

Narcolepsy Network, Inc. 2011 Annual Report



25
YEARS

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 thirteen 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 seventy-five 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 ten 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 seventy-nine. 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 twenty-five years and beyond.

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From the President



Sara Kowalczyk, MA, MPH
2011 President,
Board of Trustees

Dear Friends,

2011 has brought a year of inspiring developments in the narcolepsy community, and time and again Narcolepsy Network has been the organization driving these gains. From our 25th Anniversary Conference in Las Vegas to exciting new research findings to *Avalon* magazine's dream-inspired issue, it is an incredible time to be involved in the Narcolepsy Network.

In short, Narcolepsy Network CARES — our mission motto now includes an “S” for the support we provide in individual and group formats. Here's a quick look at some ways NN CARES:

C — Communication: NN continues to develop our 12-page quarterly newsletter, *The Network*, dedicated to all things narcolepsy. In each edition, articles cover healthy living, research breakthroughs, wellness advice, personal stories, event updates, ways to get involved, and creative contributions from our members.

A — Advocacy: Working in tandem with NN, two college campuses included events linked to narcolepsy advocacy and awareness. Dr. Ayelet Gneezy taught a marketing course at the University of California at San Diego where students developed marketing plans related to narcolepsy awareness in schools. Also, Boston University hosted the first official NN student intern who focused on communications and research.

R — Research: Three current or past Board members played key roles in developing the National Institutes of Health's *Sleep Disorders Research Plan*, released in November 2011, ensuring that narcolepsy was a core consideration of the plan. In addition, NN facilitated a research questionnaire about narcolepsy and pregnancy to better understand women's perceptions and experiences during this time of their lives.

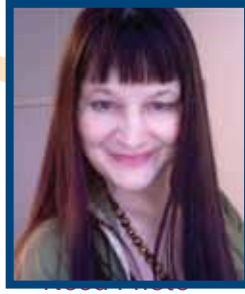
E — Education: Eveline Honig, NN's Executive Director, continued traveling the country in 2011, giving her presentation on sleepy children to school nurses. By spreading our informed perspective to school health professionals, NN plays an invaluable role in getting children who show signs of narcolepsy the help they need.

S is for Support: This year, our three-day, 25th Anniversary conference in Las Vegas, Nevada, focused on building better support systems for attendees. As a result, NN has already seen a growth in new support groups across the nation.

As the current president of Narcolepsy Network, I am dedicated furthering the Network's **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 membership dues, donations, and grants to further our mission. I thank you for your contributions in 2011, and urge you to continue supporting the Network in improving lives of people with narcolepsy in 2012.

Sara Kowalczyk, MA, MPH
2011 President, Board of Trustees

Reason to give: Linda Black



Linda Black is a writer, journalist, and spoken-word poet. Since 2010 she has been Editor-in-Chief and Publisher of *Avalon* magazine.

in publishing and journalism too, in that I'm always interested in stories, whether the stories come from the dream world or the waking world.

How would you describe the inspiration for starting *Avalon* magazine?

I was so tired of going to women's sections of magazine stands and finding the same format over and over—celebrity oriented, an image on the cover of a celebrity or model, and all the headlines about what we need to do better. I wanted to see something that appeals to our intelligence and celebrates what we're doing well.

The other part was, I'd been living on Martha's Vineyard for about 18 years. The Vineyard has a community of incredible artists and poets and writers and fashion designers. The first time I arrived, I was coming over on the ferry from the mainland on a foggy day, and the mists parted to reveal this beautiful island. In my first few weeks there I met one extraordinary woman after another. I thought, wow, this is the island of the goddesses, this is Avalon. The Vineyard and the women who crossed my path over the years were definitely part of the inspiration for *Avalon*, for the idea of sharing inspiring stories.

Finally, I've chosen to not take medication. That has always made a 9-to-5 office environment challenging, including the magazine office where I was working as an Associate Editor at that time—I'm sure it's difficult for PWNs who do take medication as well. But I really needed a job where I could work at home. So, one morning in January 2010, after lying awake all night, I called my sister and said, 'We're going to start a magazine!' And she said, 'Okay!' She is an artist with a background in graphic design, so it's a perfect pairing of her artistic background and my editorial background.

