

CARE

Narcolepsy Network, Inc. 2010 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 (ANA), which no longer exists today. At the Akron meeting, they formed a Task Force team to write bylaws for ANA Chapters and they met at Niss Ryan's home in the fall of 1984 and accomplished this work. However, by May 1985 issues facing the ANA could not be resolved and so they set out to form a new chapter organization. They elected Mary Babcock their provisional President, decided on the name "Network," and began writing brochures and outlining the new organization's programs. They chose 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 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 that time, NN has held Annual Meetings every year in various U.S. cities. By 1988, the third annual conference of Narcolepsy Network drew 200 people to New York City to see the first William C. Dement Research Award given in the amount of \$10,000 to Dr. John Holloman for genetic research.

The NN's activities reached a new level in 1992, as NN 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 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, NN 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 Narcolepsy 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 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 NN and its goals for the next twenty years and beyond.

Despite trying economic times, 2010 was a very good year for Narcolepsy Network. With more donations than expected, more loyal supporters, many enthusiastic volunteers, and a dedicated staff, together we made 2010 a success story.

From the Executive Director



Eveline Honig, MD, NN Executive Director

Dear Supporters and Friends:

Despite trying economic times, 2010 was a very good year for Narcolepsy Network. With more donations than expected, more loyal supporters, many enthusiastic volunteers, and a dedicated staff, together we made 2010 a success story.

We held a number of important events this past year. In March we celebrated Sleep Awareness Week with a Carnival night in New York City. While participating in this successful and enjoyable fundraiser, guests also learned about narcolepsy and the mission of Narcolepsy Network. Our annual conference, held this year in Arlington, Virginia, exceeded our high expectations, with more attendees than ever before, as well as a full slate of interesting speakers and events. Many people arrived a day early to raise awareness of narcolepsy through our first Capitol Hill Advocacy Day.

On another important front, this year we continued our outreach to school nurses, giving presentations at various school nurse meetings and events in the country. After one such presentation in Pennsylvania, I received a standing ovation from these nurses thanking me for reaching out to them. The school nurse is often the first one to hear about a child sleeping regularly during school, making him or her key to our goal of early diagnosis.

Research also continues to be very exciting; in 2010 several studies indicated the link between environmental exposures and narcolepsy in certain individuals. In a key development, NN attended several meetings at the National Institutes of Health (NIH), demonstrating our interest in participating in research. As a result, the NIH sent out a Request for Information (RFI), which brought an overwhelming response from the narcolepsy community in the summer of 2010.

Our continuing commitment to raising awareness, support, science, and advocacy continues to define Narcolepsy Network. Together, let's keep pursuing these goals in 2011. No matter how much you give, know that your donations are helping us move forward.

Thank you for all your support!

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

Reason to give: Charlie Severson

Charlie Severson, a member of Narcolepsy Network's 2011 Board, lives in Minneapolis, Minnesota, where he works in the restaurant business. He was diagnosed with narcolepsy in 2004, when he was twenty-one.



I hear you're getting married. Congratulations.

Yes, in October. We got engaged on the Fourth of July, during fireworks. We've known each other since we were about seven years old. We went to the same school and the same church.

How's the wedding planning?

It's going along well. We're starting to realize it's coming up quicker than we thought, but I think every couple goes through that. She already has her dress. We have the priest and the church and the reception venue. So those are some big things crossed off the list. Our reception is going to be a three-hour cruise on the Mississippi River.

You work as a waiter and manager, and you had to advocate for yourself in this job, correct?

Oh yes. They were very unpleasant when I told them I had a sleep disorder. A new manager had come along in 2007, and wanted to do this rotating schedule, meaning I'd work days sometimes, nights other times. I said I couldn't do that and provided him with my doctor's note saying I had a disability. He told me he couldn't have a manager with "special needs." He said, "Maybe your doctor should just put you on disability." He got what he asked for because I called my doctor after that happened, and I went right to her office, where she wrote letters that took me out of work immediately. I ended up being out for twelve weeks. The doctor had to make clear to them exactly what my schedule would be. After that things improved at work. Having a doctor like that, who will help you advocate, is essential.

It sounds like a hard thing to have to bring up on the job.

