



2021-2022

FISCAL YEAR JULY 1, 2021 – JUNE 30, 2022

ANNUAL REPORT



because your dura matters®



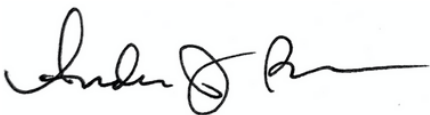
a year's overview

LETTER FROM THE EXECUTIVE DIRECTOR

Our 2021-2022 year has been an exciting experience of growth, rebuilding, and looking ahead to more new and exciting opportunities.

This year, we continued our mission to educate physicians about spinal CSF leak. We connected with other organizations to help advocate for people with headache disorders. We were recognized for our work in our disease space with a generous one-time operating grant from the Silicon Valley Community Foundation. We debuted a newly redesigned website. We created inclusive marketing campaigns to reflect the experiences of people in our community. And above all we continued to make a difference in the lives of those affected by spinal CSF leak.

We are so grateful to our community, our volunteers, and our donors for their unwavering support. We can hardly wait to see what 2022-2023 has in store for us!



Andrea J. Buchanan
Executive Director

annual report

TABLE OF CONTENTS



<u>Executive Summary</u>	3
<u>About Spinal CSF Leak</u>	5
<u>Organizational Profile</u>	6
<u>Mission, Vision, Values, & Goals</u>	9
<u>Programs</u>	10
<u>Financial Report</u>	23

annual report

EXECUTIVE SUMMARY

The Spinal CSF Leak Foundation was established as a 501(c)3 non-profit organization in 2014 by individuals affected by spinal cerebrospinal fluid (CSF) leak. Our mission is to reduce the suffering of persons affected by intracranial hypotension or spinal CSF leak. We do this through education and awareness-raising, community support and advocacy, and the funding of research.

All of our board members and our Executive Director are either currently or formerly affected by this disorder, and several remain moderately to profoundly disabled. Our Medical Advisory Board is composed of a diverse group of physicians, all of whom are expert in understanding spinal CSF leak. Our teams include board members and volunteers, all of whom are affected by the disorder in some way and therefore invested in our mission.

Our program categories are (1) education and awareness; (2) research; and (3) community support and advocacy

Education and awareness. We have garnered a reputation as the leading voice for up-to-date and reliable information for both laypersons and medical professionals. We co-direct an annual symposium in partnership with a major academic institution that brings together clinician experts, patients, and caregivers. Additional medical professional conferences are supported through planning and/or grant support. The power of storytelling is harnessed in both narrative and video formats. Our annual awareness week (leakweek) and virtual activity challenge (duradash®) effectively engage our patient community and beyond.

Research. Since its inception, the Spinal CSF Leak Foundation has been a leader in fostering collaborative efforts in education, awareness, and research around this disorder. Our medical advisory board is a strong, diverse, multidisciplinary, multi-institutional group of specialists that is engaged in both educational and research-oriented activities. We worked with stakeholders to create—and successfully implement—relevant ICD-10 codes so that spontaneous intracranial hypotension (SIH) due to spinal CSF leak could be properly coded and billed, thus facilitating research including essential epidemiological

annual report

EXECUTIVE SUMMARY

studies and access to care. For several years we have provided grants of \$5,000 to \$50,000 to researchers, one of which has led to a larger NIH-funded project. In 2021, we established our first patient advisory panel for research, and we are currently working with clinicians, researchers, and patients to building the infrastructure for a patient registry and collaborative research network, all to accelerate advances in this field and improve patient outcomes. Our medical advisory board continues to collaborate with an international multidisciplinary team to develop needed diagnostic and treatment guidelines. And in 2021, we were awarded a one-time operating grant from the Chan-Zuckerberg Institute in support of our work.

Community Support and Advocacy. High-quality compassionate informational and emotional support is essential for people affected by spinal CSF leak. We partner with Inspire as our support community, and we network with other organizations representing related disorders to make our advocacy efforts even more effective.

