



# BECOMING A NARCOLEPSY ADVOCATE TOOLKIT



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projectsleep



# TOOLKIT INDEX

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# WELCOME!

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We're so glad you are here. This toolkit is designed for people living with narcolepsy and their loved ones to share a few key considerations, best practices, and opportunities to maximize the impact of your advocacy. Project Sleep created this toolkit as part of the **Narcolepsy Nerd Alert** Series.

**Narcolepsy Nerd Alert** is an educational series diving deeper into specific topics relevant to narcolepsy. Each month, Project Sleep broadcasts a live event via Facebook, hosted by Julie Flygare, JD, Project Sleep's President & CEO.

After each live broadcast, we create a corresponding toolkit (like this one!) to capture our collective knowledge to help others down the road. Quotes featured in speech bubbles throughout toolkit are from participants who joined us for the live broadcast.

## PLEASE NOTE

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The Narcolepsy Nerd Alert series is intended for educational and awareness purposes and is not a substitute for medical attention. We want to empower people with information. If anything in this toolkit sparks questions for you about your medical management, please bring those questions to your sleep doctor or narcolepsy specialist.



# BECOMING A NARCOLEPSY ADVOCATE

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## Sharing your story matters.

On February 24, 2021, we hosted the “Becoming a Narcolepsy Advocate” live event to discuss what being an advocate means to narcolepsy community members. This toolkit is our attempt to compile those insights for future advocates.

- Watch the [Becoming A Narcolepsy Advocate video](#)
- Learn more about [Narcolepsy Nerd Alert Series](#)



## WHAT DOES NARCOLEPSY ADVOCACY MEAN TO YOU?



# MEET THE PANELISTS

Two guest speakers, Ana Lara and Matt Horsnell, joined our host, Julie Flygare, for this broadcast and shared insights and take aways from their journeys becoming narcolepsy advocates.



ANA LARA

Ana E. Lara is a poet and stay-at-home mom who is passionate about writing. She is a person with narcolepsy, who advocates for sleep health and serves on the board of directors for Project Sleep. She aims to educate and bring hope to her community through her poetry.

"I started writing some poetry and it just kind of took off from there. Little by little, I started to meet more people in the narcolepsy community, and I started to feel a sense of involvement... like this is where I belong."



MATT HORSNELL

Matt Horsnell is a father of three and science nerd living with type 1 narcolepsy with cataplexy. He is a Rising Voices of Narcolepsy trained speaker and the National Lead for Project Sleep's Sleep State Champion program. Matthew also serves as a facilitator for Wake Up Narcolepsy online small groups and is a co-host for #NChat on Twitter.

"I wanted to change a lot about how I was approaching my condition. I wanted to take more ownership of it. I wanted to treat this condition as more of an asset in my life, and look through the positives, and tease those out."



# MEET THE HOST

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Julie Flygare, JD, currently serves as President & CEO of Project Sleep. She is an internationally recognized patient-perspective leader, an accomplished advocate, and the award-winning author of Wide Awake and Dreaming: A Memoir of Narcolepsy.



"I remember that feeling when I first said, 'I want to do *something* to make a difference. This is so frustrating, how can I be part of the change?' So becoming an advocate is a journey."

JULIE FLYGARE



# WHERE TO START?

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Many community members have expressed that they want to become narcolepsy advocates, but don't know where to start. The biggest message we aim to impart: **you are already a narcolepsy advocate.**

"I would love to use my story to help and educate others on their journey with narcolepsy."

- Allison

- **You are already a narcolepsy advocate.** If you have ever had to talk about narcolepsy to a friend, a family member, a doctor, or supervisor, or if you've ever dealt with an insurance challenge or healthcare access issue, you are already an advocate. There are no rules around what this means, and no certification for advocacy. Your experience matters, so feel empowered.

- **Your story matters.** Living with narcolepsy every day or supporting a loved one living with narcolepsy means you have experiences others can learn from.
- **There's no one right or specific path.** Everyone's journey into advocacy is different and there's no one way to become a narcolepsy advocate. However, we are excited to share some tips and ideas in this guide. We hope this guide offers some new perspectives and energizing inspiration as you continue on your advocacy journey!

"Advocacy means self-empowerment and finding my voice."

-Margaret



# WHY ADVOCATE?

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Project Sleep's efforts in the narcolepsy space are guided by the **challenges** that we aim to address through **solutions** (in the form of programs and services). So what are some of the the biggest challenges and unmet needs facing the narcolepsy community? Below are some the major challenges.