You're also a performing poet.

A lot of my poetry comes almost verbatim from dreams. I perform mostly from memory. Although I do write them down, I wake up and I start reciting what I've dreamt until it *sounds* right. The thing with narcolepsy is that it doesn't feel like I 'woke up,' it's not that black and white. It's more like I arrived from somewhere else, like I have an experience in the dream world and then I shift to the waking world. That helps

Would you say your dreams have an overall character to them?

There are recurring themes. The stalker theme is very prevalent among PWNs. For me the stalkers have usually been vampires. But my relationship with the vampires has evolved over my life; now, sometimes there's even an element of humor. For example, I dream I'm flying to San Francisco, being chased by five or six vampires. I get there and it's dawn and I walk into a Starbucks and the barista is a young woman with cropped blond hair and a sunrise tattooed on her back, and her name is Dawn. She turns around and she's one of the vampires. I'm like, 'You're kidding. It's dawn.' She smirks, 'The rules are changing.' And I'm like, 'Seriously? Okay, can I at least have my coffee?' And she says, 'Sure.' I drink my coffee, then she chases me, and we end up in this abandoned warehouse, up on the top floor, where I'm against a wall and she's against a door. I put my hand on her chest and say, 'You know what happens when you push a vampire through a door?' She says, 'Nothing.' I say, 'Well, the rules are changing,' and I push her through the door and she turns into vapor and disappears.

Anything else you want to say about your experience with narcolepsy?

Ultimately, I've found there are many challenges to having narcolepsy, but I've come to embrace it as a package deal. And overall, I have a wonderful life. As I said in the *Avalon* dream issue, this is how I navigate the world. You know those movies where you get a chance to redo your life? I'm not sure I would redo it if that diminished my creative life, my incredible dream life, or my perspective on the world. I have a friend who calls my living with narcolepsy being 'cracked open.' When you have hardship or loss, it cracks you open and makes you more compassionate and understanding of other people's challenges or differences. I'm grateful for that, and I don't know if I would trade it.

Visit Linda online at **AvalonMag.com**. You can also see videos of her performing her poetry by searching "Linda Black poetry" on **YouTube.com**.

Reason to give: Trinity Hamilton



Trinity Hamilton has had a passion for dance since an early age. After years of training, in 1996 she became a dancer at the Joffrey Ballet, one of the nation's top companies. Trinity had always experienced fatigue, which she attributed to dancing. However, in 2000 she received a diagnosis of narcolepsy. After struggling with the illness for several years, Trinity left the Joffrey in 2004. A stint as ballet director for the New Tampa Dance Theater followed. In 2009, Trinity returned to dance as a performer with Cirque du Soleil in Las Vegas.

Narcolepsy Network spoke to Trinity a few months after this year's conference in Las Vegas, where NN members saw her perform in Cirque's *Mystere*, and attended her conference session "The Joy of Movement" with Julie Flygare.

When you taught "The Joy of Movement," you described how narcolepsy brought setbacks to your dance career.

My cataplexy became so bad, it was one of the reasons I left the Joffrey. I no longer had confidence I could be on stage and not fall down. Losing the passion I'd had since I was a child took me to my lowest of lows. I gained weight until I weighed 185 pounds. I was a ballet dancer and now I had no physical evidence of ever being a dancer. It was very hard to look at myself in the mirror and think, this is where I'm at because of the disease.

What helped you to move on?

It was definitely the extreme patience, love, and support of my family and my boyfriend at the time. Also, I discovered Dr. Feldman, and he helped me find the correct medication, Xyrem. My body's reaction was extraordinary and inspired me that I could have a second chance.

How did you get back to movement, exercise, and dancing?

I definitely took baby steps. I did Pilates, Ashtanga & Vinyasa yoga. I saved Bikram yoga (yoga in a heated room) for last to

tone and push myself, as it is so hot. Then I mixed it up with ballet and working out. Once I got used to this routine, I lost 65 pounds.

