



**NARCOLEPSY
NETWORK®**

Annual Report 2021

Mission Statement

Narcolepsy Network is dedicated to improving the lives of individuals with narcolepsy. The organization's goals include increasing public awareness to foster early diagnoses, advocating for all people with narcolepsy (PWNs), promoting and supporting narcolepsy and related research, and providing education and resources both to people living with narcolepsy and the public at large.

A Brief History of Narcolepsy Network

Narcolepsy Network emerged from the vision of 13 women from self-help groups across the United States.

In 1984, most of these women met for the first time. 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 1986, the team completed the new organization's 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 its founders. They incorporated the organization that spring, and later held the first Narcolepsy Network Annual Meeting and election of officers in May. Approximately 75 members attended that first meeting.

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 people with narcolepsy, and building the organization were foundational goals.

By 1996, after ten years as an all-volunteer organization, Narcolepsy Network hired 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 Narcolepsy 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. As newly diagnosed join our organization, they bring with them the energy and creativity to advance Narcolepsy Network and its goals into the future.



A Message from the President



Dear Friends,

For more than 36 years, we've been connecting people with narcolepsy and idiopathic hypersomnia—providing educational resources, raising awareness, and supporting each other along the way. 2021

was no different, save for the fact that we continued to expand our virtual programs.

Narcolepsy Network is the only membership-based organization in the United States for people with narcolepsy and idiopathic hypersomnia. Why is this important? Members have the ability to vote on the leadership of our organization. We are committed to listening to our community, and the engagement of our members helps us build greater impact.

In 2021, we introduced Clinical Updates, an important new educational series that provides a forum to learn more about current, approved therapies and investigational research that is underway. We also began sharing frequent updates via email, and through postings on our website.

Even though we couldn't be together in person, we made the best of our virtual events by celebrating Suddenly Sleepy Saturday in the spring and World Narcolepsy Day in the fall.

We finished the Virtual Mini-Conference series that began in 2020 and held our first ever Virtual Annual Conference with many wonderful speakers and hundreds of attendees. Narcolepsy Network was able to pivot from our initial in-person plans and still deliver educational content to the narcolepsy community.

In November, our marathon team came together in person to run the first post-pandemic New York City Marathon. This was an exciting event to participate in, and set the stage for our eventual return to more in-person activities.

This year also marked the beginning of our Listening Journey—an effort that aims to understand how Narcolepsy Network can best serve this community. We launched several focus groups to kick off this effort. As a person with narcolepsy, I understand the spectrum of symptoms that we all experience—one size does not fit all when it comes to providing support for people with narcolepsy and idiopathic hypersomnia.

Narcolepsy Network continues to play a critical role in our community. The support, education, and advocacy programs that we provide are vital to thousands of people across the United States. I am excited for the future of this organization as we continue to learn more about how we can best serve your needs.

Thank you,

A handwritten signature in dark ink, appearing to read 'Keith Harper', with a long, sweeping horizontal line extending to the right.

Keith Harper,
Narcolepsy Network Board President



What Others are Saying

Since the very beginning, we have strived to be a respite to those living with narcolepsy and idiopathic hypersomnia. We make sure that those with the disorder are not alone. We will continue to serve this community now and in the future. Here are just a few stories on the impact we are having.

Dorene Finer



Twenty-five years ago, I received a narcolepsy diagnosis. I was in my early 50s and knew nothing about the disorder. I read all I could find to learn more about my condition, but there remained a missing piece - knowing others who could understand this life-altering disorder. That

void was filled when I began attending Narcolepsy Network's Thursday night virtual support group meetings. The group offers a comfortable and safe environment to share experiences and the many emotions surrounding life with narcolepsy. Attendees can exchange information about events, clinical studies, suggestions for controlling symptoms, filling out disability forms, or for finding help to pay for prescribed medication. Most importantly for me, it's comforting to truly realize I am not alone.

Wayne Mosher



The Thursday night support group is the only place in America where a narcoleptic can attend [virtually] and identify with others the complex and disabling symptoms of narcolepsy, share experiences, and discuss various treatment regimens. This meeting also gives courage

and hope to those of us who cannot use traditional medications. For example, this group has encouraged me to do my own research to better understand how hypocretin is produced and how it functions in the brain. I've been able to balance my blood sugar to prevent spikes which has reduced my narcolepsy symptoms and the need for a nap after eating starchy foods. By attending this group, I continue to find ways to manage my symptoms without the use of central nervous system medication.

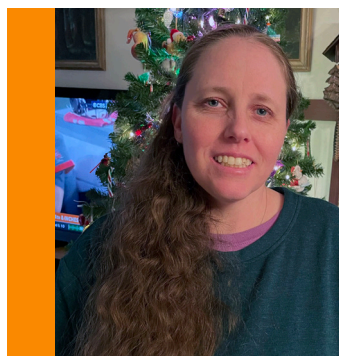
Chris Oudemann



Narcolepsy Network's Virtual Support Group has been a Godsend for me at a very difficult time in my life. My symptoms are the worst they have ever been and being able to talk to people from around the country who are experiencing the same things as me is priceless. I've been

able to get some great advice and also get myself in a better mental state. I also find it very helpful to help others with narcolepsy. Especially with how isolating the pandemic has been, it is great to have a place like Narcolepsy Network's Virtual Support Group to meet and socialize with other people with narcolepsy.