Our mission drives our specific activities within each program category. Over the next year and beyond, we plan to build upon our successes, broadening our efforts in education, research, and advocacy such that persons affected by intracranial hypotension or spinal CSF leak will experience shorter diagnostic delays, receive more timely and appropriate diagnostic testing and treatments, and have better long-term outcomes.

an overview

ABOUT SPINAL CSF LEAK

Spinal cerebrospinal fluid (CSF) leak is an important and underdiagnosed cause of new-onset headache. The brain and spinal cord are bathed in fluid known as cerebrospinal fluid (CSF) in one continuous compartment. This fluid is held inside by a tough layer of connective tissue surrounding the brain and spinal cord called the dura mater. When the spinal dura mater has a hole, tear, or other defect, CSF can leak out of this compartment. These defects, whether small or large, can result in a low volume of CSF remaining around the brain and spinal cord. It is this loss of CSF volume that affects the brain and spinal cord in a number of ways.

While there are many symptoms, the most common is head pain that is worse after minutes to hours upright and improved when lying flat, or head pain that is less obviously positional but gets worse as the day goes on. Most of the time, this is mistakenly assumed to be a migraine headache, or is attributed to another cause. Many patients are quite disabled by their limited functional upright time each day. Very rarely, this condition can be life-threatening.

Spinal CSF leak is a diagnosis that tends to be missed when it occurs spontaneously, while cases that arise after medical procedures like spinal taps and spinal surgery are usually recognized more quickly. Spontaneous spinal CSF leaks have known associations with underlying heritable disorders of connective tissue and/or bone spurs along the spine.

Because awareness remains low among health professionals and because there is considerable variability in the symptom patterns and complications, spinal CSF leak can be challenging to diagnose. The diagnosis is suspected based on symptoms and evaluated with imaging of the brain and spine.

Treatments include spinal injection procedures and surgery. With the correct diagnosis and treatment, the prognosis is generally good, but an improved quality of life remains elusive for many patients due to the limitations of current imaging and treatments. There is much that remains unknown about the incidence and prevalence, underlying causes of spinal CSF leak, and about CSF dynamics, complications, and long-term outcomes.

the foundation's

ORGANIZATIONAL PROFILE

Spinal CSF Leak Foundation has an Executive Director, a Board of Directors, and a Medical Advisory Board. Each member of the Board of Directors supports the work of Spinal CSF Leak Foundation to provide mission-based leadership and strategic governance. Board members serve a one-year term and are eligible to be reappointed for successive terms. Medical Advisory Board members serve two-year terms and are eligible for reappointment for successive terms.

The Foundation operates with just one paid staff member and limited contract help, and is powered primarily by volunteers.

Board of Directors

The current board of directors includes Martha Bond, Jodi Ettenberg, Megan Kocher, Jen MacKenzie, Amanda J. Pickard, PhD, and two members with significant disability due to spinal CSF leak who wish to remain anonymous.

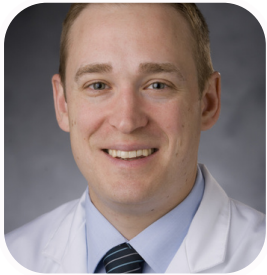
Executive Director

Andrea J. Buchanan is a *New York Times* and internationally bestselling author whose most recent book is the novel *Five-Part Invention*. Her memoir of her experience with spinal CSF leak, *The Beginning of Everything*, was a finalist for the 2019 PEN E.O. Wilson Award for Literary Science Writing. Andi brings over 20 years of experience in the publishing industry, where she has a wealth of leadership experience as a publisher, as co-founder and managing editor of a non-profit literary magazine, and as co-founder and director of a marketing/publicity company.

the foundation's

ORGANIZATIONAL PROFILE

Medical Advisory Board



Timothy J. Amrhein, MD

Associate Professor
Director of Spine Intervention
Department of Radiology
Duke University Medical Center,
Durham, NC



David Dodick, MD

Professor of Neurology
Medical Director of Headache Program
Medical Director of Sport Neurology and
Concussion Program
Mayo Clinic, Scottsdale, AZ
Past President, American Headache Society
Past President, International Headache Society



Ian Carroll, MD, MS

Associate Professor of Anesthesiology,
Perioperative and Pain Medicine
Stanford Headache Clinic
Stanford University School of
Medicine, Redwood City, CA



Deborah Friedman, MD, MPH

Neuro-Ophthalmologist and Headache
Medicine Specialist
Dallas, Texas



Jeremy Cutsforth-Gregory, MD

Assistant Professor of Neurology
Department of Neurology
Mayo Clinic, Rochester, MN



