



NARCOLEPSY  
NETWORK®

# Annual Report 2022



## Our Mission

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

## A Brief History

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

In 1986, the team completed the new organization's Articles of Incorporation and Bylaws, appointed Ruth Justice Nebus as its incorporator, elected Niss H. Ryan, and named Sue Brockway Carella, Jan Wright, Norma J. Potter, and Ruth Justice Nebus as founders. By that spring, the organization was incorporated and Narcolepsy Network's Annual Meeting and election of officers was held.

From the beginning, 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. 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, resources, and more. Every time someone joins our organization, they bring with them the energy and creativity to advance Narcolepsy Network and its goals into the future.

# Message from the President

Dear Friends,

As we reflect on a remarkable year, we are thrilled to share the many highlights that have shaped our work and our community in 2022. One of the most exciting moments was our return to in-person events, with our conference in Atlanta being a truly special occasion. It was wonderful to reconnect face-to-face, make new friends, and hear from such wonderful speakers.

A highlight of the conference was listening to Dr. Mignot share his expertise and insights with us. His presence underscored the importance of coming together as a community to advance knowledge and support those affected by narcolepsy and idiopathic hypersomnia.

While we were excited to gather in person, we also remain committed to offering virtual programming that provides support and connection year-round. Our virtual support groups continue to be a vital resource for many. We launched our Clinical Updates & Lifestyle program this year, which includes a series of educational webinars and practical tips delivered through our e-news. This initiative is designed to provide the latest insights and guidance to enhance both clinical care and everyday well-being.

We are excited for what's to come and deeply grateful for the continued engagement of our community. Together, we are building a future of shared learning, support, and progress. Thank you for being part of our community!

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## What Others Are Saying

Since the very beginning, we have strived to be a respite to those living with narcolepsy and IH. We make sure that those with the disorder are not alone. We will continue to serve this community now and in the future. Here is just one recent insight from a narcolepsy patient:

“I enjoyed meeting other narcoleptics. I learned so much more about [narcolepsy]. And I was elated to see two other people who had been diagnosed with central apnea. I thought I was the only one. I had such a blast and am looking forward to the next one.”  
*Hurlicia Hardway, 2022 Annual Conference Attendee*

## Message from the Transition Director

Dear Friends,

Reflecting on the past year, I am grateful for our community of patients, supporters, and donors. This year, we welcomed new friends and got reacquainted with old friends as we headed to Atlanta for our in-person conference. Not only were we excited to finally be back in person after years of virtual-only events, but renowned speakers joined us as well.

During 2022, we focused on bringing awareness to narcolepsy and idiopathic hypersomnia. I was honored to attend the World Sleep Congress in Rome, along with Board President Keith Harper, to spread awareness of narcolepsy to those who work in sleep medicine. Narcolepsy Network was also an exhibitor at the annual SLEEP meeting where we highlighted the patient experience to give voice to those who are living with narcolepsy or IH.

As we look towards 2023, we are determined to raise awareness for these invisible disorders and to bring together more patients so they do not have to walk their journey alone.

I'd like to send my sincere gratitude to all of you – staff, board members, volunteers, donors, partners, and advocates. You are making a difference to those with narcolepsy and IH.

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## 2022 Highlights



### Annual Conference October 28-30, 2022

After two years of entirely virtual events, we traveled to Atlanta, Georgia, for our 36th Annual Conference. We welcomed Dr. Emmanuel Mignot as our keynote speaker who presented a journey through narcolepsy. The conference also brought an informative discussion with clinicians Dr. Lois Krahn, Dr. Kiran Maski, Dr. Emmanuel Mignot, Dr. Chad Ruoff, and Dr. Michael Thorpy with topics on on aging and narcolepsy, diagnosis, links between narcolepsy and other medical conditions, medications, lifestyle management strategies, and pregnancy and family planning. There was a storytelling and self advocacy for young adults workshop, a patient experience panel, and many other speakers and presentations.



### Suddenly Sleepy Saturday March 12, 2022

We once again asked members and supporters to request proclamations from their governors and/or mayors recognizing Suddenly Sleepy Saturday as a day for narcolepsy awareness. In 2022, 39 individuals across 28 states requested proclamations. Of those, 21 state and five city proclamations were granted.

