

Narcolepsy Network, Inc. 2013 Annual Report



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 Shrewsbury, 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.

From the Executive Director



Eveline Honig, MD, MPH
Executive Director

Dear Friends,

2013 has brought a year of exciting developments in the narcolepsy community, and Narcolepsy Network continues to be at the forefront. From our annual conference in Atlanta, attended by more than 400 people, to the historic FDA public meeting on narcolepsy drug development, and exciting new research findings, it is an inspiring time to be a part of Narcolepsy Network.

Narcolepsy Network CARES for people with narcolepsy and their families. Here is a quick look at some of the ways NN CARES:

C — Communication: NN's communication with its members and supporters around the world helped bring more than 800 people to the FDA's public meeting on narcolepsy drug development. People attended the meeting both in person and via the Internet. FDA officials described attendance at the meeting as "unprecedented."

A — Advocacy: Suddenly Sleepy Saturday/Narcolepsy Awareness Day on March 9 was an especially big day this year with NN members in 15 states requesting official proclamations for the day and supporters sparking news coverage all over the world.

R — Research: Three researchers who published groundbreaking narcolepsy and hypersomnia research this year spoke at our annual conference in Atlanta, and our Researcher of the Year award recipients, Dr. Thomas Scammell and Dr. Jerry Siegel, received monetary awards to support their ongoing narcolepsy research.

E — Education: I continued traveling the country giving presentations on sleepy children to school personnel. By spreading our informed perspective to educators, NN plays an invaluable role in getting children who show signs of narcolepsy the help they need.

S — Support: Our discussion group on Facebook grew exponentially in 2013. This international support group provides help to PWNs round-the-clock. In addition, we added in-person support groups in several states this year.

As Narcolepsy Network's Executive Director, I am dedicated to furthering our **CARES** mission. I encourage all people with narcolepsy and their families to become members and show their commitment to the narcolepsy community. NN relies on memberships, donations and grants to further our mission. I thank you for your contributions in 2013 and urge you to continue your support in 2014 as we continue to improve the lives of people with narcolepsy.

A handwritten signature in black ink that reads "Eveline Honig". The signature is written in a cursive, flowing style.

Eveline Honig, MD, MPH
Executive Director

Reason to give: Dianne Kernell



Describing one of her first experiences with cataplexy, Dianne Kernell recalls, “I was at a party and said something funny and the next thing I knew, I was on the ground. ... I just thought I was tired.”

Dianne’s daughter was three or four months old at the time, so she had a very good reason to be tired, but the episodes of weak knees and sleepiness continued. She saw a neurologist in San Diego who “had never seen anyone with narcolepsy but remembered reading about it in a book.”

A more experienced doctor confirmed the diagnosis, and Dianne started taking Ritalin to control the daytime sleepiness and an antidepressant for the cataplexy. The medications helped some, but there were negative side effects and they didn’t control all of her symptoms.

Narcolepsy Network

Shortly after she was diagnosed, Dianne and her family spent some time at Stanford where she learned about the American Narcolepsy Association, the forerunner of Narcolepsy Network.

At first, “I didn’t know anybody with narcolepsy,” she remembers, “That’s the odd thing. I’m very concerned about people who are just now getting diagnosed, that they meet someone, talk to people, just so they have someone they can relate to. That’s what’s good about having Narcolepsy Network. You can go to a meeting, a local support meeting or the big annual meeting and just meet some people. I think that’s a really important factor.”

Challenges

Adapting to life with narcolepsy was challenging at times and Dianne sometimes had a hard time keeping up with her energetic daughter.

“When kids give up their naps, they don’t understand why you still need to take one,” Dianne recalls.

Her medications didn’t really help with her cataplexy, so she learned other ways to control it. “Cataplexy kind of prevents

you from being yourself,” she says. “I think I just kind of learned to control a lot of my personality, and try not to be emotional in front of people. And that’s been hard for me. Trying to put a lid on things like that is just hard.”

