

COMMUNICATION
ADVOCACY
RESEARCH
EDUCATION



Narcolepsy Network, Inc. 2009 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 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 the women were members of the American Narcolepsy Association, which no longer exists today. By May 1985, they had decided the issues facing the Association could not be resolved, and so set out to form a new group. They elected Mary Babcock their provisional President, decided on the name “Network,” and began writing brochures and outlining the new organization, choosing the 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, 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 the organization's founders. They incorporated the association that April, and held the first Narcolepsy Network convention that May in Shrewesport, NJ, with approximately seventy-five attendees.

Since then, the Network has held conventions every year in various U.S. cities. By 1988, the third annual conference of

the Narcolepsy Network drew 200 people to New York City to see the first William C. Dement award given to Dr. John Holloman.

The Network's activities reached a new level in 1992, as Network members crisscrossed the country in the “Wake Up Narcolepsy” caravan. Part of a concerted drive to raise both public and Congressional awareness about sleep disorders, this effort bore fruit in 1993 as President Clinton signed The National Sleep Disorders Research Advisory Board into law.

By 1996, after ten years as an all-volunteer organization, the Network hired its first part-time paid employee. Since then, we have had four paid Executive Directors: Howard Wolfe (1998 – 1999), Robert Cloud (1999 – 2003), Stan Bard (2003), and Eveline Honig (2004 – present); and seven Presidents: Ruth Justice Nebus (1986 – 1990), Sue Brockway Carella (1990 – 1993), Niss Ryan (1993 – 1995), Robert Cloud (1995 – 2001), Barbara Heitzenroeder (2001 – 2003), Sharon Smith (2003 – 2008), and Patricia Higgins (2008 – present).

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 vital information encompassing symptoms, diagnosis, treatments, research, resources, and more. Our membership has grown from seventy-nine to over 1,100 paid members today. 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 years and beyond.



President's Message



Patricia Duffin Higgins,
2009 President,
NN Board of Trustees

2009 has been an inspiring year for Narcolepsy Network. Despite an extremely challenging economy, our mission to **INCREASE AWARENESS, IMPROVE TREATMENTS, and PROVIDE SUPPORT** for people with narcolepsy (PWN) continued to resonate with donors, members, and volunteers. Thank you all so much for keeping us moving forward with our initiatives to support the Narcolepsy Network Community!

NN held several notable events in 2009, including both our annual conference and the first ever Narcolepsy Network "Spring Dreams" fundraiser in New York City. Both were resounding successes, and are featured with other 2009 highlights later in this *Annual Report*.

This year, we published four editions of our newsletter, *The Network*, distributing them to members in winter, spring, summer, and late fall. These publications offered the latest news, research, and coverage of issues important to PWN, family members, friends, and professionals who treat PWN.

2009 also saw a major advance in narcolepsy research, with the groundbreaking finding that *a new gene for narcolepsy (T cell alpha receptor gene) implicates the immune system* as the cause for narcolepsy. This *Annual Report* also features a discussion of this important study.

As you read the stories and information in this *Annual Report*, please take a moment and remember why you support NN. With your help, we're looking forward to an exciting 2010, and to achieving our goals of earlier diagnoses, improved treatments, and greater support for the narcolepsy community. Once more, thank you for a great 2009!

Patricia Duffin Higgins
2009 President, NN Board of Trustees

Reason to Give: Kailey Profeta

Kailey Profeta learned to live with narcolepsy starting at a young age. After receiving a diagnosis at nine, finding the right doctor and treatment took years; only after connecting with Narcolepsy Network did Kailey's mom, Michele, start seeing positive changes in her daughter. Even then, adjusting to narcolepsy was a struggle and remains a constant balancing act. Yet Kailey has succeeded in managing her narcolepsy, working within its limitations while not letting them define her. Narcolepsy Network caught up with Kailey, now a high school senior at the top of her class, to hear about her plans for the future and thoughts on her experience so far.



[ed: Kailey doesn't mention that she won a competition to attend], where I met designers and other people in the industry. They told us about where they came from, how they got here, gave us tips. It was a really cool experience.

How have you used the Narcolepsy Network?