Was it hard returning to performance with Cirque du Soleil?

When I first started with Cirque we had a lot of rehearsals, and I would fall asleep while I was trying to put my makeup on. That was so embarrassing. I eventually came out to the girl sitting next to me. And she was like, 'I'm relieved you told me that. I thought you were a partier.' I'm so the antithesis of partier! [laughs] At first we kept it in the dressing room. Once I knew I could maintain 176 shows per year, I no longer felt compelled to hide my illness. Cirque du Soleil has been extremely supportive. I feel so blessed to be a part of their family and the arts community.

If someone's not a professional dancer, how might they start getting into movement?

I think the biggest thing is to look in the mirror and say, what would bring me the most joy? What have I always wanted to try? It could be ballroom dancing (I actually would like to try that), or something else. Listen to your heart.

What is your advice to help get others started?

At the conference, someone whose son is suffering from narcolepsy asked, what you do when they don't want to do anything? First you've got to open your mind and theirs to the possibilities that movement opens up. We have this idea that physical activity equals tired. But that's not the case. Even after only 10 minutes of exercise, the body often thanks you with more energy. So to go back to the mother, the answer is, when her son's ready. Always keep the communication open and supportive. Not, 'why haven't you started yet?' Instead, try things like, 'I heard about a great special that's going on at the yoga studio.' As long as your encouragement comes from a loving place.

2011 Highlights



Kansas City Dream Team Teen Narcolepsy Day

Member Ann Austin represented NN in Kansas City, Missouri, at the Mercy Children's Hospital Teen Narcolepsy Day. The doctors and professionals who developed the event dubbed themselves the "Dream Team" for their holistic, multi-dimensional approach to treating young people with sleep disorders. Austin traveled across the state from her home in St. Louis to share her story, her support, and NN materials and resources during the one-day conference. Teens with narcolepsy and their parents received tips for managing their symptoms, practical skills for school and college, and a chance to open up with each other about their experiences with narcolepsy.



Dream Team: Ann Austin, Pam Troutwine, Ellen Meier, Dr. Robert Beckerman, Jamie Neal, Dr. Kevin Smith



Patricia Higgins, Eveline Honig, Shawn Auman, Ramon Werbeach

SLEEP 2011 Sleep Medicine Conference

NN attended this year's SLEEP Conference, which took place in Minneapolis, MN. President Patricia Higgins, Board members Ramon Werbeach and Shawn Auman, and Executive Director Eveline Honig represented NN and distributed materials and information to the sleep medicine community. In addition, NN member Sean Kelley surveyed the many paper presentations relevant to narcolepsy research, including new findings pertaining to hypocretin/orexin, drugs, and inflammation responses. You can read a detailed report on these presentations in the Fourth Quarter 2011 Network Newsletter.

UCSD Business Students Tackle Narcolepsy Awareness

This spring, a unique collaboration occurred between the Narcolepsy Network and MBA students at the Rady School of Management of UC San Diego. This partnership began when Ayelet Gneezy, whose daughter received a narcolepsy diagnosis several years ago, decided to bring together her work as a marketing professor with the narcolepsy cause. Working with Eveline Honig, Gneezy posed an entrepreneurial challenge to her students: research and design the best narcolepsy awareness campaign to reach elementary school teachers and staff. Dr. Honig reviewed the entries and picked a winner among them. However, the entire narcolepsy community was the biggest winner, as this entrepreneurial match-up yielded many creative ideas for communicating our cause.



Eveline Honig with students



Dr. Ayelet Gneezy

Narcolepsy in the Media

People's experiences with narcolepsy received coverage in several major media outlets in 2011. MTV's program *True Life* ran an episode titled "I Have Narcolepsy" that profiled two PWNs. In print (and online), *Avalon* magazine (AvalonMag.com), edited and published by NN member Linda Black, brought out a holiday "Dream" issue this year. The issue included several stories that touched on narcolepsy, including a feature article by NN member Julie Flygare. Flygare also was profiled in the article "Eyes Wide Shut" in the October, 2011 issue of *Marie Claire*. These multiple media outlets have boosted the public's awareness of narcolepsy in a very important way.