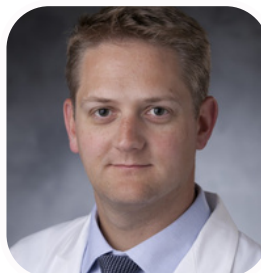
Linda Gray Leithe, MD

Associate Professor
Division of Neuroradiology
Department of Radiology
Duke University Medical Center,
Durham, NC



Connie Deline, MD

Founder, Spinal CSF Leak
Foundation
Camp Hill, PA



Peter G. Kranz, MD

Associate Professor
Chief, Neuroradiology Division
Department of Radiology
Duke University Medical Center,
Durham, NC

the foundation's

ORGANIZATIONAL PROFILE

Medical Advisory Board



Charles Louy, PhD, MD, MBA

Anesthesiologist
Los Angeles, CA



Jill Rau, MD, PhD

Neurologist- Headache Specialist
HonorHealth Neuroscience
Institute, Scottsdale, AZ
Chair, Special Interest Group on
CSF Pressure Disorders, American
Headache Society



M. Marcel Maya, MD

Co-chair, Department of Imaging
S. Mark Taper Foundation Imaging
Center
Cedars-Sinai, Los Angeles, CA



Wouter I. Schievink, MD

Professor of Neurosurgery
Director, Cerebrospinal Fluid Leak Program
Director, Vascular Neurosurgery Program
Cedars-Sinai, Los Angeles, CA



Abhay Moghekar, MBBS

Associate Professor of Neurology,
Otolaryngology and Neurosurgery
Research Director, Center for
CSF Disorders
Johns Hopkins, Baltimore, MD



Stephen Silberstein, MD

Professor of Neurology
Director, Jefferson Headache Center
Thomas Jefferson University,
Philadelphia, PA
Past President, American Headache Society



Simy Parikh, MD

Assistant Professor of Neurology
Jefferson Headache Center
Thomas Jefferson University,
Philadelphia, PA

Our mission is to reduce the suffering of persons affected by intracranial hypotension or spinal cerebrospinal fluid leak.

MISSION, VISION, VALUES, & GOALS

our vision

Our vision is for each person affected by intracranial hypotension or spinal cerebrospinal fluid leak to receive prompt diagnosis, access to appropriate testing and treatments, and a favorable outcome.

our values: compassion, integrity, inclusiveness, hopefulness

Our compassion for affected individuals fuels our efforts, and everything we do, we aim to do with the utmost integrity. We honor and respect the diversity of our community. And we maintain hope for the future despite the challenges.

our goals

Elevate awareness

We seek to raise the level of awareness of spinal CSF leak among laypersons and health professionals.

Educate

We support and provide professional education on all clinical aspects of spinal CSF leak.

Support

We provide each person affected by spinal CSF leak access to compassionate, high-quality informational and emotional support.

Advocate

We contribute our voice in advocating for better access to care and better support systems.

Connect

We promote collaborations among all stakeholders to accelerate advances.

Research

We encourage and support research on the epidemiology, causes, diagnostic testing, treatments, complications, and outcomes of spinal CSF leak.



our programs

EDUCATION & AWARENESS

our website and social media

In November of 2021, we debuted our new, updated website, which was redesigned for greater clarity and ease of use. We post frequent content on our website as well as on Facebook, Twitter, and Instagram. Our YouTube channel has a growing library of over 100 videos, which have been viewed almost 600,000 times for a total of over 64,000 hours of watch time. We also regularly update our subscribers via a monthly email newsletter.

storytelling: patient storytellers

Our library of video and narrative format patient stories continues to grow, featuring 23 video stories (with accompanying narrative) and 12 narrative stories. During the COVID-19 pandemic, we updated our filming process to involve sending equipment and instructions to our patient storytellers, then guiding them through the set-up of equipment and the filming process via zoom.

In the spring of 2022, we published seven new video stories featuring, for the first time, teenaged patients ([Hailey](#), [Emma](#), and [Jack](#)) and their caregivers ([Karri](#), [Amberly](#), [Jody](#), and [Burke](#)). We also shared more informal narrative stories about people [navigating spinal CSF leak while in lockdown during COVID](#), searching for [almost 30 years for a diagnosis](#), and [raising awareness on social media from bed](#). Our continued goal is for the diversity of patient stories to reflect the broad range of affected individuals, clinical presentations, clinical courses, and outcomes.

our programs

EDUCATION & AWARENESS

storytelling: spotlights

These brief features published in conjunction with awareness events allow us to share small glimpses of the lives of those in our community.