It was hard. To this day I have trouble saying no. They know I have trouble saying no, so I've asked them not to even ask me to do certain things.

Now you feel good about your job into the foreseeable future?

I do. Back in November, we got our performance reviews, and I got the best review there. They looked past the disability. They want their highest performing employees to stay with the company.

About a year and a half after being diagnosed with narcolepsy, you went to your first conference. What was that like?

I was in tears after the first night. People could finish my sentences for me. It was very validating. It's one thing to be told by a doctor, "you've got this sleep disorder," but half your family doesn't believe it exists and the other half believes it exists but it's not as bad as you say. You go to a conference and everybody there is supportive. It told me, you're not crazy. Now, being involved in creating the conference every year since then, and as a board member, I really want to make sure newcomers feel welcome and that they are getting that validation. I would say that first conference was probably the best experience of my life.

Were there any other things you wanted to do while on the board?

Yes. Tricia assigned the committee chairs well this year. She assigned me to be the head of the advocacy committee. That's perfect for me since I had to advocate so strongly for myself. I have a lot of compassion for people who are going through that. So a major goal I have is helping other people with narcolepsy be successful students and employees in whatever they choose to do.

Reason to give: Joyce A. Scannell

Joyce A. Scannell joined Narcolepsy Network in 1998. She has worked part-time in the Network's office since 2004, and today holds the position of Office Manager.

As the Network's Office Manager, you pick up the phone when someone with narcolepsy first reaches out to NN, right?

Yes. I often talk to people who just found out they have narcolepsy. Maybe their doctor told them, maybe they have a brochure, maybe they find us on the Internet. And they're so excited when they learn I have narcolepsy. I have to let them know I can't give medical advice. I can't give legal advice. But I can talk to someone as a fellow person with narcolepsy and tell my own story. I do that and I love that part of it.

Once I got a call from a police officer who had arrested someone for filing a false report. The man claimed he was robbed. Turned out he had narcolepsy. He bought a lottery ticket and then went to his car, where the store video camera shows him falling asleep. In his dream someone took his winning lottery ticket from his car. He complained and the police came and viewed the video, which doesn't show him getting robbed. The clue was, his "winning" ticket was stolen. How did he know it was a winning ticket? He just bought it. The officer didn't want to cite him for a false report because he seemed so convinced. I said, don't charge him, he really did think it was real, and then congratulated the policeman for taking the time to call us.

Vivid dreams were a big part of your experience with narcolepsy too.

I've got a very logical brain, but I would have long, action-packed movie dreams starring Mel Gibson and myself. Before being diagnosed I didn't realize that you don't have four-hour dreams.



Action movies? Really?

It was always action. It was like I did the opposite in my dream as I did in real life. I wasn't an action-packed girl. Because I'm always tired, it was like a release to have dreams where I'm moving all over the place, saving the day. Now Xyrem more or less keeps the dreaming under control. I have that last morning dream that everybody has, but it's short.

You were diagnosed in your forties, and have written that you're glad to see more early diagnoses. Why would you say these are important?

Before being diagnosed, I thought I was dumb or lazy or just not interested in things. That made me doubt my own brain. So it was a relief to find out I had narcolepsy. And I had a good family. Some people don't have nice families and their life is even worse. They're called lazy, no good. I used to think I was lazy but no one ever called me that. So it's very important to get diagnosed and not spend years, I don't want to say suffering, but wondering if your quality of life is less.

You went to your first NN conference in 1998, and now encourage others to go.

People call the office and ask, is it worth going to a conference? I always tell them, you come and see me on Sunday and tell me if your life has changed. They always come see me, and sometimes with tears in their eyes. Especially the ones who've been diagnosed for a while, because they've been alone. They may be in a smaller town and don't know anyone else with narcolepsy. Even their own sleep doctor may not have other patients with narcolepsy.

One of my sayings is, there is life after narcolepsy, and one of the most important things is to connect with other people, whether through e-mail, the website, join the network, go to a conference. Just know that you're not alone.

2010 Highlights



Shawn Auman (left) Wisconsin Rep (right)

The 2010 NN Conference: A Decade of Hope

More people with narcolepsy, their families and friends, and sleep researchers than ever before took part in our Annual Conference on October 7 – 10, 2010 in Arlington, VA. In the days just prior to the event, NN members visited Capitol Hill offices to advocate for narcolepsy research and awareness (see page 8 of this report).