They're the ones who helped us find the doctor I have now, which is a big part of why I'm doing so well. Also the conferences – I've gone since I was eleven. I've just learned so much valuable information and met so many wonderful people. When you're there, it's like you're normal, because everyone has it too. In my day-to-day life I'm the only person who has this – most people don't know what narcolepsy is – but when we're there we're not the one-in-a-million.

So you have friends you've met there?

Yes. Unfortunately none of them live nearby, but I still talk to them. We text and I talk to them on Facebook. I see them at the conferences, although this year I wasn't able to go because I had to take the SATs to make the Early Action deadline for University of Georgia and Emory-Oxford.

What would you say to someone your age who's just being diagnosed with narcolepsy?

I'd tell them that their life definitely isn't over, even though it might feel like it. I did have to stop doing things that I loved. But just because you have to stop doing one or two things you love doesn't mean you have to stop doing everything. I'm not going to stop loving fashion or wanting to be a fashion designer just because it's going to be hard. If anything, I'd say I've become more determined because of narcolepsy, just because I've had to work harder for everything.

You're currently applying to colleges. What schools do you want to go to?

I want to major in fashion design, but a lot of universities don't have that. A lot of art schools have it, but I would like to go somewhere where I'm not only surrounded by art people. Not that I don't love them, but I like being surrounded by all types of people. The school I'd most love to go to is the Rhode Island School of Design. I'm going to apply, but I'll probably start out somewhere here, probably University of Georgia. Then after a year or two I'll probably transfer somewhere else. I also applied to the Emory of Oxford campus. It's a two-year college, a different campus than the Atlanta campus, and after those two years you go to Emory. It would be a really great place for me to start out.

What do you do to follow your interest in fashion?

Well, I work at a bridal shop. I learn a lot about the industry and selling, retailers and pricing, that sort of thing. I take art. That helps a lot, because I wouldn't say I was the best at sketching before I started taking it. I just went to New York for this *Teen Vogue* event called *Teen Vogue* Fashion University

Dr. Mignot: Two Narcolepsy Research Findings in 2009

This year, *Nature Genetics* published a major finding related to narcolepsy/cataplexy (“Narcolepsy is strongly associated with the T-cell receptor alpha locus,” June 2009), confirming the disease as an autoimmune disorder. Narcolepsy Network spoke to Dr. Emmanuel Mignot, a lead author of the study and Director of the Center for Narcolepsy at Stanford University, to discuss this result, as well as other 2009 narcolepsy research.



A big finding this year linked narcolepsy to the immune system through the T-cell receptor alpha locus. What are the research implications of this study?

Having this genetic marker in the T-cell receptor (TCR) indicates a special TCR is involved with narcolepsy. Unfortunately, the marker doesn't tell us which one. So it's like a signpost showing us where to study further: the TCR in people with narcolepsy.

The TCR gene is very particular. There aren't enough genes in the body to create the diversity we need for immune responses to all possible bacteria and viruses, so the TCR gene is an example of how DNA has adapted to this particular need. The TCR gene doesn't produce just one TCR protein...it reshuffles itself to produce more like one *billion* TCR protein subtypes. Because of the genetic association, we now think that there is a specific TCR variant involved in causing narcolepsy. So now we're isolating millions of T-cells (immune white blood cells carrying T cell receptors) from patients with narcolepsy and controls, and sequencing the TCR of each of these cells. If we find T-cells carrying the genetic variant we found associated with narcolepsy, it will almost surely be the receptor involved in the immune response that causes narcolepsy. Discovering that receptor would be a huge prize for diagnosis and prevention, because we could then develop reagents to detect it in the blood, and treatments to block this TCR.

Besides the *Nature Genetics* paper, were there any other important advances in the field?

Thanks to increased awareness, we have the opportunity to

diagnose and see patients closer to when they first develop the disease. Based on this knowledge, it seems that most often, narcolepsy starts quite abruptly. In this context, I believe narcolepsy can be called a “hit and run” autoimmune disease. Probably, the immune system goes into the brain, kills hypocretin-producing cells, then leaves without a trace quickly. So early diagnoses are very important, because they enable us to search for remaining traces – for example, in the cells we're

now sequencing for the TCR gene. In addition, we're looking at traces of environmental factors that could be involved in triggering narcolepsy, for example winter infections. In 2009, we discovered that most cases with onset within one year had high levels of antibodies signaling a recent strep infection. So I believe now, pretty strongly, that strep is often involved in triggering an immune response that precipitates narcolepsy.