In spite of the medications she was taking, for many years Dianne still had trouble with cataplexy and found it hard to stay awake. She remembers going to friends’ houses only to fall asleep, or going to the movies with a group and sleeping through the first 10 minutes of the film. Keeping her hands busy helped her stay more alert, so Dianne got in the habit of quilting while watching television, or other potentially sleep-inducing activities.

“Not driving is hard too,” Dianne says. “I mean I drive, but not very far — 5 or 10 miles, maybe. I think that’s always been a challenge in applying for jobs. I mean, most people, when they look at a job they don’t think, ‘oh no, that’s 15 miles from here.’ I was always looking for the closest job in the city.”

Dianne recalls looking specifically for jobs that were close by or accessible by public transportation. At first she worked from home as a freelance writer, and then later she got a part time writing job. She has also worked for a pharmaceutical company and as a writer for a non-profit. She was always up front with her employers and found that they were generally willing to work with her.

Looking Forward

Today Dianne takes Provigil and Xyrem and says she feels more alert and is less worried about cataplexy. She is involved in her local narcolepsy support group, and this past fall she participated in the FDA hearing on narcolepsy by phone from her home in California, and attended Narcolepsy Network’s conference in Atlanta. She hopes that NN will continue to work on raising awareness about narcolepsy and hopes that more public knowledge about the disorder might lead to greater funding for narcolepsy research.

Dianne is retired, although she still does some editing, and lives in southern California. Recently, she was pleased to learn that her daughter does not have the genetic marker for narcolepsy, and she is looking forward to the arrival of her first grandchild.

Reason to give: Megan Phillips and Kevin Gonzales



After learning she had narcolepsy in August 2012, Oklahoma State University student Megan Phillips was worried that the diagnosis would damage her relationship with boyfriend Kevin Gonzales. Megan recalls, "I joke a lot that I slept my life away before being diagnosed with narcolepsy, but I feel like there really is some truth to that. [...] Kevin used to call me 'sleepy head' because I slept so much."

Contrary to her fears, Megan found that narcolepsy actually strengthened her relationship with Kevin. After he realized that there was a reason why Megan was always so tired, Kevin gained a better understanding for what she was going through and became more sympathetic. He decided he wanted to do something to show his love and support for her and also to raise awareness about narcolepsy, and hit on the idea of a benefit concert.

Using his contacts among the OSU student body, Kevin recruited five student groups to preform in an acoustic setting for the *Dream Big Concert*. At first, Megan says, "He told me that he had something cool that he wanted to do, but that he didn't think he would be able to figure out the logistics by himself. But he did!" Eventually, it was time to spread the word about the concert, so Kevin spilled the beans and the couple worked hard to publicize the upcoming event with help from Kevin's Alpha Tau Omega fraternity, and Megan's sorority, Omega Phi Alpha. The organizations did a lot to promote the concert, and Megan thinks it also helped the members understand what she was going through a little better.

On Feb. 15, 2013, the *Dream Big Concert* attracted an audience of more than 250 people and raised more than \$2,000 for Narcolepsy Network through ticket and T-shirt sales, a blog, advertising on campus and the support of friends and family. It was a great success, and Megan says that seeing her boyfriend go so far above and beyond merely being supportive made her appreciate him all the more.

"At that point, I already knew that I wanted to spend the rest of my life with him," she explained, "but his organizing the

concert solidified those feelings!" The couple got engaged last April, and they will be getting married on May 31, 2014.

Since the benefit concert, Megan has graduated from OSU and continues to raise awareness about narcolepsy through social media. Her posts about narcolepsy even prompted an old high school friend to ask her for more information on the subject. She was later diagnosed with narcolepsy as well, and Megan is very happy to know that her efforts have helped at least one person. Last August, a company flew her to Chicago where she shared her story for a video shoot to raise awareness about narcolepsy. She is eagerly awaiting the finished product.

