

Narcolepsy Network, Inc. 2012 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 Shrewesport, 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 President



Sara Kowalczyk, MA, MPH
2012 President,
Board of Trustees

Dear Friends,

2012 was a year full of exciting developments in the narcolepsy community, and Narcolepsy Network continued to be in the forefront. From our annual conference in Cleveland, attended by more than 325 people, to our informative quarterly newsletters and expanded social media presence, it has been an inspiring time to be connected to 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 social media presence grew by leaps and bounds in 2012, with a brand new Twitter feed and over 1,800 people liking us on Facebook by year end. Social media outlets provide a worldwide platform to increase awareness about narcolepsy and the work NN does.

A — Advocacy: Suddenly Sleep Saturday/Narcolepsy Awareness Day on March 10 was an especially big day this year with three awareness walks held around the country. Narcolepsy was also represented at public events and professional meetings from coast to coast (see page 6 for more).

R — Research: NN offered members several opportunities to hear about research advances directly from the researchers this year. We co-hosted Research Update programs in Boston and Nashville featuring Dr. Emmanuel Mignot of the Stanford Center for Narcolepsy, as well as several research-focused sessions at our annual conference.

E — Education: Executive Director Eveline Honig continued traveling the country giving presentations on sleepy children to school nurses. By spreading our informed perspective to school health professionals, NN plays an invaluable role in getting children who show signs of narcolepsy the help they need.

S is for Support: Our annual conference featured a host of support-focused sessions from starting a support group to communicating about narcolepsy. These programs were particularly well attended.

As president of Narcolepsy Network's Board of Trustees, I am dedicated to further 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 2012 and urge you to continue your support in 2013 as we keep working to improve the lives of people with narcolepsy.

Sara Kowalczyk, MA, MPH
President, Board of Trustees

Reason to give: Kathleen Randell



Mother of three. Wife. Accounting manager. College student. Those are just a few ways to describe Kathleen Randell. With all those responsibilities comes a hectic, busy life.

So there's one more phrase that might surprise you: person with narcolepsy. Yes, Kathleen is a busy woman who makes it all look easy. But it hasn't always been that way. Reaching this point was a series of small steps.

Diagnosed with narcolepsy 16 years ago while pregnant with her second child, Kathleen struggled at first. "I felt broken," she recalls. "It was a really difficult time."

She left her full-time job as a bookkeeper, sought information about her disorder and slowly found ways to cope. She discovered Narcolepsy Network as a great resource and attended her first conference in Atlanta in 2003. The conference was a life-changing step.

"I met other people with narcolepsy," she remembers. "All those things I thought only I experienced were their experiences too. I wasn't all alone."

After returning from the conference, she took another step and began attending NAPS (Narcolepsy Association of Philadelphia & Suburbs), a support group near her home in southern New Jersey. The leader of the group was retiring and before long, Kathleen stepped into the role of support group leader.

In 2004, NN hired her as the accounting manager, handling bookkeeping, payroll, and assisting the Board of Trustees. Because NN does not have a physical office, Kathleen, like all NN employees, works from home.

"The job with Narcolepsy Network gave me the confidence to try and do something," Kathleen says. "It showed me that I am able to be productive and that gave me hope."

Kathleen's next step was to enroll in Camden County College to study business administration. In addition to her work and family lives she now finds herself tackling calculus tests and finishing homework assignments. When she completes her associates degree in 2014, she plans to transfer to Rowan University to earn her bachelors in accounting and then become a licensed CPA.

"My 10-year goal is to be off of Social Security Disability and able to help support my family financially," Kathleen says.

Kathleen says that medication and sticking to a rigorous schedule are the keys to her success. She tries to get up and go to bed at the same time every day as well as eating properly and drinking lots of water. She takes naps as needed. Support from her husband Russell is also essential.

"He helps me stay on a schedule, which helps with my sleep," Kathleen says. "We make a good team."

The couple splits jobs in to parts, such as sorting laundry and washing it. One of them does the first part and the other takes on the other, so jobs get done efficiently. The children Ashley, 22, Ryan, 15, and Rachel, 13, also help around the house.

Keeping narcolepsy in perspective also helps, Kathleen says. "You have to accept that narcolepsy is a part of you, but it doesn't define you."

"You have to accept that narcolepsy is a part of you, but it doesn't define you."