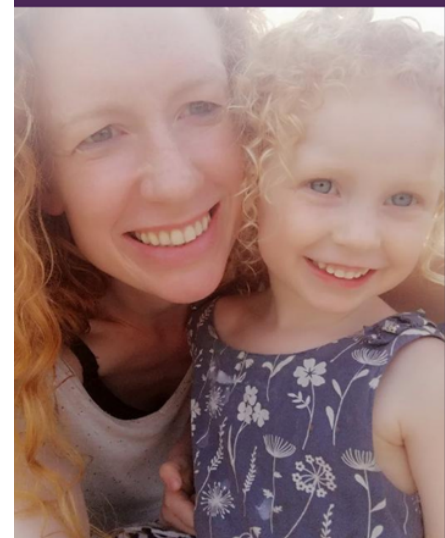
During our fundraising push for #GivingTuesday, we invited people to share with brutal honesty the debilitating nature of spinal CSF leak and how it affects their lives. (See their “Patient Voices” spotlight here: [Carolina](#), [Jen](#), [Michell](#), [Kellye](#), and [Shana](#).)

During the week leading up to Mother's Day, our “Tough Mother” spotlight featured stories from [Ketura](#), [Kellye](#), [Lindsay](#), [Sanela](#), and [Cara](#)—all mothers in our community —about what it’s like to parent while living with a spinal CSF leak. Their experiences of grappling with uncertainty, grief, and resiliency as they navigate illness and parenthood illuminated how learning to be vulnerable, flexible, and creative honors the “tough mother” in all of us.

And during #duradash, over the course of the two-week event select, we invited participants to share their experiences with spinal CSF leak, their hopes for future research, and how they embrace our theme of “start where you are.” (See their spotlights here: [Bridget](#), [Cosmo](#), [Lindsay](#), and [Jennifer](#).)

“This isolated version of living is lonely and frustrating as I’m aware life continues on in an upright active world that I’m unable to join.”

JEN
Spinal CSF leak patient



“WHAT’S GOT ME THROUGH IS NOT FOCUSING ON THE BIG PICTURE, BUT ACCEPTING SLOWING DOWN AND BEING IN THE MOMENT.”

KAT,
MOTHER OF ONE



Spinal CSF leak is a very difficult diagnosis that requires much fortitude to endure. It is all-encompassing: mental, emotional, and physical. Self-advocacy and finding a community is key in the journey.



Jennifer Harding
spinal CSF leak patient and #duradash2022 participant

our programs

EDUCATION & AWARENESS

duradash® 2022: start where you are

This year's duradash®, which took place June 1 - June 12, was a two-week virtual activity challenge to raise awareness about spinal CSF leak. For people living with spinal CSF leak, being upright at all is a challenge, and that's why our theme of "start where you are" is so important. When you start where you are, every activity counts, whether it's reading in bed or going for a walk.

The #duradash goal for participants was to do 150 minutes of any activity, anytime between June 1 and June 12—but exactly what to do and when to do it was up to them. As our instructional materials put it, "Any movement or activity that is appropriate for your current state of health counts towards your #duradash goal. That includes anything from meditation to relaxation, self-care, gardening, sitting, standing, tai chi, walking, biking, hiking, or even running, if that's appropriate for you—and any other kind of "everyday life" activity you might do in the course of a day. (Yes, showering counts!)"



Bridget Janney and family

In the end, our community logged over 13,000 minutes of activity and raised almost \$24,000!

This year, we had duradashers who took photos, read books to their children, went to exercise classes, and even played video games. Participants were encouraged to raise funds through their campaigns in order to enable the Foundation to continue to raise awareness among

medical professionals and others through education and research that specifically advances the understanding, diagnosis, and treatment of intracranial hypotension and spinal CSF leak. In the end, our community logged over 13,000 minutes of activity and raised almost \$24,000!

our programs

EDUCATION & AWARENESS

duradash® 2022: start where you are

To help people share the news about #duradash and leakweek, we created a #duradash toolkit with everything from event graphics and information about spinal CSF leak and the Foundation, to customizable templates for people to use whether sending email, posting on social media, or texting their family and friends about it.

We worked with a group of volunteers, giving them early access to the toolkit and our #duradash platform, so that they could begin to get the word out about the event and start getting people excited to participate. And of course we created #duradash t-shirts!