At this point, "it is tough to know that it isn't something that I can just 'get over,' but I have finally come to terms with the fact that I will have narcolepsy for the rest of my life," Megan says. Finding the right combination of medications has really improved her quality of life, and although the medicines have some side effects, she feels like she is somewhat back to "normal."

Megan graduated in May of 2013, but she is still on the OSU campus for her job as an Academic Success Coach. She helps students who are struggling with issues like time management or difficulties getting involved on campus, and she feels like her experiences as a college student struggling with narcolepsy help her relate to the students. She really enjoys her current job, but Megan's long term goal is a job in the criminal justice field. She knows that her narcolepsy may make it difficult to work nighttime shifts, but is confident that she can make it work with the proper medications.

After Kevin graduates from OSU in May of 2014, he and Megan will be moving back to Texas, where Kevin will spend the next two years in the Teach for America program, teaching math in an at-risk high school.

Thanks to Megan and Kevin for their hard work in raising awareness and their support of Narcolepsy Network.

2013 Highlights



Research Breakthroughs

Narcolepsy and Histamine

In June, two separate studies were published showing that histamine-producing neurons in the brain may play a role in narcolepsy.

One study, by Thomas Scammell, MD, professor of Neurology at Beth Israel Deaconess Medical Center in Boston, was presented at the 2013 SLEEP meeting in Baltimore. It found that people with narcolepsy have an increased number of neurons that produce histamine. The study suggests that histamine signaling could be a new way to treat narcolepsy.

Another study, by Jerome Siegel, PhD, director of the Center for Sleep Research at the UCLA Semel Institute for Neuroscience and Human Behavior, appeared in the online

edition of *Annals of Neurology*. This study reported that an excess of a type of brain cell containing histamine may be the cause of the loss of hypocretin cells in narcoleptics.

Molecular Mimicry

In December, a study by Elizabeth Mellins, MD, and Emmanuel Mignot, MD, PhD, of Stanford University's School of Medicine showed that in genetically susceptible people, narcolepsy can sometimes be triggered by "molecular mimicry," in which the normal immune response to a pathogen can trigger autoimmunity. The study, published in the journal *Science Translational Medicine*, suggests new interventions that could stop the destruction of hypocretin cells, and could also lead to a new blood test to diagnose narcolepsy.



NN representatives Sara Kowalczyk, Suporn Sukpraprut, Mark Patterson, Melissa Patterson and Patricia Higgins at the FDA.

Narcolepsy Community Shines at FDA Public Meeting

Representatives from Narcolepsy Network joined hundreds of others from the narcolepsy community at the FDA's public meeting on narcolepsy drug development on September 24, 2013. Approximately 150 people attended the meeting in person at FDA headquarters in Silver Spring, MD, with nearly 700 more attending via an Internet webcast. The FDA also collected information from PWNs through a public docket, which remained open for two months after the meeting.

Patient perspectives will provide the FDA with helpful insights when conducting benefit-risk assessments for new drugs to treat narcolepsy. Patient responses could also show the FDA that they need new ways to measure the effectiveness of treatments being reviewed.

The FDA is reviewing the information gathered and creating a report on the meeting, which expected to be released in the spring of 2014.

Another Successful Swinging for Sleep Campaign

LPGA golfer Nicole Jeray's Swinging for Sleep campaign had another successful season. Individuals and groups pledged donations for each birdie and eagle shot Jeray made during tournament play. In the 2013 season, Jeray made 129 shots and raised just over \$38,000. Proceeds were split between Narcolepsy Network and another narcolepsy organization.



Nicole Jeray

NN Marks National Sleep Awareness Week/Suddenly Sleepy Saturday



The Narcolepsy Bed Race's fastest team.