Reason to give: Nicole Jeray



Professional golfer Nicole Jeray is finding herself especially motivated on the golf course these days. As the driving force behind “Swinging for Sleep,” a campaign to raise both money and awareness for narcolepsy, Jeray knows she’s in the spotlight. For every birdie and eagle she makes in tournament competition on the LPGA tour, money is donated to narcolepsy organizations, including Narcolepsy Network. As a person with narcolepsy, Nicole knows first hand how important organizations such as Narcolepsy Network can be.

Starting a Career

Nicole began golfing as a teenager. A natural athlete, she picked up the sport right away, and because she was a girl and a good golfer, she gained a lot of attention. She received a scholarship to play golf in college, thinking she would use golf to pay for college and then get a “real” job after graduation. But as her game improved, she drew more notice as she started winning tournaments. During her junior year in college, she decided to see if she could qualify for an LPGA event.

“I shot 68,” recalls Nicole. “It was the first time I had ever broken par in my whole life, and I qualified for the tournament. I thought it was the coolest thing in the whole world. I thought, *I want to do this.*”

And so began her LPGA career.

Struggling with Narcolepsy

While she was excelling on the golf course, Nicole was struggling with undiagnosed narcolepsy. She was so sleepy she would fall asleep driving to tournaments and had muscle weakness when she laughed.

As the sleepiness grew worse, Nicole started visiting doctors and trying to find a solution. She tried everything from vitamins to a vegan diet, but nothing helped. Finally after several severe cataplexy attacks on the course, she saw a doctor who recognized her symptoms as narcolepsy.

Getting her diagnosis was only half the battle. Finding a treatment that worked for her took some time too. At first Nicole was treated only for cataplexy, so sleepiness was still a problem.

“I’d be playing in an event and staying awake would be my goal, instead of making a birdie. You cannot play golf like that,” she says.

In 1999, Nicole hit her low point. Almost unable to stay awake, and gaining weight, she decided to make a change. She went on a diet, lost some weight and started taking Provigil.

“But what really started helping me was when I went to the Narcolepsy Network conference in 2000,” she recalls. “I met other people with narcolepsy and I learned that you have to take better care of yourself. I didn’t realize there were other things you could do. That was like a revelation. From there, things got much better.”

Swinging for Sleep

After Nicole found the right combination of routine and medications, she was less sleepy, lost weight, and eventually wanted to find a way to give back and help others with narcolepsy. As part of the LPGA tour, she participated in many golf outings to raise money for good causes. She was always thinking of how she could do the same for narcolepsy.

She came up with “Swinging for Sleep,” and in 2011, she pitched the idea to Jazz Pharmaceuticals who signed on as a sponsor right away. They started out donating \$25 per birdie. In 2012 Jazz increased their contribution to \$250 per birdie and \$1,000 for an eagle. Suddenly the pressure was on.

Now, “When I’m playing, I’m thinking I’ve got to make birdies, because that’s a lot of money for narcolepsy. This could be changing people’s lives,” she says.

The motivation paid off. In 2012, Nicole shot 121 birdies, and Swinging for Sleep raised more than \$37,000.

This year, Nicole has set \$50,000 as her fundraising goal. To get there, “I need to make more birdies, and more people need to donate.”

The 2013 LPGA season is already underway. To donate to Swinging for Sleep and check in on Nicole’s progress, visit www.nicolejeray.com.

2012 Highlights



Breakthrough research on hypersomnia published



David Rye, MD, PhD

Narcolepsy Network Medical Advisory Board member David Rye, MD, PhD, and a team of researchers at Emory University School of Medicine published research showing that dozens of adults with primary hypersomnia have a substance in their cerebrospinal fluid that acts like a sleeping pill.

The results, published in the online journal *Science Translational Medicine*, show that in the hyper-sleepy patients, the newly discovered substance affects GABA receptor function more than twice as much on average as in the control group subjects.

Identifying the mysterious “somnogen” could provide greater insight into how our brains regulate alertness and sleep, and could lead to new treatments for primary hypersomnia.

Narcolepsy well represented in print

Three books published in 2012 highlighted aspects of narcolepsy:

- Dr. Oliver Sacks’ book “*Hallucinations*” includes a chapter on hallucinations experienced by people with narcolepsy. Sacks worked closely with NN members to gather many of the accounts featured in the chapter.
- Narcolepsy advocate Julie Flygare published “*Wide Awake and Dreaming, a Memoir of Narcolepsy.*” The first-hand account shares Julie’s experiences as a person with narcolepsy and how narcolepsy changed her life in unexpected ways.
- “*Island Practice*” by Pam Belluck chronicles the life of Dr. Timothy J. Lepore and the patients he treats, including two with narcolepsy, during his years in practice on Nantucket Island.