We also created a video overview of what #duradash was all about, to help participants and donors understand the importance of raising awareness and funds, and what we hoped to accomplish. And we partnered with CauseVox again, to give our participants a platform that's easy to use and mobile-friendly—which is very important to our community, as many are unable to be upright at a computer.

Finally, we capped off #duradash with a social media awards ceremony. Everyone who participated was honored with an award of some kind, from the “Start Where You Are” award to the “Because You Matter” award, to the “Busy Bee” award, to awards for most funds raised by an individual and by a team.

our programs

EDUCATION & AWARENESS

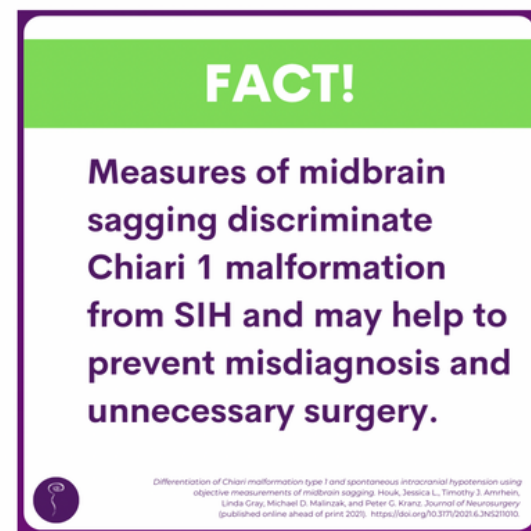
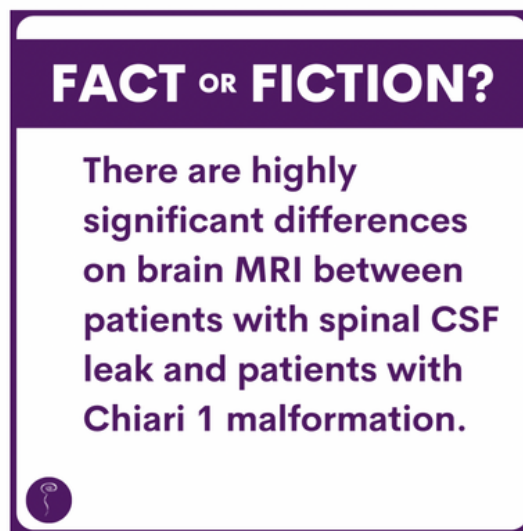
leakweek 2022

The theme of [leakweek 2022](#) was “Education and Awareness.” All throughout the week of June 6 – 12, we shared new videos featuring stories from both patients and caregivers; raised funds and awareness via duradash®; and made the event truly international by teaming up with Spinal CSF Leak Canada and the CSF Leak Association to bust myths and share facts about spinal CSF leak.

During our international leakweek event, we published seven new patient story videos featuring people who experienced spinal CSF leak as teenagers (Hailey, Emma, and Jack) and the family members who advocated for them ([Karri](#), [Amberly](#), [Jody](#), and [Burke](#)).

We also shared informational resource documents and fact sheets from our website to help raise awareness, and gave updates on Foundation-funded research.

We celebrated our annual GO PURPLE day of awareness in conjunction with Spinal CSF Leak Canada, and all throughout [#leakweek2022](#), we invited our community to test their spinal CSF leak knowledge via “Fact or Fiction?” graphics devised by the Foundation, Spinal CSF Leak Canada, and [The CSF Leak Association](#). We were thrilled to collaborate with Spinal CSF Leak Canada and the CSF Leak Association and create a truly informative, memorable, and international leak week! All three groups worked together to work on the event, and all were excited to share it—and to emphasize that awareness, education, and research are global issues that all three of our organizations are passionate about working on.

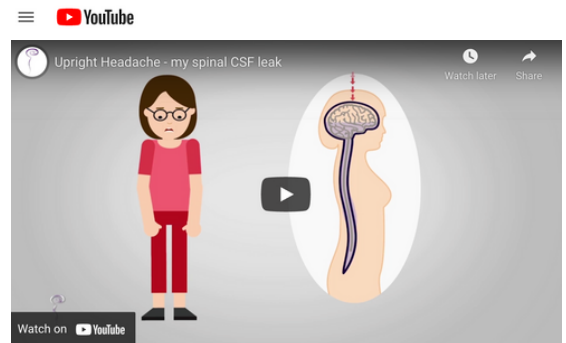


our programs

EDUCATION & AWARENESS

explainer videos

Our animated video on “Upright Headache,” which we produced in 2017, has now been viewed over 100,000 times. Additional explainer videos are being planned.