Sabrina-Hope McDougal



Narcolepsy Network has been an incredible blessing in my life. They provided me with a scholarship that helped me attend the [Annual Conference] where I was able to not only gather important information about all aspects of my narcolepsy, but just as

importantly, meet in person with the other members of the weekly virtual support group. This online support group has provided me with my first opportunity to speak with other PWNs (people with narcolepsy). For the first time since being diagnosed, I was truly and completely understood. This support group has blessed me with not only a lifeline where I can get and share information about my narcolepsy and how it is affecting me, but I've gained new friends who I'm lucky to call family.

2021 Highlights

In 2021, we were still in the middle of the COVID-19 crisis. In-person activities like conferences and support groups remained online. Even though this was the case, we were able to connect with people with narcolepsy and their loved ones and spread important awareness.

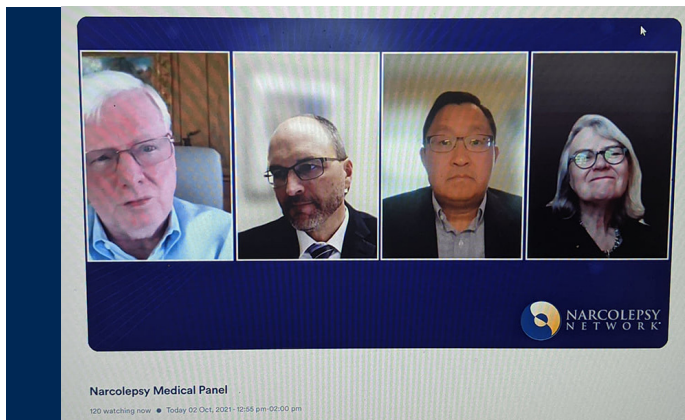
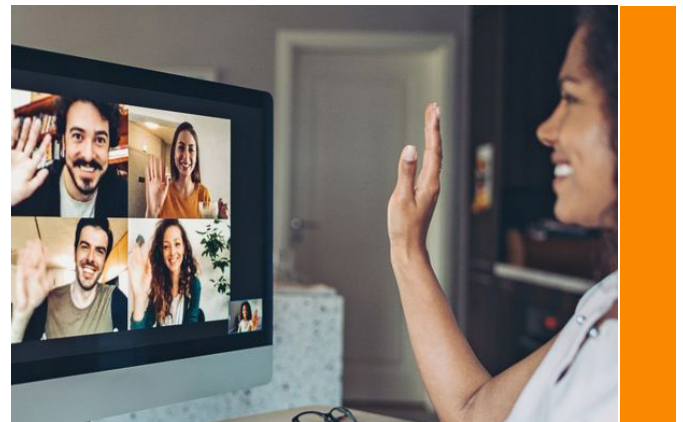


Suddenly Sleepy Saturday

We once again asked the narcolepsy community to celebrate Suddenly Sleepy Saturday, also known as Narcolepsy Awareness Day, by requesting proclamations officially recognizing the day from a governor or mayor. In 2021, 23 proclamations were granted from US governors and five from US mayors.

Virtual Support Groups

Even though there were restrictions on in-person meetings, people still needed support. We offered weekly support groups for people with narcolepsy and their loved ones every Thursday.



Virtual Mini-Conference

We were able to bring education and the latest narcolepsy information through online virtual seminars. In October, we held our two-day Annual Virtual Narcolepsy Conference. We welcomed Dr. Lois Krahn who presented a history of narcolepsy. The conference also brought an informative discussion with clinicians Dr. Michael Thorpy, Dr. Chad Ruoff, and Dr. Charles Bae on the correct diagnosis, treatment, finding the right doctor, different classes of medications, and clinical trials. There was a NIA® session to get energized, a patient story from a person with narcolepsy and cataplexy, and many other speakers and presentations.

Thank You 2021 Donors!

Narcolepsy Network thanks the following donors, whose generous gifts 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 to help further Narcolepsy Network's mission.

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January
February
March
April
May
June
July
August
September
October
November
December

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Narcolepsy Network, Inc. Financial Report

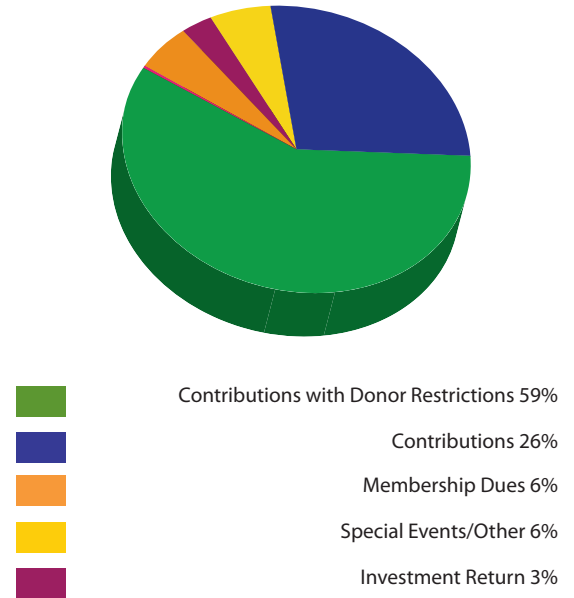
Statement of Financial Position - As of December 31