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NN Marks National Sleep Awareness Week

Network members spread the word about narcolepsy and idiopathic hypersomnias as part of National Sleep Awareness Week 2011. As an annual campaign to highlight sleep health and safety, the National Sleep Foundation aptly timed NSAW to coincide with the loss of a nighttime hour due to Daylight Savings Time. This year, NN focused on raising narcolepsy awareness by mailing out two orange bracelets to each member. Each bracelet's message reinforced healthy sleep habits with the motto "Sleep well. Live better." All members were encouraged to wear one bracelet and give the second to a friend to wear.



Wake Up Nashville and Wake Up Narcolepsy Fundraisers

The organization Wake Up Narcolepsy (WUN) held several successful events this year to raise funds support research and education in the area of narcolepsy. First among them was Wake Up Nashville, in which up-and-coming musicians took part in a songwriting contest and concert to benefit narcolepsy awareness and research. Several Network members made the trip to the Country Music Hall of Fame for the event, where they mingled with "Music City's" elite as well as producers from the Savannah Music Group, who judged the competition. Notable among the finalists was Sean Higgins, son of Network Board President Patricia Higgins, and his songwriting collaborator Danielle Eva, who has narcolepsy.



WUN fundraising events also included their annual golf outing in September and their Boston Marathon Run, completed by this year's team John Leahy, Monica Gow, and Kim Grady.

Swinging for Sleep

Professional Golfer Nicole Jeray made supporting NN's mission a part of her LPGA tour this year, with sponsors donating to the Network every time she hit a birdie. Thank you for making us a part of your game, Nicole!



Support Groups Grow in 2011

New narcolepsy support groups sprang up this year in Arizona, Hawaii, and at the University of Wisconsin. In addition, existing groups developed their membership and support structure. Notably, the Midwest Narcolepsy Support Group in Illinois launched a new website and Facebook page. Since then, they have already received and answered queries not only from their backyard, but also from countries across the globe such as Japan and Israel. The Greater Boston Area Support Group sent motivational emails in between support group meetings to foster relationships and positive thinking, and they doubled their attendance at their annual summer picnic. In addition, PWNs in Pasadena organized a fundraising lunch; among many other positive steps taken by narcolepsy support groups in 2011.



Greater Boston Area Narcolepsy Support Group Picnic

Narcolepsy Network Celebrates 25 Year Anniversary with a “Sky-High” Conference in Las Vegas



This year, at Narcolepsy Network’s Silver Anniversary, nearly 300 members, presenters, and supportive family members journeyed to fabulous Las Vegas, NV for a record-breaking national conference.

Spanning a full three days for the first time, the 2011 Conference took place at the Stratosphere Hotel, with sessions held over 1,000 feet above the Strip at the top of the Stratosphere’s Tower. As bungee jumpers whizzed past the windows and the city’s landmarks glittered below, NN members traded information and attended presentations, panels, and support group sessions geared towards “everything narcolepsy.”

The conference featured a special focus on support groups, with sessions tailored to address key needs of the narcolepsy



Teen support group

community. The support groups provided a vital opportunity for people with narcolepsy (PWNs) to talk to one another with honesty and compassion, trade ideas and experiences, and build relationships. In addition, the

emphasis on support groups reinforced member initiatives to build more groups, an effort that’s yielding steady progress in connecting more PWNs around the country.

Dr. Eve R. Rogers began the conference with a keynote address on “Narcolepsy, The Basics” that concisely summarized the current understanding of the illness.



Dr. Eve Rogers giving the Keynote presentation



Attendees then ascended the tower for a wide range of sessions, covering everything from business topics like out-of-the-box entrepreneurship with Mark Shilensky, or narcolepsy and effective

communications with Kimberly Ratliff; to medical topics such as narcolepsy and pregnancy with Dr. Michael Thorpy; to family topics including Morgan Hart’s family dynamics workshop and a parenting discussion facilitated by Sara Kowalczyk; to creative workshops led by Dr. Rubin Naiman on dreaming, Jamie Bennett on writing, and Audrey Kindred on performance and well-being.