## Awareness

- We joined Project Sleep to encourage members of the narcolepsy community to take action for sleep research. An official Congressional Sign On Letter was sent to the Appropriations Committee asking them to prioritize sleep and sleep disorders research and awareness.
  - Every Thursday, we offered weekly support groups for people with narcolepsy and IH including groups for parents and supporters.
  - We facilitated a number of clinical and lifestyle webinars throughout the year, including:
    - January: The Value of Clinical Research: An example of a Patient-Centric Study with Jazz Pharmaceuticals
    - March: “Journey to Fitness” with Matt Horsnell
    - March “WAKIX® (pitolisant): Clinical Trial Results, How it is Thought to Work, and More” with Ellen Wermter
    - May: “Understanding the Orexin System: Why it Matters” with Dr. Thomas Scammell and Takeda
    - June: “Depression and Anxiety in Narcolepsy: Can CBT Help?” with Dr. Russell Rosenberg and Dr. Anne Bartolucci
    - August: “Update from Avadel on Investigational Clinical Treatment”
- Additionally, we held a Young Adult Self-Advocacy Workshop, and throughout the year, a number of Young Adult Social Hours.

## 2022 Highlights



## New York City Marathon November 6 2022

In November, runners on #TeamNarcolepsy ran 26.2 miles through the boroughs of New York City to raise narcolepsy awareness at one of the globe's largest marathons. The #TeamNarcolepsy roster was filled by our Board President Keith Harper, Bill Gannaway, Cameron Gates, Alicia Soto, and Rob Dezendorf. Collectively, they raised about \$15,000 for Narcolepsy Network.

We have been an Official Charity Partner of the TCS New York City Marathon since 2018. This event has become our biggest fundraiser of the year, enabling us to continue to grow our advocacy, awareness, support, and education programs to best serve the needs of people with narcolepsy and IH and their supporters. We are grateful to each of these runners for their hard work and dedication!

## Medical Community Conferences

### World Sleep Congress March 11-16, 2022

In March, our Transition Director Amy Kant and Board President Keith Harper traveled to Rome for the 2022 World Sleep Congress. The World Sleep Congress consistently gathers the best minds in sleep medicine and research for multiple days of scientific sessions and networking.

### SLEEP 2022 June 4-8, 2022

In June, we attended the 36th Annual Meeting (SLEEP 2022) of the Associated Professional Sleep Societies (APSS), in Charlotte, NC. This event brings together thousands of sleep researchers and healthcare providers to discuss the latest advances in sleep science and new developments in the diagnosis and treatment of sleep disorders.

As an exhibitor, Narcolepsy Network had the opportunity to share patient stories with medical professionals to ensure that people with narcolepsy have a seat at the table when it comes to the advancement of clinical research and new therapies.

# Thank You 2022 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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# Thank You 2022 Donors!

Narcolepsy Network thanks the following donors, whose generous gifts made it possible for us to provide information and support to people living with narcolepsy and IH 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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Beverly Chang

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## Board of Directors conference calls were held on:

January 5  
January 18  
March 3  
March 29  
April 26  
May 9  
May 17  
May 31  
June 12  
June 21  
July 19  
August 16  
September 20  
November 15  
December 13

# Narcolepsy Network, Inc. Financial Report



This past year was unprecedented to say the least. We experienced shutdowns, virtual school, and quarantines. While we were saddened to have to cancel our in-person events, we were excited to present educational and informational programs in a new format through our online patient days and

our virtual mini-conferences.

As we all tried to adjust to everything happening around us, more people felt isolated and alone. That meant making connections and having a sense of community was still needed. We saw this need and held virtual support groups, virtual meetings for teens and young adults, and virtual gatherings for kids and their parents.

We thank everyone for your continued support. You allowed us to reach more people in new ways as we all navigated this new normal.