Assets	2020	2021
Cash and cash equivalents	\$566,278	\$481,079
Pledge receivable	5000	4,035
Prepaid expenses and other	33,532	21,028
Investments	98,663	109,700
Total Assets	\$703,473	\$615,842
Liabilities		
Accounts payable and accrued expenses	\$5,442	\$7,236
Accrued payroll and related	4,226	3,456
Deferred membership dues	12,588	5,603
Total Liabilities	\$22,256	\$16,295
Net Assets		
Unrestricted	\$422,881	\$442,972
Temporarily restricted	258,336	156,575
Total net assets	\$681,217	\$599,547
Total liabilities and net assets	\$703,473	\$615,842

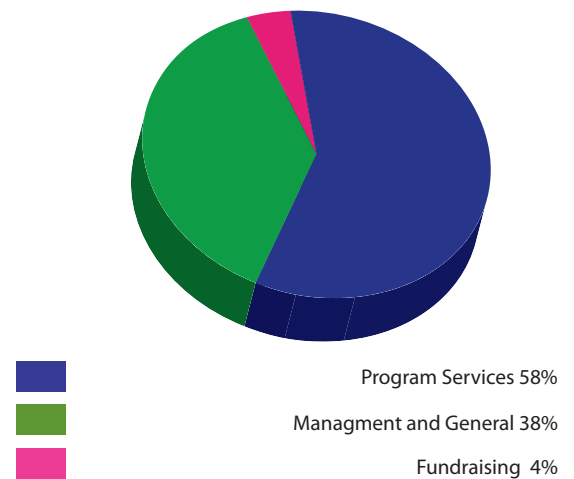
Statement of Activities - Year ended December 31

	2020	2021
Support and Revenue		
Contributions	\$111,679	\$100,464
Contributions with Donor Restrictions	303,995	225,000
Annual Conference	1,375	575
Membership Dues	36,105	21,286
Investment Return	14,773	11,712
Special Events/Other	20,000	21,455
Total Income	\$487,927	\$380,492
Expenses		
Programs	\$57,932	\$269,248
Management and General	91,223	174,234
Fundraising	67,614	18,680
Total Expenses	\$305,036	\$462,162
Net increase (decrease) in net assets	\$182,891	(81,670)

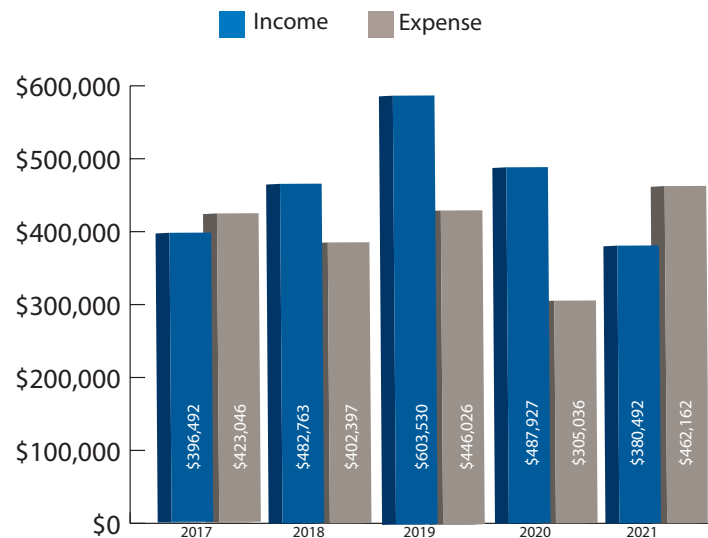
2021 Support and Revenue



2021 Expenses



Five Year Revenue and Expense Comparison



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Other Ways to Support Us

If you do a lot of your shopping online, you can shop and help out NN at the same time. Just remember to go to www.smile.amazon.com for your online shopping. When a purchase is made through the Amazon Smile website, the company donates a portion of the purchase price of items you buy to an organization of your choice, like NN. If you are new to Amazon Smile, the website will ask you to pick an organization when you first create your account and you can select Narcolepsy Network at that point. For returning users, you can select NN by going to Your Account and selecting Change Your Charity.

Create a Fundraising Campaign on Facebook

Are you thinking about doing something special for your birthday or other special event? How about create a fundraising campaign on Facebook where you can ask your friends to support your cause? To start a fundraiser, click Fundraisers in the left menu of your News Feed, then click Raise Money. Select Narcolepsy Network as your charitable organization, choose a cover photo, and fill in the details. Then click Create. That's it!


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