Eveline Honig, Sara Kowalczyk and Dr. Mignot (from left to right) following the presentation

NN co-hosts two research update events

Narcolepsy Network, Wake Up Narcolepsy and the Stanford Center for Narcolepsy came together to present Research Update programs in Boston and Nashville. At both programs, Dr. Emmanuel Mignot of Stanford spoke on the latest advances in narcolepsy research. More than 100 people attended these presentations, where they also had the opportunity to participate in Dr. Mignot’s genetics research studies by giving blood.

Narcolepsy’s inclusion on FDA initiative

Narcolepsy was one of 39 disease areas nominated for inclusions in a new initiative to better inform the FDA’s drug review process with input from patients who experience particular diseases. Working with narcolepsy advocate Julie Flygare, NN rallied members and supporters to make their voices heard. Several hundred people responded with comments on the public docket. The FDA is in the process of reviewing the comments and will announce the 20 disease areas chosen in early 2013.



Julie Flygare
Photography by Matt Spaulding

NN Marks National Sleep Awareness Week/Suddenly Sleepy Saturday



Sarah with Meghan, designer of the Sleep Walk sign she is holding

Volunteers across the country worked to raise awareness of narcolepsy during National Sleep Awareness Week, March 5-11, and particularly on March 10, dubbed Suddenly Sleepy Saturday or Narcolepsy Awareness Day.

Sarah DiDavide organized the first-ever Chicago Sleep Walk. In Washington, DC, more than 110 people gathered on the National Mall for Sleep Walk 2012. Suddenly Sleepy Saturday was also marked on the west coast with a walk in Sacramento organized by Ming Lai.

Second annual Kansas City Narcolepsy Education Day

NN member Ann Austin returned to Children's Mercy Hospital in Kansas City for the second annual Narcolepsy Education Day Teen Conference. Ann began with a message of hope and practical tips. She enjoyed reuniting with the multidisciplinary "dream" team she met in 2011. Most of the young attendees had never met an adult with narcolepsy or heard about the support available through NN.



Ann Austin

Narcolepsy Network reaches out to health care providers at professional meetings

NN continued its efforts to increase the understanding of narcolepsy among healthcare professionals by attending the *SLEEP 2012* meeting and the National Sleep Foundation's *Sleep, Health and Safety* meeting. At both, NN volunteers distributed information about narcolepsy and NN.

Executive Director Eveline Honig was invited to give her presentation "Sleep Disorders in Children" at both the Kentucky School Nurse Association meeting and the National Association of School Nurses' meeting. Dr. Honig covered narcolepsy and other sleep disorders in children as well as information on good sleep habits. Both audiences were extremely interested and had many questions following the presentation.



Executive Director Eveline Honig

Awaken survey

In July results of AWAKEN (Awareness and Knowledge of Narcolepsy) were released. The national online survey by Jazz Pharmaceuticals assessed public and physician knowledge of narcolepsy.

Among the results, **70%** of people in the general public indicated that they had heard of narcolepsy, but only **55%** rated narcolepsy a very or extremely serious disease.

Among medical doctors, **24%** of primary care providers (PCPs) and **62%** of sleep specialists considered themselves very or extremely knowledgeable about narcolepsy. An even smaller number of PCPs (**9%**) and sleep specialists (**42%**)

said they were very or extremely comfortable diagnosing narcolepsy.

These results reveal the lack of awareness of narcolepsy in the general public, as well as a serious education and knowledge gap among physicians, especially sleep specialists.

The survey outlines the challenges that Narcolepsy Network continues to address: the need for greater knowledge among the public, and better understanding among health care providers. We enter 2013 with a renewed energy to truly "awaken" the public to narcolepsy.

*We enter 2013 with a renewed energy to truly
"awaken" the public to narcolepsy.*

Narcolepsy Network 2012 Patient Conference

Narcolepsy Network's 27th annual patient conference in Cleveland broke records, with a capacity crowd of 325 people attending. Attendees from all over the world arrived at the InterContinental Hotel Cleveland on Friday, October 19 and enjoyed an optional outing to the Rock and Roll Hall of Fame before registration and the opening reception.

Saturday began with the conference keynote address given by Emmanuel Mignot, MD, PhD, of the Stanford Center for Narcolepsy. Dr. Mignot provided the standing-room-only crowd with the latest news on research into narcolepsy and the autoimmune system.