## MAJOR CHALLENGES FACING THE NARCOLEPSY COMMUNITY

- Public awareness of narcolepsy is limited and often inaccurate.
- There is an 8 - 15 year average delay between narcolepsy symptom onset and diagnosis.
- People with narcolepsy face stigma and report feeling isolated.
- Narcolepsy research is limited, and more research is urgently needed to better understand and treat narcolepsy.

Reviewing the above list of challenges, some may be closer to your heart or your personal experience. Your approach to advocacy may be guided by which issues are most important to you. For example:

- If **social isolation** is most troubling to you, you may get involved in support groups that aim to reduce isolation.
- If **scientific research** is your passion, you may get involved in federal advocacy aiming to increase funding for narcolepsy research.
- If **public misperceptions or reducing delays to diagnosis** feel urgent, you may consider participating in Project Sleep's Rising Voices of Narcolepsy program and sharing your story publicly.



# FORMS OF ADVOCACY

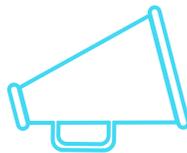
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Narcolepsy advocacy happens in many different areas which often overlap. Here are three categories of advocacy that this toolkit will introduce:



## SELF-ADVOCACY

Doctor's office, pharmacy, school, work, disability and accommodations processes, friends & family.



## RAISING YOUR VOICE PUBLICLY

Speaking engagements, social media, blogs, and media outlets.



## LEGISLATIVE ADVOCACY

Local, state and federal advocacy. In-person or virtually.



# SELF-ADVOCACY

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Here are a few key phrases that can be useful when advocating in your own life (or in your loved one's life if you are a supporter of a person with narcolepsy).

- **"Is there someone else I can speak with?"**

If you are not getting through to the person you are speaking with, it can be important to ask this question.

- **"How should I proceed to resolve this issue?"**

If people you are working with to find solutions seem to be dropping responsibility, asking this can help them to think from your perspective and problem-solve with you in a step-by-step way.

"Very important to be a bit assertive."

- Peter

- **"Can I ask a favor?"** This is one approach that might help break the ice if you're feeling apprehensive.

- **"I love it when friends do/read/ask...."** Matt says, "I love to offer people resources, whether it be Rising Voices of Narcolepsy presentations, Julie's book, or something else. It's a great way to learn from somebody else because sometimes just hearing it from a third party, hearing about it from somebody on the internet, it can really help people understand."

- **"Thank you for thinking of me but I can't this time."**

Learning how to say no is invaluable. This can be really difficult, but it's important to balance one's schedule and "spoons."

Further, you do not need to explain your "no." It is okay to simply decline an invitation without providing a full explanation.

"For me, self-advocacy has meant becoming more assertive about my needs and seeing this as my own form of self-care."

- Ana



# SELF-ADVOCACY

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Here are a few key phrases that can be useful when advocating in your own life or in your loved one's life if you are a supporter of someone with narcolepsy.

- **"What do you know about narcolepsy?"**  
or **"Are you familiar with narcolepsy?"**  
Advocacy is a conversation, it's a two-way process. When you're communicating with a family member or your doctor, asking this question will help you understand where the other person is coming from.
- **"What questions do you have about narcolepsy and how it impacts me?"**  
This gives others an opportunity to ask questions, or share thoughts that have come up in their minds.

"Asking what someone knows about narcolepsy is awesome because it really draws the person in and brings them into the conversation."  
- Katie





# RAISING YOUR VOICE PUBLICLY

At what point do you decide to become "public" about your narcolepsy? What motivates this decision and how do you get started?

- **Disclosure.** It is a deeply personal decision whether or not to talk about narcolepsy publicly, and when.

Julie says, "I made a very conscious decision because my dad had been an employment lawyer, and he had really emphasized being careful about disclosing my narcolepsy diagnosis online because of job considerations. But at some point, my thinking shifted and I thought, 'If I do share about my narcolepsy, I could be part of the solution to reduce stigma, so that other people don't have to be afraid to disclose in the future. I could write a book, and do some media work.' Once I switched my way of thinking, there was no going back really. It was a big moment."

"The fear of my career being negatively impacted if my colleagues learned about my narcolepsy was the biggest factor that kept me from speaking up publicly."

- Richelle

"Advocacy means making narcolepsy a story in someone's life rather than just a medical diagnosis. Advocacy brings narcolepsy off the page!"

- Kim

- **Social media** Sharing your experience with narcolepsy on social media can have a huge impact, personally and for the community.

Ana says, "I started trickling narcolepsy into my social media, and I liked the response that I got from some family members. They said, 'Oh I didn't know that this is how it was for you.' And I think slowly the things for me to share [about narcolepsy] kind of chose me."