During the conference itself, researchers both presented their findings in speeches and took part in informal Q&A sessions. Activities ranged from information sessions to socializing to dancing to yoga. And, taking advantage of the Columbus Day weekend, attendees ventured out to see the sights in and around Washington, DC, rounding out our Decade of Hope with this exciting and meaningful gathering. A big thanks to the staff and volunteers who worked so hard to make this wonderful experience possible!



Informal Q&A session.



(from left to right) Drs. Rye, Trotti, Mitler, Mignot, and Twery

National Sleep Awareness Week Carnival

NN gathered for Night at the Carnival, their second annual New York City event, on Thursday, March 11, 2010. Taking place over the entire fifth floor of the Bowlmor, the carnival games and lively conversations proved both entertaining and delightful. Among many others, Patricia Higgins, Joyce Scannell, Eveline Honig, Kathleen Randell, and Mee Ng attended to support, educate, advocate for, and improve narcolepsy awareness.



Network Sponsored Summer Picnics

This year, NN sponsored several Summer Picnics in an effort to reach out to local support groups, as well as offer the chance to start new groups. Chicago, Boston, Long Island, San Diego, and several other locations all saw successful picnics over the summer, giving people with narcolepsy a chance to come together, share their experiences, and have some fun. We're excited to continue these picnics in 2011! If you're interested in having a picnic with your group this summer, contact Eveline Honig at ehonig@narcolepsynetwork.org.

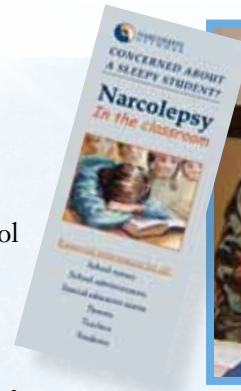


New York State Society of Sleep Medicine Meeting

NN had a booth at the NYSSM meeting in October, where we passed out brochures and spoke with physicians and sleep technicians. Both groups were eager to learn more about narcolepsy, a positive indication that we should continue our outreach to these professionals in the future.

Presenting to Nurse Groups

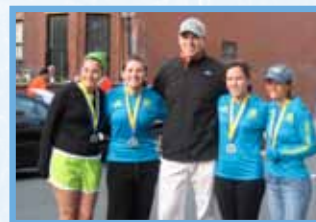
Over the year, members and staff gave a number of presentations to school nurse groups around the country, supporting our recently published brochure *Narcolepsy in the Classroom*. These included major meetings in Lancaster, PA, and White Plains, NY. After warm receptions from the nurses, including a standing ovation, we plan to continue this outreach as a key aspect of our effort to promote early diagnoses.



Eveline Honig, MD, NN Executive Director (left) and Patricia Higgins, RN, NN Board of Trustees President (right) representing Narcolepsy Network at the New York State Association of School Nurses annual meeting on November 6, 2010

Wake Up Narcolepsy Boston Marathon Team

Four runners, including NN's own Julie Flygare, successfully completed the Boston Marathon and raised a combined total of \$30,000 for narcolepsy research and awareness in association with Wake Up Narcolepsy, a separate group devoted to fundraising. Great job, ladies!



WUN co-founder Kevin Cosgrove (middle) with runners (from L to R) Crystal Ellis, Julie Flygare, Monica Gow, and Becky Polenski.

Capitol Hill Advocacy Day

On October 8, 2010, more than 40 attendees arrived in Arlington at the Narcolepsy Network conference a day early to raise awareness about narcolepsy on Capitol Hill in the inaugural Capitol Hill Advocacy Day. They visited over twenty Congressional offices, relating their own stories and advocating for increased narcolepsy research funding through the National Institutes of Health. Here are a few of the participants' reflections from the day.

"I felt like a rock star, all the attention was on me, people were listening. It surprised me. For twelve years I have wanted to give narcolepsy the attention it deserves, and this day made that possible. Advocating on Capitol Hill felt genuine. We were committed to presenting narcolepsy and making it real for all those who could not advocate for themselves."