Upright Headache - my spinal CSF leak
80,899 views • Feb 26, 2017

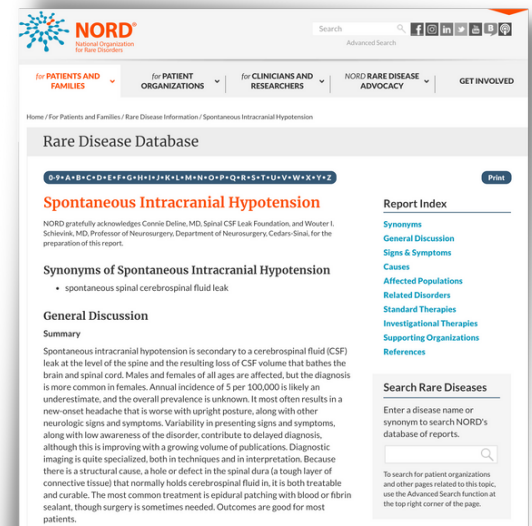
medical education

We support intracranial hypotension medical education with planning support, promotion, and/or educational grants. In 2021, for the fourth year in a row, we provided an educational grant to the annual Cedars-Sinai Intracranial Hypotension Symposium. The all-virtual symposium was held on October 2, 2021, in partnership with the Foundation. Medical professionals, patients, and laypeople were able to attend remotely, and video replays of the presentations have been added to our educational library.



rare disease database report

This summary, updated in 2020, was co-authored by Dr. Connie Deline and is an [excellent introduction to and overview of spontaneous intracranial hypotension](#).





our programs

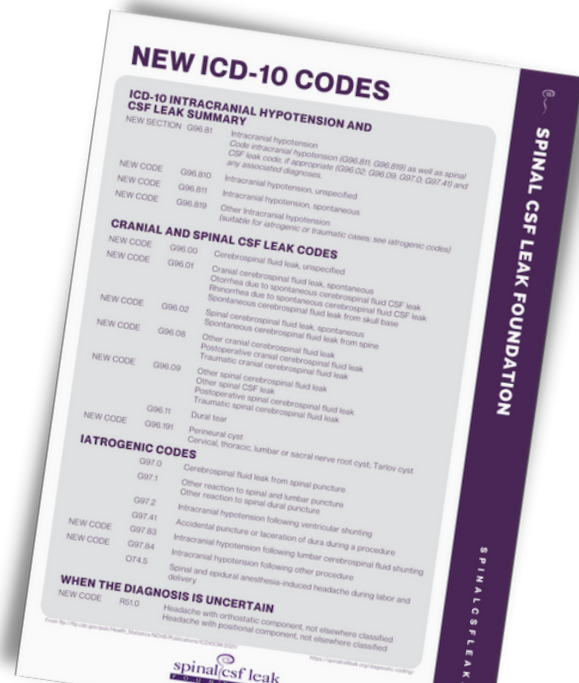
RESEARCH

spontaneous intracranial hypotensions guidelines project

This ambitious project was initiated by Dr. Connie Deline and Dr. Stephen Silberstein, under the umbrella of the American Headache Society, and is still ongoing. The panelists on this project represent several academic institutions and subspecialties including primary care, headache neurology, general neurology, neuroradiology, neuro-ophthalmology, anesthesiology, neurosurgery, and genetics. Dr. Wouter Schievink and Dr. Deborah Friedman co-chair while Dr. Connie Deline and Dr. Simy Parikh are the primary drivers and administrators of the project. The Foundation has been funding meeting expenses.

ICD-10 coding proposal

Thanks to sustained effort by the Spinal CSF Leak Foundation in collaboration with our medical advisory board and a team of key opinion leaders, the ICD-10 Coordination and Maintenance Committee approved proposed our new and revised codes related to intracranial hypotension and CSF leaks. These codes spearheaded by the Foundation were implemented on October 1, 2020, in the United States. This is critical for accuracy of medical records, insurance reimbursement of testing and treatments, disability benefits, and research. [A summary of these codes is available here.](#)



our programs

RESEARCH

research grants

To date, we have awarded six research grants. Several of our previously funded studies are nearing completion and/or publication. You can read about these Foundation-funded research updates [here](#).