# RAISING YOUR VOICE PUBLICLY

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- **Finding community, organizations, trainings, and awareness days.**

Matt says, "While I was talking about my condition with other people, I started to realize that I had been living an isolated existence because I didn't have peer support, which has since become so essential for me. I started participating in awareness days to see who's posting, who's using the hashtags, and those are great ways for me to increase my support network."

- **You never know who you might reach.** You may not know if something you post on social media, or an article about you in a magazine or community newsletter ends up helping someone.

Raising your voice means taking lots of little actions without necessarily receiving instant gratification, and without always knowing the full impact of your efforts. Keep going anyway. Your story matters and will make a difference in the lives of others!

- **Relationship-building.**

Advocacy doesn't have to be done every day, but consistency is powerful. It takes time to build relationships and trust with people, the same way friendships are built organically.

"For me, being a narcolepsy advocate means sharing my story in order to help others gain more awareness of narcolepsy as an actual disorder and not just a punchline. It took me 38 years to receive a proper diagnosis and access to treatment. Hopefully, sharing my own journey will help people not have to wait so long to get help."

- Elizabeth

- **Leveraging other interests and skills.** Ana can connect with people beyond narcolepsy through her poetry, and Matt through his strength training. Julie says, "I think connecting through other interests is super important because we all are people who have so much more to us than just narcolepsy. And from a storytelling perspective and a communications perspective, sometimes empathy comes in realizing that you share other things with people."



**"Social change can only  
move at the speed of trust."**

- JOSEPH PHELAN  
#FRANK2019 CONFERENCE



# WHAT TO SHARE?

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## FACTS AND STATS

- Sharing narcolepsy facts and statistics online is popular and easy. If you do share facts, please share fact sheets and graphics created by leading non-profit organizations or professional societies. This information is generally carefully vetted for health communications best practices and scientific and medical review.
- Be careful not to fall into the trap of thinking sharing facts will effectively educate or inspire empathy. Research has shown that a wealth of information **does NOT change people's views**. Therefore, sharing narcolepsy facts may not be the most effective approach to educate and change people's views about narcolepsy.



## SHARING YOUR STORY

- Personal stories of health and illness issues are invaluable public education tools. Research shows that **audiences are much more likely to engage with and retain information when it is delivered by someone with lived experience**, giving a "face" to medical terminology and statistics.
- Sharing one's health and illness story is also a powerful method of creating reflection, and finding meaning in one's experience. For example, maintaining a public blog about one's health has been shown to decrease social isolation and nurture a sense of purpose among people living with chronic illnesses.

Learn more about the research on this topic in the Resources section.



**"The stories we tell become  
the world we live in."**

- THE OP-ED PROJECT



# HEALTH COMMUNICATIONS BEST PRACTICES

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As you start sharing your story, Project Sleep strongly recommends using **people-first language** and **a balanced first-hand perspective**.

## WHAT IS PEOPLE-FIRST LANGUAGE?

Disease-Only Language	Disease-First Language	People-First Language
<ul style="list-style-type: none"><li>• a narcoleptic</li><li>• narcoleptics</li></ul>	<ul style="list-style-type: none"><li>• a narcoleptic person</li><li>• narcoleptic people</li></ul>	<ul style="list-style-type: none"><li>• a person with narcolepsy</li><li>• people with narcolepsy</li></ul>

Using people-first language choice is not a matter of political correctness. It's based on a scientifically-established phenomenon in which condition-first language subconsciously propagates stigma and dehumanization in the audience's mind. Major studies examining language choices include:

- "disabled people" vs. "people with disabilities" (Feldman et al. 2002)
- "the mentally ill" vs. "people with mental illness" (Granello and Gibbs 2016)
- "epileptics" vs. "people with epilepsy" (Fernandes et al. 2009, Friedrich et al. 2015)

Research studies and further information on language choice in the Resources.



# USING A BALANCED FIRST-HAND PERSPECTIVE

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- **Personal experience v. collective experience**

When referring to a broader group, it's important to use neutral language that respects diversity and personal autonomy.

Avoid non-neutral statements like "everyone with narcolepsy is suffering." You can personally say, "I feel that I am suffering," but suffering is very personal to your experience and it shouldn't be assumed that you know how other people are feeling.

- **Avoid absolutes & generalizations**

Speaking in absolutes—using terms like "everyone," "no one," "always," or "never"—can decrease your credibility because absolutes leaves no room for outliers and exceptions. Absolute-thinking can cause errors in judgment about oneself, others, or the world in general. It is better to use softer language that leave room for outliers, terms like "often," "sometimes," or "a common experience for many people with narcolepsy..."