—Patricia Higgins



"One thing that I took away from advocacy day was how many people had just heard the word 'narcolepsy.' We have all had the experience of learning a new word and suddenly start hearing it more frequently. I feel like all of those people are much more likely to respond to 'narcolepsy' in the future."

—Allena Rusziewicz

"I visited the NC Representative and Senatorial offices along with my son Ben. Both offices were considerate and listened to our plea for funding for narcolepsy. It was clear to me that the offices would pay attention to the loudest voices—for sure we need the whole community of narcolepsy supporters to be writing their Congresspersons about the need for funding."

—Robert Burnside



"My father and I visited NC Representative Brad Miller's office, as well as NC Senator Kay Hagan's office. We met with a senior aide at Senator Hagan's office who was polite and informative, and strongly recommended that the NN come up with a specific 'ask.' At Representative Miller's office we met with a younger aide, who was very friendly and gracious. Her helpful advice was to try to bring PWN or narcolepsy-related issues to their radar going forward, for example, by calling, emailing, sending some narcolepsy related articles to

them, letting them know of narcolepsy related political issues, and so on. She seemed to suggest developing a relationship with Rep. Miller's office via email, mostly.

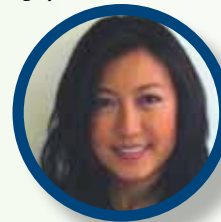
On a personal level, I found the whole process empowering. The first Constitutional amendment, more famously known for guaranteeing freedom of speech and the free exercise of religion, also establishes the right of the people to petition their government for redress. One doesn't often get the opportunity to exercise this particular first amendment right, and it felt good to speak as a person with narcolepsy on behalf of all those affected by this illness. I enjoyed giving narcolepsy a face and a voice, as it were, in whatever small way I could. I hope to do it again in the future!"

—Ben Burnside



"I felt empowered by being able to exercise my right as an American to voice my concerns and interests to the government. But more so, I was inspired by my fellow Americans, and supporters of narcolepsy, who came from afar to do the same."

—Mee Ng



"After the Capitol Hill Advocacy Day, one of my fellow narcolepsy advocates told me that, through our training session, she'd not only learned how to talk about narcolepsy on Capitol Hill, but she'd also learned invaluable tools that would help her communicate more effectively with her friends and family back home. I realized that our advocacy efforts would have an impact in Washington DC and far beyond!"

—Julie Flygare



In Memoriam Dr. Robert Clark

Dr. Robert Clark was a renowned neurologist specializing in sleep medicine and the Medical Director of the Columbus Community Health Regional Sleep Disorders Center. Patients from four continents and all over the U.S. sought his care. A longtime member of the Narcolepsy Network Medical Advisory Board, he served in various professional organizations including committee memberships in the American Academy of Sleep Medicine and a directorship in the American Narcolepsy Association. He gave talks at various locations in the United States, Canada, Europe, and South America. He was named one of America's top physicians in 2006 and again in 2009, and his practice was cited for quality and excellence. Dr. Clark initiated the development and implementation of the first comprehensive sleep medicine outcomes database in the country. He was a man of integrity and determination who was well respected by his staff, who



described him as dedicated and kind. His patients loved him not only for the special way he treated them, but also for the way he viewed them as equals.

Robert could bring a smile to anyone's face. A talented flamenco guitarist, he will be missed by the many friends with whom he shared his love of this music. He was a dear and devoted husband, father, and brother, and he was thrilled to be a grandfather to three wonderful grandchildren. His smiling eyes, dry sense of humor, and strong hugs will be dearly missed by all those who knew him or were influenced by his work.

The family would appreciate that donations in his memory be sent to Narcolepsy Network, 110 Ripple Lane, North Kingstown, RI 02852.

Narcolepsy Research Advocacy at the National Institutes of Health

I urge you to join me in taking action — contact your Congressional representatives and make sure your voices are heard.

On August 27, 2010, Network President Patricia Higgins visited the National Institutes of Health (NIH), taking an important step as NN continues to expand its push for greater research into narcolepsy.