Attendees also had the opportunity to explore all that Las Vegas has to offer. One highlight was the Saturday night outing to Treasure Island to see NN member Trinity Hamilton perform in the Cirque du



Eveline Honig and Trinity Hamilton

Soleil spectacular, *Mystere*. Structured leisure activities were also available in the conference’s hotel and included a support group session for leaders by Sarah DiDavide, a Saturday night social activity, and a silent auction that ran throughout.

Designed as PWN-friendly, the conference format emphasized ample napping opportunities, interactive sessions and panels, and diverse programming that addressed the most important concerns of PWNs. At the annual membership meeting, NN’s leaders presented several major awards (see sidebar), put several resolutions forward for a vote, and revealed Cleveland, Ohio, as next year’s conference location.



Conference presentation

Conference “High Points”

Congratulations NN Award Winners

Lifetime Achievement Awards

NN Founder Niss Ryan
NN Founder Sue Carella

Ruth Justice Nebus
Volunteer of the Year Award
Marcia Coy

Public Awareness Award
Julie Flygare, JD

Public Education Award
Ayelet Gneezy, PhD

Researcher of the Year Award
David Rye, MD

Dr. Robert Clark
Clinician of the Year Award
Neil Feldman, MD

My enduring memory of the Vegas conference will be of a narcoleptic teen's father. I first met him several years ago, when narcolepsy was new to him and it didn't seem like he would be able to get it after thinking that his child was willfully disorganized or out-and-out lazy. Flash forward a few years, and there he was, adamantly encouraging other parents that you do what you need to do.

This gave me such an appreciation for the transformation education and love can create. Narcolepsy Network conferences rock!

Sharon Link

“[My high point was] meeting so many other PWN from around the country, feeling like I was for once fully accepted and not judged. I could be myself! The connections to other PWN has been wonderful, especially with those who have gone through pregnancy!”

Amy Ryan

My fondest memory of the Las Vegas National Conference was meeting and speaking to the mother of someone who's been newly diagnosed. I saw my own mother in her. This woman was concerned about her child, she was devastated over a diagnosis without a cure, and generally upset and frustrated, yet she pushed on and did her best to learn everything, in an effort to try and do what all moms want to do: Make it all better. And it was clear she was quickly coming to the conclusion that she couldn't. I made a point of telling her that it was important to not blame herself; she wasn't a failure as a parent. It was a relatively brief encounter, and I did not see her again, but I know that moment will stick with both of us forever.

Marcia D. Coy

“[My high point was] meeting people I've known via the Internet for a year or more in person for the first time. I am so grateful for the GBLT [Gay, Lesbian, Bisexual, and Transgender] Support group and that the YAWNs [Young Adults With Narcolepsy] had a place to gather. I know and love a number of the YAWNs. Those five young people, who are normally so reticent and shy, were luminous with joy together. Together, they laughed and talked with each other, partied, giggled. It was like seeing them step into the sunlight and burst into bloom.”

Saraiah



Research Update **Dr. Michael Thorpy**



Dr. Michael Thorpy is a professor of clinical neurology at Albert Einstein College of Medicine and director of the Sleep-Wake Disorders Center in the Department of Neurology at Montefiore Medical Center, both in New York. In addition to treating patients with sleep disorders, he conducts research in narcolepsy, insomnia, and sleep apnea. Dr. Thorpy also has a significant role as an educator, making media appearances as well as giving lectures to patients and clinicians. NN spoke with Dr. Thorpy about some exciting trends in understanding and treating narcolepsy.

What are you working on at the moment involving narcolepsy?

I currently have two books for physicians in development. One is on the neuroimaging of sleep and sleep disorders. That's the first book of its kind, on new techniques that will inform us about the pathophysiology of sleep disorders. The other book is about genetics and sleep disorders. We're starting to accumulate a lot of genetic information about the cause of sleep disorders and how genes control normal sleep-wake patterns.