Volunteers across the country worked to raise awareness of narcolepsy during National Sleep Awareness Week, March 3–10, and particularly on March 9, dubbed Suddenly Sleepy Saturday or Narcolepsy Awareness Day. NN volunteers requested official Narcolepsy Awareness Day proclamations to raise awareness in 15 states.

In Roanoke VA, the first Narcolepsy Bed Race drew more than 100 spectators and six teams, who raced beds on wheels through a course. Prizes were given for the fastest bed and best design, and all funds raised were donated to Narcolepsy Network. The fastest team also entered their bed in Roanoke's St. Patrick's Day parade the following week, raising even more awareness.

Oklahoma State University Student Dreams Big

Oklahoma State University student Kevin Gonzales organized the *Dream Big Concert* at OSU in honor of his fiancée Megan Phillips, who was diagnosed with narcolepsy in 2012. Using his network of talented friends, Kevin enlisted five student groups to perform. The February 15 concert was a huge success with an audience of more than 250 people. Through tickets, T-shirt sales, and donations, the concert raised more than \$2,000 to benefit Narcolepsy Network. The concert also raised awareness of narcolepsy in the OSU community. NN Executive Director Eveline Honig attended the concert, where she spoke about narcolepsy and provided informational brochures and awareness bracelets. (See more about Kevin and Megan on page 5.)



Kevin, Eveline and Megan

First New York City Walk Raises Awareness and Funds

On April 27, 2013, NN supporters gathered at Chelsea Waterside Park in New York City for DREAM BIG! a 2.2 mile walk along the Hudson River to raise awareness about narcolepsy and funds for Narcolepsy Network. More than 130 people participated in the walk, raising over \$6,500. The highlight of the event for several participants was meeting and bonding with a fellow PWN for the first time. A second walk is scheduled for April 26, 2014.



Participants head south along the Hudson River Greenway and enjoy a view of the Freedom Tower along the way.

Outreach to Healthcare Providers and Educators Continues in 2013

NN continued its efforts to increase the understanding of narcolepsy among healthcare professionals by attending the *SLEEP 2013* meeting in Baltimore and the National Sleep Foundation's *Sleep, Health and Safety* meeting in Washington, DC. At both meetings NN staff and board members distributed information about narcolepsy and NN to attendees.

In September, Executive Director Eveline Honig attended the World Association of Sleep Medicine meeting in Spain, where she distributed materials in both English and Spanish.

Dr. Honig also gave her presentation "Sleep Disorders in Children" at the National Association of Elementary School Principals meeting.

In Memoriam

Two long-time Narcolepsy Network leaders passed away in 2013. Both Sue Carella and Sharon Smith gave tirelessly to Narcolepsy Network and their contributions of time and talent were instrumental in NN's success. Both these amazing women will be missed by all in the Narcolepsy Network community.

Sue Brockway Carella

On April 2, Sue Brockway Carella, one of the founders of Narcolepsy Network, passed away after a long illness.

Sue helped establish Narcolepsy Network as well as its predecessor organization, The American Narcolepsy Association. She served on NN's Board of Trustees as president, treasurer, and secretary. She was also an editor of *The Network* newsletter.

Sue dedicated her life to the community and medical fields for awareness, research, treatments and the ultimate hope — a cure for all sleep disorders. She was an outstanding public speaker and made presentations before Congress and the National Institutes of Health, and appeared on numerous television shows including "60 Minutes," "20/20" and "Nightline." In 1990, as President of Narcolepsy Network, Sue boarded a 48-foot motor home and took part in the "Wake Up America" caravan across the United States, stopping to speak at 17 universities and medical centers.



Sue and the Wake Up America caravan crisscrossed the country raising narcolepsy awareness.

Sue was born in Iowa and grew up in San Bruno, CA. At the age of 40 she returned to school and graduated from San Francisco State University with a degree in organizational development and human behavior. In addition to her work for narcolepsy awareness, Sue enjoyed her family, collecting depression glass and button books, fishing and reading.