What I'm not sure of now, is whether the strep infection is the specific factor leading to narcolepsy or just a nonspecific co-occurring factor that reactivates a preexisting T cell that pushes patients to the edge so that they develop narcolepsy. Indeed, strep infections are known to boost the immune system non-specifically through proteins called “superantigen.” Recently, narcolepsy cases after H1N1 flu vaccination have been described in Europe (not the US). As the European vaccine contains a strong immune system booster (called an adjuvant), strep could instead precipitate narcolepsy as a secondary factor, with another more specific factor involved (for example another virus, as winter infections often involve various viruses and bacteria together).

In a simple model, the immunological synapse is like a molecular sandwich, with the HLA on one side, the TCR on the other, and in the middle the environmental factor like a piece of strep bacteria or a winter infection virus. Once everything's aligned, the narcolepsy-specific TCR would be activated, beginning that abnormal immune response destroying hypocretin cells. So we want to define the environmental factor to understand what's in the “sandwich.”

2009 Highlights

Narcolepsy Network held our *annual conference* in Jacksonville, FL, on October 23 – 25. Narcolepsy researchers from around the world attended, and presentations featured keynote speaker David Rye, MD, PhD, a neurologist at Emory University and director of Emory Healthcare's Program in Sleep; as well as keynote speaker Juliette Faraco, PhD, Senior Research Scientist at Stanford University's Center for Narcolepsy. Donations from Cephalon enabled a number of scholarship recipients to attend; most were meeting other people with narcolepsy for the first time—a powerful, renewing, and supportive experience.



David Rye, MD, PhD

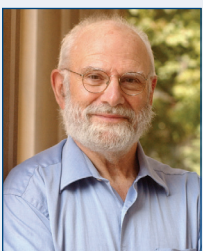


Juliette Faraco, PhD

IMPROVED TREATMENTS

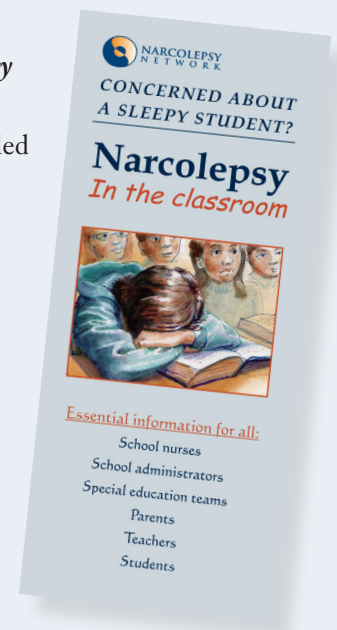
To further our goal of aiding early diagnosis, this year NN published a new brochure, “*Narcolepsy in the Classroom*,” to raise awareness among teachers, nurses, and other school professionals. Recognizing that these educators may be the first to notice the symptoms of narcolepsy, NN mailed this new brochure to 10,000 school nurses across the country.

We held our first *Spring Dreams fundraiser* in New York City on March 7. **Dr. Oliver Sacks** made a special appearance, and enjoyed meeting a number of NN members. Members and non-members alike in the NYC area embraced this event, allowing us to raise both donation dollars and awareness. “Spring Dreams” appeared in local news sources, as well as our newsletter and website. We are very grateful to Rosalee Kalwara for funding this event.



Dr. Oliver Sacks

Dr. Oliver Sacks is currently writing a book about hallucinations, including those experienced in near-sleep and narcoleptic states. He welcomes brief accounts from NN members about their experiences with these hallucinations. You can write to Dr. Sacks at mail@oliversacks.com.



EARLY DIAGNOSIS



With earlier narcolepsy diagnoses affecting children at younger ages than ever before, the face of Narcolepsy Network is changing. In response to this trend, we launched our *Pediatric Advisory Board* with the goal of providing parents the tools they need to enable their child to succeed. This Board marks a celebrated milestone for the Narcolepsy Network community!