Dr. Mignot gave the keynote address

The conference schedule allowed plenty of time for naps and fun along with the more serious sessions on research, treatment, and advocacy. More relaxing and lighthearted sessions included yoga, tai chi, and a group nap. Attendees also enjoyed optional outings to local restaurants and a dinner cruise aboard the Nautica Queen.



Other conference highlights included:

Sessions for Young People With Narcolepsy

For the first time, the NN conference offered special programming for children and young adults with narcolepsy. For many of these kids, it was the first time they had met anyone else their age with narcolepsy. Sessions for the young PWNs included mask making to “face” their narcolepsy, youth-focused support group and Q&A sessions, and plenty of time with new friends. For many of the young conference goers, another highlight was making a “narc-umentary” — a video presentation about being a young person with narcolepsy.

More Conference Firsts

Before the conference, Nancy Foldvary, DO surveyed female NN members on their experiences with pregnancy and shared the results of the survey during her presentation on Xyrem and pregnancy at the conference.

Iris Bell, MD, PhD conducted her presentation “Dietary & Environmental Strategies for Managing Narcolepsy Symptoms” on video followed by a live Q&A with audience members via Skype.



Interactive sessions kept young PWNs engaged

*“I found it most interesting
and even countries,*

What attendees said about the conference:

“Attending the Breakout Sessions was a major highlight of the conference. The information covered in the sessions was enlightening, fascinating, and captivating. I left the sessions with a greater comprehension of research, treatments, therapies, and the importance of a strong support system. I often find myself wishing I could sit through the sessions again.”

“This weekend of information and fellowship may have been just as life changing as being diagnosed with narcolepsy was a few years back. It is an amazing feeling to not only be surrounded by people who understand but to hear world renowned doctors and researchers validate just how life altering and serious narcolepsy is. There are no words to adequately express how thankful I am to have had the opportunity to be part of such an intelligent and kind group of individuals...”

“I found it most interesting that we came from so many different backgrounds, and even countries, and yet shared a very significant bond: narcolepsy.”

2012 NN Award Recipients Recognized

The 2012 Narcolepsy Network awards were presented at the conference.
Congratulations to the honorees!

Public Awareness

Julie Ann Fain, Robby Roden, and Katy Scruton

Researcher of the Year

Florian T. Merkle, PhD

Dr. Robert Clark Clinician of the Year

Siobhan Kuhar, MD

Public Education

Julie Law

Lifetime Achievement

Sharon D. Smith



Jackie Benton (front) and her family traveled to Cleveland from Australia to attend. The conference gave her grandson, who has narcolepsy, his first-ever opportunity to meet other people with narcolepsy.



Conference goers prepare to board the Nautica Queen for the Saturday evening dinner cruise

*that we came from so many different backgrounds,
and yet shared a very significant bond: narcolepsy.”*

Research Update Dr. Attila Szakács



Dr. Attila Szakács is a pediatrician and aspiring pediatric neurologist at Children's Hospital of Halmstad in western Sweden. The majority of his patients have some form of neurological disease including narcolepsy. He lectures on child neurology and rehabilitation at both Children's Clinic and the University of Halmstad. He is also responsible for Sweden's National Narcolepsy Registry for children and young people.

How did your research into narcolepsy begin?

My research in narcolepsy is designed as a PhD project at Sahlgrenska University and is implemented with supervisors Niklas Darin and Tove Hallböök, both pediatric neurologists. After the H1N1 influenza vaccination in October 2009, we diagnosed several narcolepsy patients in our office within a few months compared to before vaccination, when we diagnosed only one patient in three years. Knowledge of narcolepsy in children was very limited and those newly diagnosed children could not get a really good understanding of their disease. With my supervisor's support we were able to quickly launch a well-planned PhD project which hopefully will lead to important changes in narcolepsy care in the future.

What did you learn from that study?

We mapped the incidence of narcolepsy in western Sweden over a 10 year period, including the period after vaccination against the H1N1 flu. The study's strength was that it was a population-based study. The most important result was that we were able to demonstrate that the risk of suffering from narcolepsy in the period after vaccination was much higher than before. Similar but lower figures have also been presented by other research groups, which strengthened our conclusion that the increase was due to the H1N1 vaccine, Pandemrix.

Where will your research go from here?

We continue now with two studies in which we have met 36 children and their parents to study the extent to which the disease leads to psychological disorders, social difficulties, psychiatric complications, or learning disabilities. These aspects are sparsely studied worldwide.