- **Speak from your experience**

Audiences may not realize that people with narcolepsy have very different experiences depending on a number of factors. As an individual advocate, share your personal experience and then remind your audience that experiences vary across all people with narcolepsy. Here are a few key phrases around speaking from your own experience:

- "In my experience..."
- "Not everyone's the same, but for me..."
- "It's my understanding that..."

Julie explains, "I'm often asked if I drive a car. Do they want to know if I, Julie Flygare drive, or do they want to know if people with narcolepsy drive? I imagine it's both, so I respond by saying: '**For me**, I do drive. I am careful about the timing of when I drive. **For people with narcolepsy**, this varies. Some people drive, some do not.' That's how I answer both to my personal experience and to the variety of experiences within the narcolepsy community, because no one experience can represent everyone."



**"I'm sharing my story  
because representation  
matters."**



**- EBONY LAY**  
RISING VOICES OF NARCOLEPSY SPEAKER  
SLEEP CONGRESSIONAL BRIEFING 2019



# LEGISLATIVE ADVOCACY

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Legislative advocacy is another great way to advance progress, and is especially powerful when conducted consistently and with expert guidance. Project Sleep focuses our year-round advocacy program on advancing federal policies and programs related **to advancing sleep health and improving outcomes for people with sleep disorders.**

## PROJECT SLEEP'S ADVOCACY GUIDING PRINCIPLES

- Advancing Sleep Research
- Accelerating Treatment Options
- Ensuring Access to Healthcare
- Furthering Education, Awareness, and Training
- Addressing Social Justice and Sleep Health Disparities

## POP QUIZ!

The National Institutes of Health (NIH) is the largest public funder of biomedical research in the world. **How much funding did NIH devote to narcolepsy and idiopathic hypersomnia research in 2019?**





# WHEN TO ADVOCATE?

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There are legislative advocacy opportunities throughout the year, but one key time of year when your advocacy is especially impactful is between mid-February to mid-April.

- Every year, Congress creates the budget for the federal government, including institutes and agencies relevant to our priorities like the National Institutes of Health (NIH), Centers for Disease Control and Prevention (CDC), United States Food and Drug Administration (FDA), Department of Defense (DoD), etc.
- This annual "appropriations process," which takes place between mid-February and mid-April each year, is a key opportunity to advance sleep community priorities via a **Congressional Sign-On Letter**.

## CONGRESSIONAL SIGN-ON LETTER

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In partnership with the Sleep Research Society, 2021 will be the third year that Project Sleep leads an annual Congressional Sign-On letter, which outlines key sleep community priorities related to the federal appropriations process.

- In February to March each year, Project Sleep puts out an "advocacy action alert" calling on sleep advocates to reach out to their Member of the U.S. House of Representatives and ask them to sign-on.
- 31 Members of the U.S. House of Representatives signed on in 2019.
- 41 Members of the U.S. House of Representatives signed on in 2020.
- How many Members of the U.S. House of Representatives will sign on in the future? This depends on your advocacy!



# YOUR IMPACT IS REAL!

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Often the legislative progress is slow and steady, but recently we've had some major tangible successes, thanks to your advocacy for the Congressional Sign-On Letter:

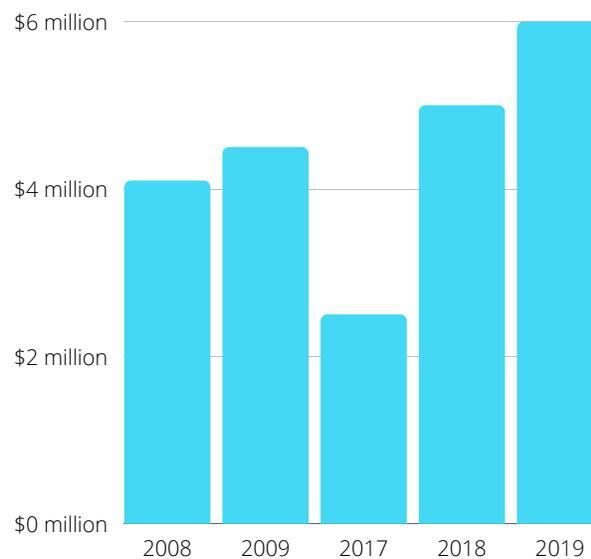
- Establishing the CDC Chronic Disease Education and Awareness program in 2020.
- Narcolepsy researchers credit our advocacy with helping them secure NIH grants.