Higgins's visit included comments to the Sleep Disorders Research Advisory Board of the National Heart, Lung, and Blood Institute, which oversees funding for the majority of sleep research projects. There, she spoke about recent promising avenues for narcolepsy research, such as those offered by younger ages of onset and diagnosis, the investigation of the European H1N1 vaccine's possible association with narcolepsy (no such association exists for

the US vaccine version), and recent findings on the immune system's role in causing narcolepsy. Higgins also stressed the need to research hypocretin replacement, as well as the impact of rising medication costs for people with narcolepsy.

The researchers present in the room offered a very positive response, yet Higgins considers this only a first step. "I am confident that the needs of people with narcolepsy were heard," she said. "But our job doesn't end here. I urge you to join me in taking action—contact your Congressional representatives and make sure your voices are heard. Together, we can influence the destiny of our shared condition."

Research Update Dr. Emmanuel Mignot



Narcolepsy Network spoke to Dr. Emmanuel Mignot, Director of the Center for Narcolepsy at Stanford University, to learn more about recent findings in and future prospects for narcolepsy research.

You had a paper come out in Nature Genetics recently, in December 2010. (“Common variants in P2RY11 are associated with narcolepsy,” December 2010)

We found a polymorphism, a DNA change, in a receptor for ATP. You know what ATP is right? It’s cell fuel. Imagine a cell that contains its fuel. If the cell is being attacked and is dying, the fuel is coming out. ATP floating around outside the cell often signals trouble. Lymphocytes and cells of the immune system have very sensitive receptors for ATP, which tells them, “oh, down there in my toe or in my brain, etc., there’s trouble. Cells are being destroyed”. Higher concentrations of ATP in some area attract immune cells. It also changes the balance of the immune cells if you have a lot of ATP. Overall, ATP is very important to signal immune cells that there is inflammation somewhere and they need to go there and attack. The ATP receptor was not known to be involved in other autoimmune diseases, so the finding it is also novel, because this receptor might also be involved in other autoimmune diseases. It’s clearly associated with narcolepsy and again it stresses the importance of understanding how lymphocytes get into certain places, and identifying the right immune cells. This finding is going to be much harder to move on to the next step, because that could be quite complicated. But the finding again points to the immune system in narcolepsy.

So there’s a developing association between narcolepsy and the study of other autoimmune diseases.

We need more immunologists, but they’re coming. That is my big goal for the next few years. First, I’ve attracted Larry Steinman, who is a very famous immunologist who works on multiple sclerosis, to work with me on the autoimmune basis

of narcolepsy. So that’s extremely helpful. I’ll also try to go to the Immune Congress to put narcolepsy on the map, so the immunology field will be set to work on it. I think there is a world of autoimmune disorders of the brain that we have not discovered yet.

What else is happening in your lab?

I think patients with narcolepsy will be very happy to hear that our main funding, an NIH program project grant, was recently reviewed and got a very high score. The best score you can get is a 10 and the worst is 90, and we got a 13. I’m very relieved that it will most likely be funded. Overall, research is going really, really well and I’ve never been so optimistic. I think the next few years are going to be extremely productive and we’ll make a lot of progress.

What do you see as some possibilities for the future?

I think we’re going to make a lot of progress in understanding the autoimmune connection and why hypocretin cells are killed, and then in someday preventing this process. The next challenge will be replacing hypocretin in people who already have narcolepsy, and the pharmaceutical industry is working on it. I think that will happen. Pharmaceutical companies have been developing drugs that block hypocretin to try to create a sleeping pill. It’s a bigger market and it’s easier to do. However, at the same time as they are looking for insomnia drugs that create narcolepsy for the night, they are looking for drugs that will do the opposite, that will replace hypocretin. Technically it’s a little harder to find what’s called an agonist that stimulates the receptor. If they find that, that could be the ideal treatment for narcolepsy.

Research Update Dr. David Rye



Dr. David B. Rye, Professor of Neurology at Emory University School of Medicine and Past Director of Emory Health Care's Program in Sleep, studies a range of sleep disorders as well as the biological systems that underlie sleep and wakefulness. Dr. Rye describes his work as "investigating the primary hypersomnias (i.e., narcolepsy without cataplexy, idiopathic hypersomnia with and without long sleep time); disorders that are sometimes misdiagnosed as narcolepsy. They appear to be caused from something different than the deficiency in hypocretin that underlies 'genuine' narcolepsy with cataplexy." Dr. Rye spoke with Narcolepsy Network about his research into these primary hypersomnias.