What kind of promise does neuroimaging hold for how we understand narcolepsy?

Sleep disorders involve the brain, which is hard to investigate because you can't look into it easily. However, neuroimaging techniques can show us the areas of the brain that are affected by the disease process and how the brain responds to medications.

Has this neuroimaging data led to any concrete developments, such as new therapies?

We're only in the process of accumulating the information — this book is part of that effort — but in the future neuroimaging will play a major role. As for developing new therapies, not yet; neuroimaging will show us how new medications will work on the brain. That's the direction where the research will go.

What about genetics and our understanding of narcolepsy?

We now recognize that many of our sleep-wake mechanisms are controlled by genetic processes. Recent findings show individual differences in the way that people respond to sleep deprivation. Basically, some people with the same amount of sleep deprivation will be extremely sleepy during the day, while others will be more alert. There are genetic differences that account for those effects, so people with a particular genetic factor seem to be better able to handle sleep deprivation. In

the future, recognizing these genes and being able to test for them will play a role in caring for patients.

This differentiation includes the population of people who have narcolepsy?

Yes. We know there are people with narcolepsy who have the same chemical abnormality — they have a loss of hypocretin — but some people have much more severe symptoms than others. In addition to understanding why some people get narcolepsy, genetic differences may also explain how people respond to narcolepsy. In the future we may be able to tell by genetic factors whether narcolepsy is likely to be progressive or whether patients may remain stable or even improve. So, genetics offers great potential for understanding narcolepsy.

You've also been doing some work on pregnancy and narcolepsy?

We did a survey of sleep specialists, and now we're going to do a survey of patients on the use of medication during pregnancy. In general, we found that most physicians tend to advise women not to take narcolepsy medications during pregnancy, unless they're at great risk from narcolepsy symptoms. In that case, the lowest effective dose is usually recommended. Reviewing the literature suggests that the potential for adverse effects from narcolepsy medications on the mother or fetus is quite low, but despite that it makes sense to try to avoid them, if possible, during pregnancy.

As an educator have you seen awareness of narcolepsy improving?

Oh yes, dramatically. When I started sleep medicine not many people knew about narcolepsy. Now it's pretty well recognized within the lay population, and physicians are also more aware of it, from primary care to specialists. Is the work completed? No. There are still a lot of physicians that need education, but compared to where things stood 10 or 15 years ago there's been a dramatic change in understanding about narcolepsy.

Research Update Dr. Scammell



Narcolepsy Network recently spoke with Dr. Thomas Scammell, an Associate Professor in Neurology at Harvard Medical School, who described three sets of experiments he's been conducting and their implications for how we understand narcolepsy symptoms.

Mapping cataplexy in the brain

We are doing several experiments to understand how emotions trigger cataplexy. In most PWNs who have cataplexy, positive emotions, such as telling a joke or laughing, are a pretty reliable trigger. But what's going on in the brain? How could positive emotions trigger muscle paralysis? People who don't have narcolepsy experience a mild version — think laughing until you're 'weak in the knees.' In narcolepsy, the response is much stronger — when you laugh, you may fall on the ground and be unable to rise for a minute or two. As a model of narcolepsy, we are working with orexin/hypocretin-knockout mice, mice genetically engineered to lack orexin/hypocretin. A typical orexin-knockout mouse will have 8-10 brief episodes of cataplexy per waking period. We can increase this number by giving them chocolate, which they love. We give them a Hershey's kiss, and instead of 10 episodes of cataplexy, they'll usually have 60. This lets us study the neural pathways that control cataplexy in detail. Yo Oishi, a postdoctoral fellow in our group, examined the brains of mice having high levels of cataplexy, and found that neurons were activated in the medial prefrontal cortex and the amygdala. Both these brain regions have been implicated in positive emotions. In a related experiment, Christian Burgess, a graduate student, found that making very small injuries to the amygdala of these mice reduced episodes of cataplexy from 60 to about 30. We're excited because these findings are the first evidence that a specific brain region — the amygdala — seems necessary for triggering cataplexy.