## POP QUIZ ANSWER

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In 2019, NIH devoted about \$6 million to research focused on narcolepsy and idiopathic hypersomnia (IH). This increase in federal spending on narcolepsy and IH research is encouraging. Project Sleep will continue to keep a close eye on these federal funding levels to ensure the sustained strong investment.

### NIH'S ESTIMATED INVESTMENT IN NARCOLEPSY AND IH RESEARCH



Project Sleep is the only organization tracking the annual federal spending on narcolepsy and IH research. We work with health policy experts to advocate specifically for more federal research funding to facilitate breakthroughs in understanding, treating, detecting, and preventing narcolepsy and IH.



**"Our only opposition  
is lack of awareness."**

**- DANE CHRISTIANSEN**  
WASHINGTON D.C. REPRESENTATIVE  
FOR PROJECT SLEEP



# RESOURCES

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Resources are important. Here are some of our favorites. We look forward to hearing what our fellow #NarcolepsyNerds find most useful in furthering advocacy!

## PATIENT ORGANIZATIONS

- Major US Organizations:
  - [Hypersomnia Foundation](#)
  - [Narcolepsy Network](#)
  - [Project Sleep](#)
  - [Wake Up Narcolepsy](#)
- International Organizations:
  - Listed on Project Sleep's [World Narcolepsy Day webpage](#)

## RAISING YOUR VOICE

- [Stop Raising Awareness Already](#), Stanford Social Innovation Review
- Brene Brown, [TEDx Talk: The Power of Vulnerability](#)
- Stanford Social Innovation Review, [Storytelling for Social Change](#) podcast
- [Rising Voices of Narcolepsy training program](#)
- [Health Story Collaborative](#)
- [The Op-Ed Project](#)





# RESOURCES

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## STORYTELLING RESEARCH

- Ryan EB. [Finding a New Voice: Writing Through Health Adversity.](#) J Lang Soc Psychol. 2006 Dec 1;25(4):423-36.
- Sallinen M, Kukkurainen ML, Peltokallio L. [Finally heard, believed and accepted--peer support in the narratives of women with fibromyalgia.](#) Patient Educ Couns. 2011 Nov;85(2):e126-30.
- Ressler PK, Bradshaw YS, Gualtieri L, Chui KKH. [Communicating the experience of chronic pain and illness through blogging.](#) J Med Internet Res. 2012 Jan;14(5):e143
- Corrigan PW, Rafacz JD, Hautamaki J, Walton J, Rüsçh N, Rao D, et al. [Changing stigmatizing perceptions and recollections about mental illness: the effects of NAMI's In Our Own Voice.](#) Community Ment Health J. 2010 Oct;46(5):517-22.
- Brennan M, McGrew JH. [Evaluating the effects of NAMI's consumer presentation program, In Our Own Voice.](#) Psychiatr Rehabil J. 2013 Jun;36(2):72-9.
- Wood AL, Wahl OF. [Evaluating the effectiveness of a consumer-provided mental health recovery education presentation.](#) Psychiatr Rehabil J. 2006 Jan;30(1):46-53.
- Pittman JOE, Noh S, Coleman D. [Evaluating the effectiveness of a consumer delivered anti-stigma program: replication with graduate-level helping professionals.](#) Psychiatr Rehabil J. 2010 Jan;33(3):236-8.



# RESOURCES

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## LANGUAGE CHOICE RESEARCH

- Rebecca E. Fuoco, MPH, [People-Centered Language Recommendations for Sleep Research Communication](#). *Sleep* 2017; 40(4).
- Granello DH Gibbs TA . [The power of language and labels: “the mentally ill” versus “people with mental illnesses”](#). *J Couns Dev* 2016; 94(1): 31-40.
- Feldman D Gordan PA White MJ Weber C . [The effects of people-first language and demographic variables on beliefs, attitudes, and behavioral intentions toward people with disabilities](#). *J Appl Res Couns* 2002; 33(3): 18-25
- Friedrich L Taslak M Tomasović S Bielen I . [How does the label “epileptic” influence attitudes toward epilepsy?](#) *Seizure* 2015; 33: 54-59.
- Fernandes PT de Barros NF Li LM . [Stop saying epileptic](#). *Epilepsia*. 2009; 50(5): 1280-1283

## LEGISLATIVE ADVOCACY

- [Project Sleep's Advocacy Webpage](#)
- [Sleep Advocacy Forum videos](#)
- [Sign up for e-updates to receive "advocacy action alerts"](#)



# THANK YOU!

We are so grateful that you took the time to check out this toolkit!

**Project Sleep** is a 501(c)(3) nonprofit organization dedicated to raising awareness about sleep health and sleep disorders.

More resources at: [www.project-sleep.com](http://www.project-sleep.com)