What are you finding about primary hypersomnia?

We have made some extraordinary inroads into understanding the origins of these disorders and how to treat them. We're getting closer to understanding the cause, but we still have a long road ahead of us. We have determined that greater than two thirds of patients presenting to us with one of these diagnoses are essentially making their own, endogenous anesthetic, i.e. they're making their own Valium®, so to speak. This explains their nearly persistent sleepiness. We are able to measure for the presence of this substance employing what is called a bioassay — i.e., measuring the effect of patient cerebrospinal fluid on the "excitability" of cells maintained in culture.

You say that you don't know exactly what the substance is, but you have an idea?

We know many of the details of how this yet to be identified substance interacts with gamma aminobutyric acid (GABA) receptors, which are ubiquitous in the brain. They're the receptors where sedatives, anesthetics, and alcohol all work. We have a cell model of the receptor that we test by changing the efficiency of the receptor. The receptor is basically a lock and the key GABA goes in, turns it, and the door opens. This lets chloride ion in, which is a negatively charged ion so the cell becomes more negative, and it shuts down, contributing to the sleepiness. The unknown substance basically acts like WD-40 in the lock. In its presence, the lock (i.e., GABA receptor), opens much more easily. As we better understand this system, we get closer to faster identification and treatment, as well as customized treatments — the "personalized" medicine the NIH supposedly advocates for.

So you're looking into treatments as well?

Many natural compounds and drugs interact with GABA receptors and antagonize this substance. We have confirmed this in our bioassay system. We have two clinical trials, one looking at Flumazenil*, the other looking at Clarithromycin to treat these patients, and these are driven directly by patients and discovery.

Unfortunately, the funding climate at the NIH and the grant-review process is making this process incredibly hard for us, and is a true disservice to "patient-oriented research." We recently received notice of a third "unscored" assessment of a genuinely patient-oriented grant that expands upon this discovery. This is particularly frustrating. The NIH calls for research that translates into better patient care. We present to them our investigation of a disorder that affects at least 1:1,000 people. We're seeking both its cause and new diagnostic and treatment paradigms. Yes, it's "ambitious," but so is any meaningful discovery. It just illustrates how hard one has to push against conventional thinking. We absolutely need to get the primary hypersomnias on the NIH's radar screen. We're going to do everything we can to see this through and make it happen.

Learn more about David Rye's work by going to ClinicalTrials.gov and searching "David B. Rye," and read a short case description in *Emory Magazine* by googling "Emory sleeping beauty."

* Dr. Rye notes as a potential conflict of interest that he and his colleague Dr. Andrew Jenkins are co-founders of Somnolytics, a company that seeks to provide Flumazenil to patients with the primary hypersomnias, as well as improved diagnostic modalities and potentially other novel pharmacologicals for treating pathological sleepiness.



Thank YOU 2010 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 2010 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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Joan & John Casey
Cephalon, Inc.
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W. Don Gillen, Jr.
Sze Ping Kuo
Mee Ng
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Board of Trustees monthly Teleconferencing calls on:

January 19, 2010
February 16, 2010
March 16, 2010
April 20, 2010
May 20, 2010
June 15, 2010
July 20, 2010
August 21, 2010
September 21, 2010
November 16, 2010
December 21, 2010

**The Board of Trustees met
in person on October 11, 2010,
in Arlington, VA.**

Narcolepsy Network, Inc. Financial Report



Mee Ng, NN Treasurer

Narcolepsy Network's strong reserves and stable financial standing has helped it survive these challenging economic times. The results we achieved in 2010 were made possible by the diligent work of staff as well as numerous friends of Narcolepsy Network. Though individual donations have declined as a result of the negative effects of the economy, we have been fortunate to

receive additional funds from corporate grants for program expansions. We are grateful for this strong, ongoing support from both individuals and firms. However, the staff and the board are dedicated to the search for additional funding, as well as to diversifying our income sources.

In the next few years, Narcolepsy Network's success will be dependent upon our outreach and community growth. We plan to keep all of the programs that you love (e.g. Annual conference, newsletters, and picnics), but we also want to offer more. We have enough assets and resources to go beyond merely surviving. It is time to take the next step. What is that step? That is for you and NN to decide. Will you walk with us?