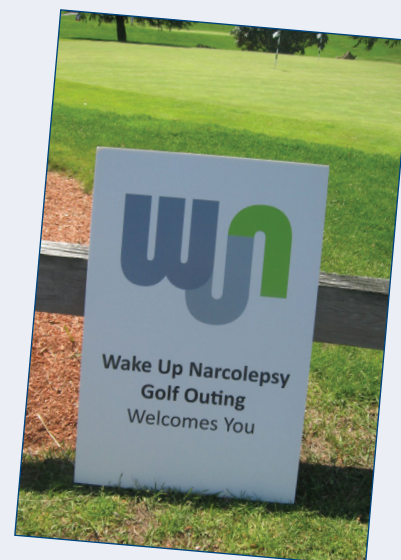
Two NN trustees were among a crowd of hundreds attending the *Cinema Audio Society's Awards Night celebrating Dennis Maitland*, a PWN receiving a Career Achievement Award to honor his distinguished contribution to film. Many attendees questioned us about narcolepsy, and we enjoyed the chance to spread awareness within the vibrant CAS community.

In June, NN ran a busy booth for the *SLEEP 2009 meeting* in Seattle. We handed out pamphlets, answered questions, and enlisted the support of many professionals who treat patients with narcolepsy.



PROVIDE SUPPORT

Wake Up Narcolepsy held their first ever *Golf Outing* in May and, with funds raised at this event, offered a sizeable donation to support Narcolepsy Network and the NN community. Through such fundraising events, this Massachusetts nonprofit is committed to educating others about and finding a cure for narcolepsy. Thank you Wake Up Narcolepsy!



Thank YOU 2009 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 2009 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.

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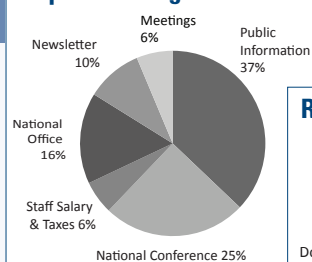
January 21, 2009	May 21, 2009	September 22, 2009
February 17, 2009	June 16, 2009	November 17, 2009
March 17, 2009	July 21, 2009	December 15, 2009
April 21, 2009	August 18, 2009	

Financial Report Narcolepsy Network Inc.

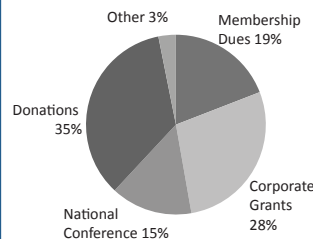
Statement of Financial Position • Years Ended December 31

	2009	2008
Assets:		
Cash and cash equivalents	\$ 267,504	\$ 260,870
Prepaid expense	\$ 4,116	\$ 1,882
Accounts Receivable	\$ -	\$ 877
Property and equipment, net	\$ 2,500	\$ 2,635
Total Assets	\$ 274,120	\$ 266,264
Liabilities and Net Assets		
Liabilities:		
Accounts payable and accrued expenses	\$ 659	\$ 1,703
Payroll withholdings and accrued taxes	\$ 1,296	\$ 604
Total Liabilities	\$ 1,955	\$ 2,307
Net Assets:		
Unrestricted	\$ 270,165	\$ 239,941
Temporarily restricted	\$ 2,000	\$ 24,016
Total Net Assets	\$ 272,165	\$ 263,957
Total Liabilities and Net Assets	\$ 274,120	\$ 266,264