She is survived by three sons, five grandchildren, two great grandchildren, a sister and many friends in the narcolepsy community.

Sharon Smith



On June 28, Narcolepsy Network lost a long-time volunteer and ardent supporter when Sharon Smith passed away after a long illness. Sharon was involved with NN for more than 25 years, including six years as President of the Board of Trustees. In her time with NN she served on every board committee and as editor of *The Network* newsletter. She devoted her entire being to helping people with narcolepsy, often putting

in 60 to 90 hour weeks on a volunteer basis despite having narcolepsy/cataplexy. Even while battling a terminal illness, Sharon was chair of the conference committee and driving force behind the 2012 conference in Cleveland. At that conference, she received NN's Lifetime Achievement award for her service to the narcolepsy community.

Sharon was born and raised on Long Island, NY. She graduated from Hofstra University with a degree in accounting and later became a CPA. She was voracious reader and an excellent bowler. She was known among her friends and colleagues at NN for her financial acumen, passion, optimism and a wonderful sense of humor. In addition to her NN family, Sharon leaves behind a husband and two sons. She is also survived by her mother, a brother and two sisters.

Narcolepsy Network 2013 Conference

Narcolepsy Network's 28th annual conference in Atlanta was the biggest conference in NN history. More than 400 people attended the event, held October 18-20, with some coming from as far away as Australia and Ireland.

Attendees enjoyed a pre-conference trip to the Atlanta Aquarium and the Friday evening opening reception. On Saturday, the conference presentations started with the keynote address on recent developments in narcolepsy diagnosis and treatment by Michael Thorpy, MD.

Conference-goers also had the opportunity to attend presentations by half a dozen other narcolepsy researchers, plus panel discussions, updates and workshops by legal and education experts, narcolepsy advocates, and fellow PWNs.

By the end of the weekend, the 2014 conference location – Denver, CO – had been announced and many people were already making plans to attend. The 2014 conference will be October 17-19 at the Hyatt Regency Denver Tech Center.

2013 NN Award Recipients Recognized

The 2013 Narcolepsy Network awards were during the conference. Congratulations to the honorees!

Public Awareness
Kevin E. Gonzales

Researcher of the Year
Thomas E. Scammell, MD, and Jerry Siegel, PhD

Ruth Justice Nebus Volunteer of the Year
Laura J. Evert



Conference attendees Jeff Loss (left), Annette Webb (center), and Richard Wynne (right) clown around.



The Narcolepsy Network Board of Trustees



Conference breakout sessions covered a wide range of topics.

Research Update Jerry Siegel, PhD

Dr. Siegel is a Professor of Psychiatry at UCLA and at the VA. In June 2013, his group published research showing a marked increase in the number of histamine cells in the brains of people with narcolepsy. He is one of two scientists to receive Narcolepsy Network's Researcher of the Year award in 2013. He sat down with us to discuss his research.



Tell us about your recent finding about histamine and narcolepsy.

It's a very surprising finding. We now know that there are two major abnormalities in narcolepsy, the 90% reduction in the number of hypocretin cells (previously reported) and the 65% increase in the number of histamine cells. Not only are there more histamine cells, but the histamine cells stain more darkly in people with narcolepsy than they do in the controls, which means there is very high concentration of histamine in these cells. So these cells are potentially capable of producing a lot of histamine, which is alerting, but apparently they're not releasing it.

We know from studies that predated this one that the histamine level is actually quite low in PWN. We expected to find a reduced number of histamine cells. We never expected to find more than the normal number because neuroscientists have assumed that cell number stays constant or decreases somewhat with age or is reduced in neurological illness. There may be a way of manipulating these histamine cells that will be therapeutically effective in narcolepsy. More generally, if we can understand how you can make more cells of a certain type, that's an approach that might be applied to hypocretin cells.

We're very excited about this because it's a huge change in cell number. It is an important clue to the cause and nature of narcolepsy. Even if it is a result of drug treatments, it is incredibly interesting. Such a change has never been seen before in any illness.