In subsequent studies, we will analyze the patients' hormonal system in a comprehensive manner, both through blood tests and clinical assessment of their growth and puberty. In the brain, the hypocretin producing cells are anatomically and neurochemically very near the pituitary gland, which is the most important hormone center in the human body. Therefore, it is conceivable that an injury involving hypocretin cells may also affect the pituitary gland. Weight gain is a known consequence but any underlying hormonal disorders are not sufficiently well studied.

How could your research change the way pediatric narcolepsy is treated?

There is a great need to understand better how children and young people with narcolepsy feel. We often see difficulties in everyday life. Many young people are sad, jaded, and isolated. Many of them lose their friends and hobbies. What is behind these symptoms? Is it caused by narcolepsy itself, or is it a reaction to narcolepsy's burden? Our studies are designed so that we can hopefully get answers to these important questions and with greater understanding, we can offer a better treatment.

Adaptation of the school environment and teaching also requires good knowledge of what type of difficulties patients have with learning, concentration, and memory.

We look forward to meaningful results from the hormonal study that can affect how we follow up with these children and thus can capture differences of growth, nutritional status, and puberty in time and prevent other secondary complications.

Research Update Florian T. Merkle, Ph.D.



Dr. Merkle is a post-doctoral fellow at Harvard University, and the recipient of Narcolepsy Network's 2012 Researcher of the Year award.

Tell us about your research.

Narcolepsy is caused by the loss of hypocretin (HCRT) neurons, but the cause of their loss is not known. It has been difficult to study human HCRT neurons directly, since they are rare and inaccessible. To address this problem, I determined how to generate HCRT neurons from human pluripotent stem cells in a tissue culture dish. Pluripotent stem cells can theoretically convert into any cell type in the body. Since pluripotent stem cells can now be generated from the skin cells of individuals with narcolepsy, I have also succeeded in generating HCRT neurons from narcoleptic patients. I now plan to test whether there are differences in HCRT neurons derived from unaffected and affected individuals that might explain why these cells are specifically lost in narcolepsy.

How might your findings change our understanding of narcolepsy and/or the way it is treated in the future?

It is difficult to predict the findings of my work until the experiments are performed. However, I am excited about the opportunities. First, any hint at what causes HCRT neuron loss might reveal new therapeutic targets. For example, if a certain biological pathway is disrupted in narcolepsy, drugs that act on this pathway might be able to slow or prevent the loss of HCRT neurons. Second, having access to HCRT neurons might enable the discovery of new drugs that selectively activate HCRT neurons. Since HCRT loss is often not complete, stimulating the remaining neurons might suppress cataplexy and excessive daytime sleepiness. Finally, it might be feasible to transplant HCRT neurons into the brains of patients with narcolepsy to permanently combat narcoleptic symptoms.

How did you become interested in narcolepsy?

I have a long-standing interest in the brain, particularly in the regulation of behavior by specific cell types. The HCRT system is a classic example of how a small population of

neurons exerts a dramatic effect on sleep/wake behavior, since narcolepsy results when the HCRT system is defective. When I looked into narcolepsy more deeply, I realized that narcolepsy is remarkably common and debilitating. Essentially, I recognized that there is a large, unmet need where I might be able to make a meaningful contribution. As a scientist, I also get really motivated by mysteries. The fact that HCRT neurons are lost in narcolepsy but that neighboring cells appear to be unaffected is a problem that still fascinates me today.

You received the Researcher of the Year award at our conference this year. What does the award mean to you?

I was greatly honored to receive the Researcher of the Year award. I am still early in my career and my choice to study narcolepsy is unconventional. For me, receiving the award was a vote of confidence that I am doing something worthwhile. Thus, I view the award not as a recognition of what I have accomplished but as the symbolic beginning of a long relationship with Narcolepsy Network and with the narcoleptic community.

How was your experience attending the NN conference in Cleveland?

Before attending the Narcolepsy Network conference, my knowledge of narcolepsy was largely based on academic papers. I found that it is quite another thing to sit down and talk to patients and family members who are affected on a daily basis. It was a moving experience. I left the conference with a newfound energy and determination to pursue my studies as well as a desire to stay involved with the NN community. Furthermore, I thought the conference was an excellent forum to interact with other researchers, clinicians, and family members who each have their own perspectives to share. I recommend it to anyone directly or indirectly affected by narcolepsy.