I look forward to our continued success and future together.

Warm Regards,
Mee Ng

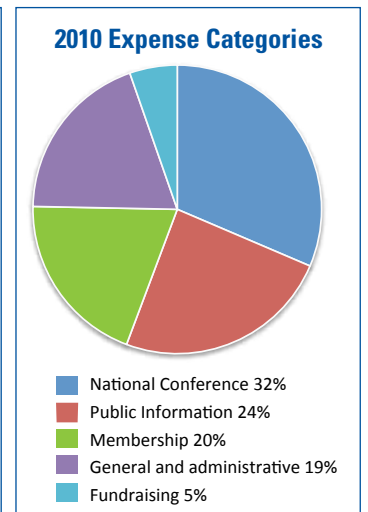
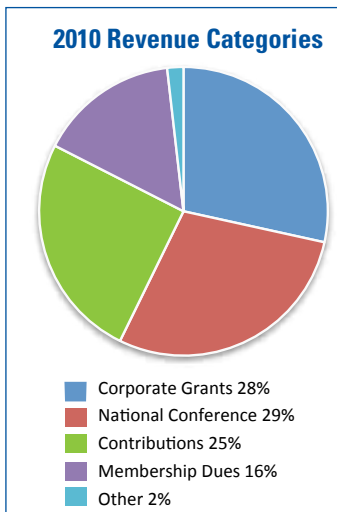
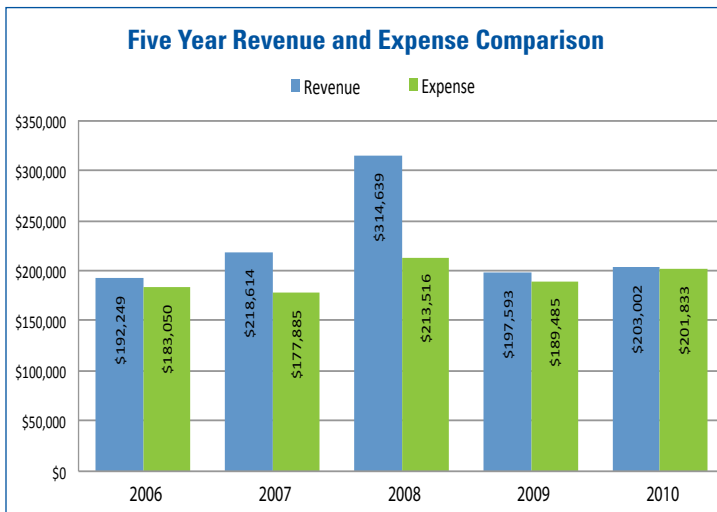
Treasurer, 2010
Narcolepsy Network Board of Trustees

Statement of Financial Position - Years ended December 31

Assets	2010	2009
Cash and cash equivalents	\$ 263,270	\$ 267,504
Prepaid expenses	3,216	4,116
Other liquid assets	20,680	—
Property and equipment, net	2,500	2,500
Total Assets	\$ 289,666	\$ 274,120
Liabilities		
Accounts payable and accrued expenses	\$ 15,312	\$ 659
Payroll withholdings and accrued taxes	1,020	1,296
Total Liabilities	\$ 16,332	\$ 1,955
Net Assets		
Unrestricted	\$ 273,334	\$ 270,165
Temporarily restricted	—	2,000
Total net assets	273,334	272,165
Total liabilities and net assets	\$ 289,666	\$ 274,120

Statement of Activities - Years ended December 31

Income	2010	2009
Corporate Grants	\$ 57,750	\$ 30,000
National Conference	58,475	53,760
Contributions	51,258	70,317
Membership Dues	31,835	37,385
Other	3,684	6,131
Total Income	\$ 203,002	\$ 197,593
Expenses		
Programs		
National Conference	\$ 63,421	\$ 47,425
Public Information	49,044	78,376
Membership	39,555	20,630
Total program expense	152,020	146,431
General and administrative	39,045	30,118
Fundraising	10,768	12,936
Total Expenses	\$ 201,833	\$ 189,485
Net increase (decrease) in net assets	\$ 1,169	\$ 8,108





Narcolepsy Network, Inc.

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