Where does your research go from here?

We continue to be interested in the hypocretin system, what regulates it and how it might be manipulated in various ways. We're interested now in this huge difference in the number of histamine cells in PWN. We need to know how that happens and what the consequences of this change are.

In the more general sense, we want to understand other arousal systems that almost certainly differ from hypocretin in their activity. We think that arousal is not a sort of volume

control on behavior that goes up or down. Rather arousal is multidimensional. In our studies in mice, rats and humans, we find that hypocretin cell activity is linked to arousal for pleasure rather than arousal in unpleasant situations. In the absence of hypocretin cells, it is difficult to maintain arousal in pleasurable situations. Other arousal systems mediate arousal in unpleasant or painful situations.

We continue to be very interested in the possibility of curing narcolepsy. There is reason to be optimistic. Certainly, better treatments can be developed because we understand it far better than we did just 15 years ago. I do hope there is more investigation of the benefits of administering hypocretin to PWN.

Do you think that's where the cure lies, with the hypocretin system?

Yes. I think the hypocretin system has to be replaced or the remaining hypocretin neurons stimulated. It's quite clear that hypocretin is the key player, because animals in which this gene is deleted have the major symptoms of narcolepsy.

On the other hand, I don't think that this is going to be the last system that we see changes in for narcolepsy. We see changes in drug response in narcoleptic dogs that are not explainable by the deficit in their hypocretin receptor, so other systems that mediate arousal – such as the acetylcholine system, the norepinephrine system – are definitely somewhat different in dogs with narcolepsy and presumably in people with narcolepsy too. The brain is very interconnected. You change one thing and everything else gets changed a little bit, or sometimes a lot, so there are many more things to understand.

How did you become interested in narcolepsy?

I was always interested in REM sleep and its relation to narcolepsy. Then, after Bill Dement discovered these narcoleptic dogs, I started working with them. We continue to maintain a narcoleptic dog colony. We had one birth just last week (March 2014).

It's very satisfying to think that a group of patients such as yourselves are interested in what we are doing. I just see all the suffering and the idea that our work can make some difference makes me very happy.

Dr. Siegel's work is available at: <http://www.semel.ucla.edu/sleepresearch>

Research Update Thomas Scammell, MD

Dr. Scammell is a Professor of Neurology at Harvard Medical School, Beth Israel Deaconess Medical Center and Boston Children's Hospital. He is one of two scientists to receive Narcolepsy Network's Researcher of the Year award in 2013.



How did you become involved in narcolepsy research?

As a medical student, I became interested in how the brain controls basic functions that we take for granted, like sleep, body temperature, and hunger. Then, when I trained in Neurology, I saw that getting a better understanding of how the brain controls wakefulness and sleep was one of the most medically pressing things I could work on. There was a big unmet clinical need, because in the early 1990s, we really didn't know much about what went wrong in the brain to cause problems like narcolepsy. Then I got lucky in the mid to late '90s; I was studying how the hypocretin/orexin system responded to modafinil, and Dr. Clif Saper and I talked with Masashi Yanagisawa who had produced mice lacking hypocretin. The animals were very sleepy and also showed signs of cataplexy, which was tremendously exciting and produced a flurry of papers. I've been working on this topic ever since. One of the things that makes narcolepsy research so appealing is that it's a disorder that on the one hand is relatively simple: loss of the hypocretin neurons causes narcolepsy. On the other hand, the impact of that neuron loss on a person's life is incredibly broad, and there are lots of things that we don't truly understand and many really big questions. So, from the perspectives of clinical need and exciting science, narcolepsy has been a rewarding topic.

What are some of the big questions or problems you're interested in?

There are currently three big questions in narcolepsy research: What causes the hypocretin neuron loss? What are the consequences of that loss? And, how do we translate this knowledge into better therapies?

