to make a new diagnostic tool and criteria by MRI (DTI) findings, which is less invasive than the examination of cerebrospinal fluid and is more convenient than PSG/MSLT examination.

What did you think of the conference in Denver?

This was my first trip to the United States. I was very honored to be invited to the Narcolepsy Network annual conference and I was very pleased to have the opportunity to give my presentation about my research and to meet you all. I would just like to say thank you to the members of Narcolepsy Network.
Thank YOU 2014 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 in 2014 to help further Narcolepsy Network’s mission.

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**Board of Trustees conference calls were held on:**
- January 12, 2014
- April 13, 2014
- July 13, 2014
- November 9, 2014
- February 9, 2014
- May 18, 2014
- August 10, 2014
- December 14, 2014
- March 16, 2014
- June 8, 2014
- September 7, 2014

The Board of Trustees met in person on October 20, 2014 in Denver, CO.

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Treasurer’s Message

Narcolepsy Network ended 2014 with increased reserves and a strong financial position thanks to continued grant support, personal donations and increased membership. The hard work that we do has achieved results in both strong corporate support and a wider base of contributors. Innovation and successful fundraisers including the Narcolepsy Bed Race in Roanoke, VA, New York City walk, and another outstanding Swinging for Sleep campaign also contributed to our growth. We are extremely thankful to the individuals, corporations and foundations for their support as we work to improve the lives of people with narcolepsy. And we are grateful for the strong efforts of staff and board members, which have contributed to these results.

As we move forward into 2015, we look forward to expanding on these activities and this has already started with a very successful Narcolepsy Awareness Day campaign, which will continue to allow us to pursue our CARES mission. Thank you for your help in making 2014 a successful year. We look forward to counting you among our supporters again this year.

Warm Regards,
Louise O’Connell
Treasurer
Narcolepsy Network Board of Trustees