Narcolepsy-like sleepiness in other neurological disorders

We think of injury to the orexin/hypocretin system as specific to narcolepsy, but other disorders can injure the orexin-producing neurons. In narcolepsy, there's about a 90% loss of these cells, and chronic sleepiness results. Other neurologic disorders such as Parkinson's disease, traumatic brain injury and possibly Huntington's disease may involve a milder injury

to these neurons resulting in persistent sleepiness that's less severe than in narcolepsy. We published a small pilot study of loss of the orexin neurons in traumatic brain injury. We're now finishing a larger study confirming what we found: a 25-30% reduction in orexin-producing neurons in people who died from severe traumatic brain injury. This finding is important because clinicians have often encountered patients with head injuries who have persistent sleepiness. Our finding suggests that the sleepiness seen in people with head injury may be similar to that seen in narcolepsy. So, the medications used to improve alertness in narcolepsy may also help people with traumatic brain injury.

Using gene therapy to restore orexin/hypocretin production in narcoleptic mice

This next project has great therapeutic potential, but it's still highly experimental. We're using a mouse model of narcolepsy in which the orexin-producing cells die during the first months of life. We wondered if we could make these mice better by getting other neurons to produce orexin. We use a gene therapy approach in which we put the genes for producing orexin inside a viral shell, then inject this into the brains of the mice. This method induces orexin production in cells that would not normally make it. We are finding that this substantially improves sleepiness in our narcoleptic mice and their activity levels return to normal. This provides evidence that, at least in mice, simply restoring orexin production in the brain can improve narcolepsy, even if the orexin is not being produced by the 'correct' neurons. Could this be brought into clinical use in people? Unfortunately, these viral vectors still have some safety issues, and they are not yet safe enough to use in people with narcolepsy. We're hoping these issues can be resolved over the next few years because many researchers agree that restoring orexin/hypocretin signaling in the brain for PWNs would be a great therapy — like giving insulin to diabetics.

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Thank YOU 2011 Donors

Narcolepsy Network wishes to thank 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 2011 to help further the mission of the Narcolepsy Network by helping individuals and families, and advocating for and/or spreading awareness about narcolepsy in their communities.

DREAM MAKERS (\$1000 and up)

Anonymous
Casey Family Fund of The Oregon
Community Foundation
Cephalon, Inc.
CFC Donations
James Chace Jr.
Joanne Clevenger
Arla DeVeau
Direct Supply, Inc.
W. Don Gillen, Jr.
Jazz Pharmaceuticals, Inc.
Dianne & Sam Kernell
Sze Ping Kuo
Mary & Dale Parker
Seidman Family Foundation c/o
Balancing Act
Bruce Stouder
Peggy & Chip Wernig

DREAM CATCHERS (\$500 to \$999)

Susan Dambrasukas
Roseann Deal
Blanton Hamilton III
Jen Kilpatrick
Richard Ober, Jr.
Penelope Przekop
Gerald Purer
Oliver Sacks, MD
Nancy Stein, The Goldie Anna
Charitable Trust
Clare Villari

DREAM KEEPERS (\$100 to \$499)

Anonymous (2)
Susan Agnello
Brian Anderson
Michael R Armstrong
Marilyn Atkins
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January 18, 2011
February 15, 2011
March 15, 2011
April 19, 2011
May 17, 2011
June 21, 2011
July 19, 2011
August 16, 2011
September 20, 2011
November 16, 2011
December 21, 2011

The Board of Trustees met in person on June 11, 2011 in Minneapolis, MN and on October 17, 2011 in Las Vegas, NV.

Narcolepsy Network, Inc. Financial Report



Shawn Auman,
NN Treasurer,
Board of Trustees

Narcolepsy Network's healthy financial position sets the stage for us to increase our efforts and better achieve our mission in 2012. These positive results are attributable to the many generous friends of Narcolepsy Network, as well as the hard work of staff. In a positive sign going forward, individual donations increased in 2011 compared to 2010. Corporate grant support also increased significantly on a year over year basis. We are grateful to both individuals and firms for their strong, ongoing support.