Thank YOU 2012 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 2012 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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Board of Trustees monthly Teleconferencing calls were held on:

January 18, 2012
February 15, 2012
March 21, 2012
April 18, 2012
May 16, 2012
June 11, 2012
July 11, 2012
August 15, 2012
September 19, 2012
October 22, 2012
November 18, 2012
December 9, 2012

Narcolepsy Network, Inc. Financial Report



Treasurer's Message

Narcolepsy Network ended 2012 with increased reserves and a strong financial position thanks to an upsurge in donations. The hard work that we do has achieved results in both strong corporate support and a wider base of contributors. 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. This year also was marked by a number of successful initiatives, including innovative fundraisers such as the Swinging for Sleep campaign.

As we move forward into 2013, we look forward to expanding on these activities, and this has already started with a very successful concert, walks, and a bed race, which will continue to allow us to pursue our CARES mission. Thank you for your help in making 2012 a successful year. We look forward to counting you among our supporters again in 2013.

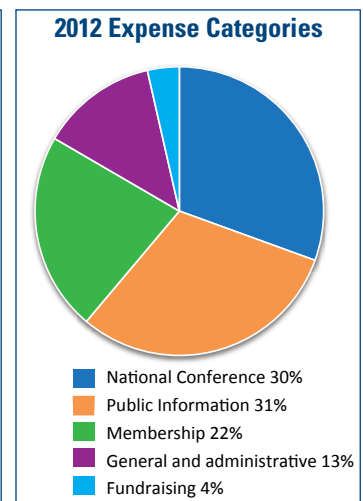
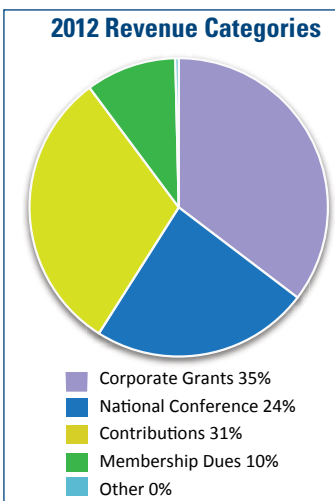
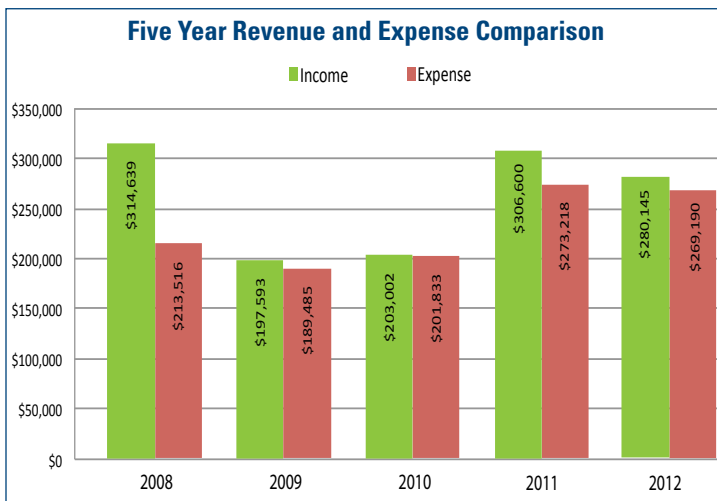
Warm Regards,
Louise O'Connell
Treasurer
Narcolepsy Network Board of Trustees

Statement of Financial Position - Years ended December 31

Assets	2012	2011
Cash and cash equivalents	\$315,074	\$300,335
Accounts Receivable	82	150
Prepaid expenses	49	—
Other liquid assets	—	8,468
Property and equipment, net	2,500	2,500
Total Assets	\$317,705	\$311,453
Liabilities:		
Accounts payable and accrued expenses	\$1,373	\$6,615
Payroll withholdings and accrued taxes	1,964	1,425
Total Liabilities	\$3,337	\$8,040
Net Assets		
Unrestricted	\$314,368	\$303,413
Temporarily restricted	—	—
Total net assets	314,368	303,413
Total liabilities and net assets	\$317,705	\$311,453

Statement of Activities - Years ended December 31

Income	2012	2011
Corporate Grants	\$99,000	\$131,600
National Conference	66,259	81,240
Contributions	86,329	59,701
Membership Dues	27,530	31,910
Other	1,027	2,149
Total Income	\$280,145	\$306,600
Expenses		
Programs		
National Conference	\$82,221	\$97,563
Public Information	82,361	64,549
Membership	59,886	62,221
Total program expense	\$224,468	\$224,333
General and administrative	35,142	50,452
Fundraising	9,579	1,736
Total Expenses	\$269,189	\$276,521
Net increase (decrease) in net assets	\$10,956	\$30,079





Narcolepsy Network, Inc.

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