Warm Regards,

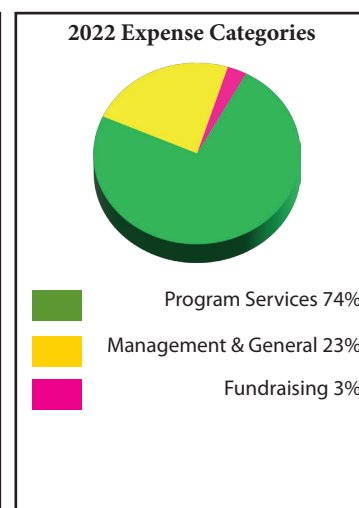
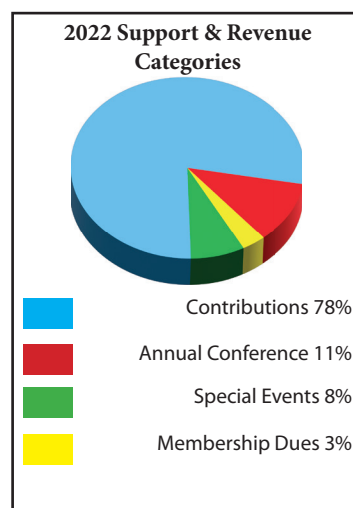
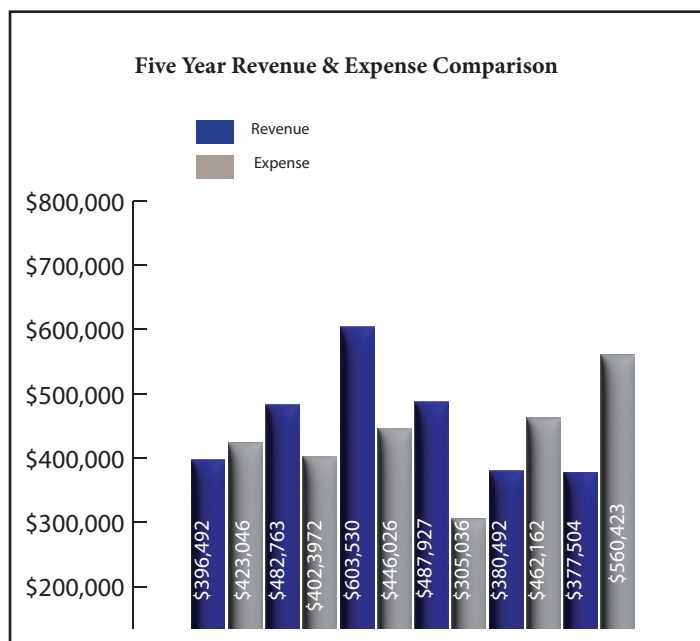
Paul Reynolds  
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Narcolepsy Network Board of Directors

## Statement of Financial Position - As of December 31

Assets	2021	2022
Cash and cash equivalents	\$481,079	\$404,373
Pledge receivable	4,035	
Long term investments	112,199	95,396
		84,896
<b>Total Assets</b>	<b>\$615,841</b>	<b>\$499,770</b>
<b>Liabilities</b>		
Accounts payable	\$7,236	\$76,480
Deferred membership dues	5,603	5,132
Other short term liabilities	3,454	1,476
<b>Total Liabilities</b>	<b>\$16,295</b>	<b>\$83,089</b>
<b>Net Assets</b>		
Unrestricted	\$442,971	\$399,305
Temporarily restricted	156,574	17,375
<b>Total net assets</b>	<b>\$599,546</b>	<b>\$416,681</b>
<b>Total liabilities and net assets</b>	<b>\$615,841</b>	<b>\$499,770</b>

## Statement of Activities - Years ended December 31

	2021	2022
<b>Revenue</b>		
Contributions	\$325,464	\$306,225
Annual Conference	575	43,135
Member dues	21,286	12,784
Investment returns	11,712	(13,779)
Special events	21,455	29,139
<b>Total Revenue</b>	<b>\$380,492</b>	<b>\$377,504</b>
<b>Expenses</b>		
Program services	\$269,248	\$414,788
Management and general	174,234	129,788
Fundraising	18,680	15,847
<b>Total Expenses</b>	<b>462,162</b>	<b>560,423</b>
<b>Change in Net Assets</b>	<b>(\$81,670)</b>	<b>(\$182,919)</b>





## Donating to Narcolepsy Network

We express our sincere appreciation to all those who support Narcolepsy Network's efforts. To make a donation, visit [www.narcolepsynetwork.org](http://www.narcolepsynetwork.org). Please consult your lawyer for additional information on planned giving through a will, trust, or estate. Narcolepsy Network is a tax-exempt 501(c)(3) nonprofit organization. Your contributions are tax-deductible to the extent permitted by law. Consult your tax advisor for details.

### Create a Fundraising Campaign on Facebook

Are you thinking about doing something special for your birthday, holiday, or other event? Why not 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!

## Narcolepsy Network Staff

**Christine Hackenbruck**  
Operations Manager

**Megan McClean**  
Marketing Manager

**Amy Kant**  
Transition Director



**Narcolepsy Network, Inc.**  
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Camas, WA 98607  
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