Our positive 2011 results have allowed us to grow our presence and boost our programming. Going into 2012, the board and the staff continue to seek out additional funding to build on this growth, while also diversifying income sources to shore up our base. We look forward to an exciting and fruitful year of serving the narcolepsy community.

I appreciate your help in making 2011 such a successful year for Narcolepsy Network.

Warm Regards,
Shawn Auman

Treasurer, 2011
Narcolepsy Network Board of Trustees

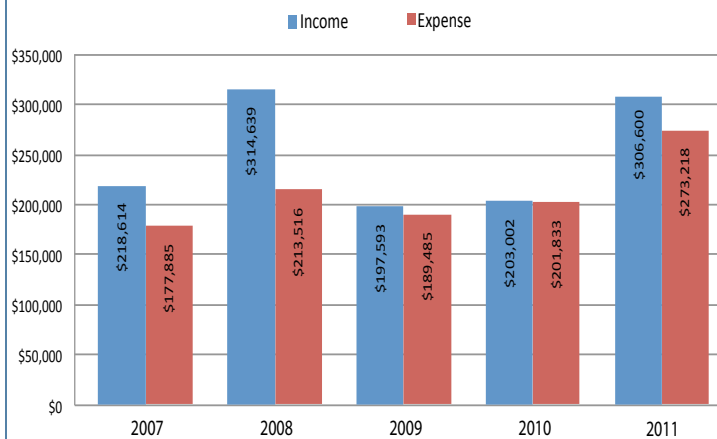
Statement of Financial Position - Years ended December 31

Assets	2011	2010
Cash and cash equivalents	\$300,334	263,270
Accounts Receivable	\$150	—
Prepaid expenses	—	3,216
Other liquid assets	8,468	20,680
Property and equipment, net	2,500	2,500
Total Assets	\$311,453	289,666
Liabilities:		
Accounts payable and accrued expenses	\$6,615	15,312
Payroll withholdings and accrued taxes	1,425	1,020
Total Liabilities	\$8,040	16,332
Net Assets		
Unrestricted	\$303,413	273,334
Temporarily restricted	—	—
Total net assets	303,413	273,334
Total liabilities and net assets	\$311,453	289,666

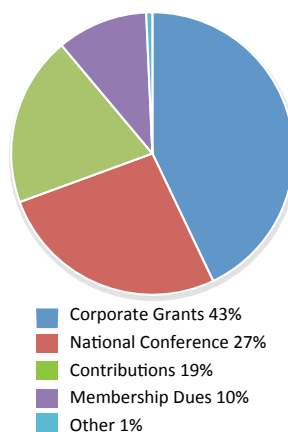
Statement of Activities - Years ended December 31

Income	2011	2010
Corporate Grants	\$131,600	57,750
National Conference	81,240	58,475
Contributions	59,701	51,258
Membership Dues	31,910	31,835
Other	2,149	3,684
Total Income	\$306,600	203,002
Expenses		
Programs		
National Conference	\$97,563	63,421
Public Information	64,549	49,044
Membership	62,221	39,555
Total program expense	224,333	152,020
General and administrative	50,452	39,045
Fundraising	1,736	10,768
Total Expenses	\$276,521	201,833
Net increase (decrease) in net assets	\$30,079	1,169

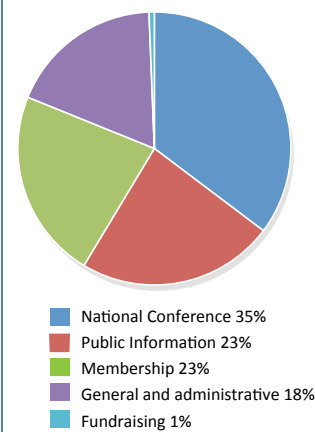
Five Year Revenue and Expense Comparison



2011 Revenue Categories



2011 Expense Categories





**25
YEARS**



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