My group has concentrated mainly on the second question. About two years ago as an offshoot from another project, Philipp Valko, a post-doctoral research fellow in my group, started looking at histamine-producing neurons in the brains of people with narcolepsy (PWN). Our prediction was that we would simply see a normal number of histamine neurons. Philipp looked at a bunch of narcolepsy brains, and surprisingly, he found a large increase in histamine-producing neurons. I then spoke with Jerry Siegel and we pursued this project in parallel with his lab and agreed to simultaneously submit papers to the same journal. We each looked at this question independently so as not to bias the other's work, but

in the end we found about the same thing: there was a statistically significant increase in histamine-producing neurons in PWN. This was quite exciting and not what anyone had predicted, which indicated that narcolepsy is not as simple as we thought. We now suspect that this increase in histamine neurons may contribute to the symptoms of narcolepsy.

It's possible that the increase is helpful, because we know that histamine helps wake people up. Maybe it's a way that the brain tries to compensate; when the hypocretin neurons die, the histamine neurons rally to try to promote wakefulness. But it's also possible that the compensation might cause some of the problems PWN encounter. If the histamine system is jazzed up because there are more cells, then perhaps that contributes to PWN's fragmented sleep. Also, if the histamine cells are keeping them awake, it may contribute to these weird in-between states, like hypnagogic hallucinations and cataplexy, that are common in PWN.

That's something we're really interested in figuring out with more animal research because we see this increase in histamine cells in narcoleptic mice as well, and we want to look into that further.

Are there any other areas you are looking into?

Another big question we're interested in is looking at the mechanisms behind cataplexy. What is it that causes the paralysis of cataplexy? How is it that strong emotions can trigger cataplexy? We just published two papers in which we describe how some brain regions involved in processing emotions, the medial pre-frontal cortex and the amygdala, are necessary for triggering cataplexy. We're hoping that if we have a better understanding of the brain circuits involved we might find new ways of improving cataplexy.

What potential treatment avenues do you see coming about from your research?

For the cataplexy story, we're still pretty far away from having anything of clinical usefulness. We first need to understand the neurons more precisely and then we could then find a way to target those pathways with new medications.

With the histamine story, I think the potential for impacting patient care is much more imminent because there are now drugs in development that enhance histamine signaling. Since the brain seems to be making efforts to enhance histamine signaling, maybe if we can push the system a little stronger, it might be beneficial for PWN. Conversely, another thing that should be carefully studied is whether the anti-histamines might help PWN get better sleep.

Thank YOU 2013 Donors

Narcolepsy Network thanks the following donors, whose generous donations 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 2013 to help further the mission of the Narcolepsy Network by helping individuals and families, and advocating for and/or raising awareness about narcolepsy in their communities.

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January 20, 2013
February 17, 2013
March 17, 2013
April 21, 2013
May 18, 2013
June 23, 2013
July 21, 2013
August 18, 2013
September 15, 2013
November 10, 2013
December 8, 2013

The Board of Trustees met in person on October 21, 2013 in Atlanta, GA.

Narcolepsy Network, Inc. Financial Report



Louise O'Connell
Treasurer,
Narcolepsy Network
Board of Trustees

Treasurer's Message

Narcolepsy Network ended 2013 with increased reserves and a strong financial position thanks to an increase in grants, donations and membership. The hard work that we do has achieved results in both strong corporate support and a wider base of contributors. Innovative and successful fundraisers including the Narcolepsy Bed Race in Roanoke, VA, our first 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 2014, we look forward to expanding on these activities. This has already started with a very successful Narcolepsy Awareness Day and a conference scholarship fundraising campaign, which will continue to allow us to pursue our CARES mission. Thank you for your help in making 2013 a successful year. We look forward to counting you among our supporters again in 2014.