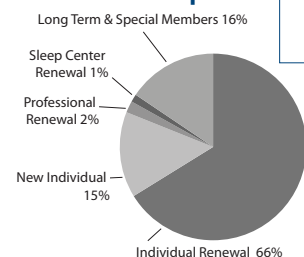
Expense Categories



Revenue Categories



2009 Membership



Statement of Activities • Years Ended December 31

	2009	2009	2009	2008	2008	2008
	Unrestricted	Temporarily Restricted	Total	Unrestricted	Temporarily Restricted	Total
Revenues, gains, and other support:						
Conference grants	\$ 53,169	\$ -	\$ 53,169	\$ 55,000	\$ -	\$ 55,000
Conference and related fees	\$ 28,760	\$ -	\$ 28,760	\$ 34,410	\$ -	\$ 34,410
Total Conference Income	\$ 81,929	\$ -	\$ 81,929	\$ 89,410	\$ -	\$ 89,410
Contributions/Grants	\$ 68,317	\$ 2,000	\$ 70,317	\$ 137,292	\$ 24,016	\$ 161,308
Membership dues	\$ 37,385	\$ -	\$ 37,385	\$ 54,777	\$ -	\$ 54,777
In-kind contributions	\$ -	\$ -	\$ -	\$ 1,595	\$ -	\$ 1,595
Investment earnings	\$ 5,981	\$ -	\$ 5,981	\$ 6,842	\$ -	\$ 6,842
Educational materials	\$ 2,037	\$ -	\$ 2,037	\$ 3,208	\$ -	\$ 3,208
Net Realized & Unrealized						
Gain (Loss) on Investments	\$ (512)	\$ -	\$ (512)	\$ (2,501)	\$ -	\$ (2,501)
Other revenue	\$ 456	\$ -	\$ 456	\$ -	\$ -	\$ -
	\$ 195,593	\$ 2,000	\$ 197,593	\$ 290,623	\$ 24,016	\$ 314,639
Expenses:						
Salaries	\$ 58,432	\$ -	\$ 58,432	\$ 57,397	\$ -	\$ 57,397
Direct Contract/Grant Expense	\$ 6,250	\$ -	\$ 6,250	\$ -	\$ -	\$ -
Payroll Taxes	\$ 4,930	\$ -	\$ 4,930	\$ 5,152	\$ -	\$ 5,152
Conference	\$ 33,616	\$ -	\$ 33,616	\$ 39,059	\$ -	\$ 39,059
Printing and reproduction	\$ 23,922	\$ -	\$ 23,922	\$ 33,451	\$ -	\$ 33,451
Travel, meals & lodging	\$ 14,056	\$ -	\$ 14,056	\$ 19,590	\$ -	\$ 19,590
Telephone	\$ 5,068	\$ -	\$ 5,068	\$ 6,011	\$ -	\$ 6,011
Postage and shipping	\$ 11,128	\$ -	\$ 11,128	\$ 14,710	\$ -	\$ 14,710
Office supplies	\$ 5,175	\$ -	\$ 5,175	\$ 7,409	\$ -	\$ 7,409
Professional fees	\$ 11,791	\$ -	\$ 11,791	\$ 5,800	\$ -	\$ 5,800
Insurance	\$ 1,706	\$ -	\$ 1,706	\$ 4,589	\$ -	\$ 4,589
In-kind expense	\$ -	\$ -	\$ -	\$ 1,483	\$ -	\$ 1,483
Office rent	\$ 3,440	\$ -	\$ 3,440	\$ 3,762	\$ -	\$ 3,762
Depreciation	\$ 135	\$ -	\$ 135	\$ 708	\$ -	\$ 708
Internet and technology	\$ 1,515	\$ -	\$ 1,515	\$ 5,300	\$ -	\$ 5,300
Dues and registrations	\$ 4,778	\$ -	\$ 4,778	\$ 4,730	\$ -	\$ 4,730
Other	\$ 3,543	\$ -	\$ 3,543	\$ 4,365	\$ -	\$ 4,365
	\$ 189,485	\$ -	\$ 189,485	\$ 213,516	\$ -	\$ 213,516
Change in net assets	\$ 6,108	\$ 2,000	\$ 8,108	\$ 77,107	\$ 24,016	\$ 101,123
Net assets at beginning of year	\$ 239,941	\$ 24,016	\$ 263,957	\$ 162,018	\$ 816	\$ 162,834
Reclassification of						
Temporarily Restricted Assets	\$ 24,016	\$ (24,016)	\$ -	\$ 816	\$ (816)	\$ -
Adjustment	\$ 100	\$ -	\$ 100	\$ -	\$ -	\$ -
Net assets at end of year	\$ 270,165	\$ 2,000	\$ 272,165	\$ 239,941	\$ 24,016	\$ 263,957



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