Warm Regards,

Louise O'Connell
Treasurer
Narcolepsy Network Board of Trustees

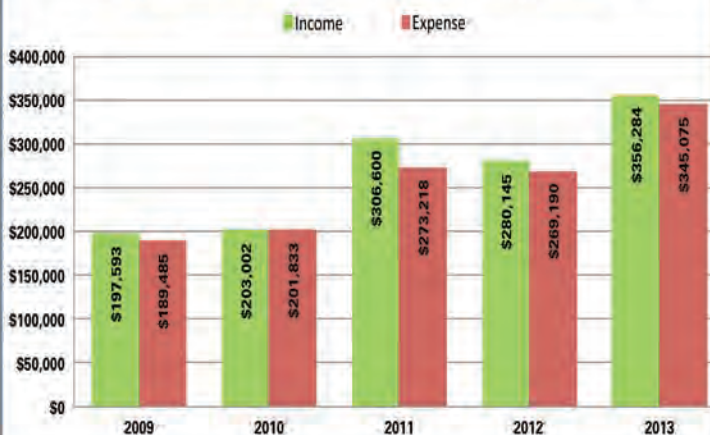
Statement of Financial Position - Years ended December 31

| Assets | 2013 | 2012 |
|---|------------------|------------------|
| Cash and cash equivalents | \$337,338 | \$315,074 |
| Accounts receivable | — | 82 |
| Prepaid expenses | 73 | 49 |
| Property and equipment, net | 2,500 | 2,500 |
| Total Assets | \$339,911 | \$317,705 |
| Liabilities: | | |
| Accounts payable and accrued expenses | \$11,910 | \$1,373 |
| Payroll withholdings and accrued taxes | 2,425 | 1,964 |
| Total Liabilities | \$14,335 | \$3,337 |
| Net Assets | | |
| Unrestricted | \$325,576 | \$314,368 |
| Temporarily restricted | — | — |
| Total net assets | 325,576 | 314,368 |
| Total liabilities and net assets | \$339,911 | \$317,705 |

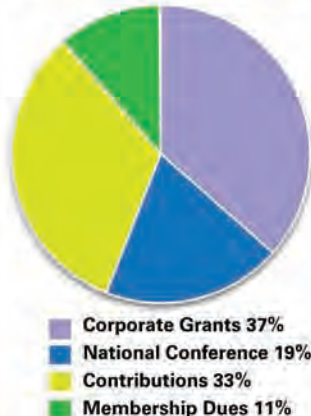
Statement of Activities - Years ended December 31

| Income | 2013 | 2012 |
|--|------------------|------------------|
| Corporate grants | \$130,000 | \$99,000 |
| National conference | 69,345 | 66,259 |
| Contributions | 116,361 | 86,329 |
| Membership dues | 40,030 | 27,530 |
| Other | 548 | 1,027 |
| Total Income | \$356,284 | \$280,145 |
| Expenses | | |
| Programs | | |
| National conference | \$126,693 | \$82,221 |
| Public information | 110,022 | 82,361 |
| Membership | 60,217 | 59,886 |
| Total program expense | \$296,932 | \$224,468 |
| General and administrative | 34,690 | 35,142 |
| Fundraising | 13,453 | 9,579 |
| Total expenses | \$345,075 | \$269,189 |
| Net increase (decrease) in net assets | \$11,209 | \$10,956 |

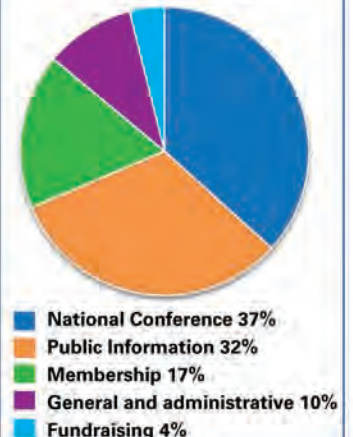
Five Year Revenue and Expense Comparison



2013 Revenue Categories



2013 Expense Categories





Narcolepsy Network, Inc.

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