In November 2021, as part of our GivingTuesday fundraising drive, we raised \$50,000 to fund a groundbreaking research project from Dr. Deborah Friedman on quality of life in spontaneous intracranial hypotension. In this study, Foundation medical advisory board member Dr. Friedman

hopes to create a validated, specific scale to quantify the level of disability experienced by people with spinal CSF leak. Dr. Friedman says that of all the disorders she evaluates and treats, spinal CSF leak is by far the most disabling.

“The observed impact of spinal CSF leak on our patients’ lives is substantial,” she says, noting that spinal CSF leak frequently produces loss of employment (with subsequent loss of health care coverage), generalized physical deconditioning, depression, or even divorce.

“Treatment is difficult and often unsuccessful, requiring multiple invasive procedures that may produce complete or incomplete relief, transient relief, or no

relief.” She also points out: “Even when successfully treated, there are often lingering manifestations, [including] anxiety about developing another leak, and the need to limit physical activities to avoid a recurrence. However, there are no studies investigating and documenting the impact of spinal CSF leak on quality of life in the medical literature.”

Funding Dr. Friedman’s study means that patients’ voices can finally be heard in terms of exactly how disabling this condition is. And ultimately, this information can be used to help speed treatment and further even more research.

“Of all the headache disorders I evaluate and treat, SIH is by far the most disabling.”

Deborah Friedman, MD, MPH
Professor, Neurology & Ophthalmology
UT Southwestern, Dallas, Texas



GIVING TUESDAY

Now more than ever
we are called to
make a difference.

#GivingTuesday | November 30, 2021



our programs

RESEARCH

patient advisory panel for research

Beginning June 2021, we invited applicants to apply to be part of our new Patient Advisory Panel for Research. A patient advisory panel for research is an effective means to formalize the vital role of patients in moving research forward. Inclusion of the patient voice in research is crucial, especially in the context of a rare disease, because no stakeholder can have the constant and relentless drive of the patient searching for cures. And no one other than the patient can better report the patient experience. Having patients and caregivers engaged in setting research priorities, ensuring the relevance of studies, choosing outcomes that matter to patients, developing study design, providing insights on recruitment of study participants, and translating results ensure that the patient experience is a central component of our research initiatives.

Over 80 patients applied to be on the panel, and in November 2021, we announced the 14 panelists who were chosen. Among them are patients who themselves are medical professionals; people who are caregivers; people with iatrogenic leaks, spontaneous leaks, and CSF-venous fistula; and people both living with and in recovery from spinal CSF leak.

To date, the Panel has met regularly to review current research interests and initiatives from our medical advisory board, and has signed a letter of support for a grant application for a study that would be the first clinical trial in spontaneous intracranial hypotension. Panelists have also represented the panel at working group meetings with our medical advisors as we work towards creating a research network and patient registry.

Patient Advisory Panel for Research

Introducing our panelists:

Isaac Brodsky
Kimberly Davey
Julia Denley
Stephanie Dowland
Jodi Ettenberg
Aiza Jose Fernandez
Salma Gharib
Asia Gibson
Julia Glace
Jen MacKenzie
Megan Kocher
Brooke William Ness
Claudia Perez Sandhu
Joyce Shoemaker

spinal/csf leak
FOUNDATION
because your dura matters®

our programs

RESEARCH

EDS comorbidity coalition

One board member participates in this ongoing collaboration between several organizations and stakeholders.

research network and patient registry

Our medical advisors are currently engaged in the process of laying the groundwork and evaluating platforms for a research network and patient registry. Our planned research network will identify and set research priorities; fund high-impact, patient-centered, multicenter research projects; and address best diagnostic practices and treatment algorithms for optimal patient outcomes to establish standards of care. To amplify the success of the research network, we will develop a patient registry—an important entity that currently does not exist for spinal CSF leak patients. Our newly formed Patient Advisory Panel for Research will be vital in ensuring the patient voice is front and center within the governance of the research network.

With a network of researchers performing multi-site studies, we will be able to accelerate not just our understanding of the disease but the development of therapies and treatments that will potentially provide a cure. Our patient registry will help us capture the true picture of what our patient population looks like, where they come from, the common traits they share, and help us understand the true scope of spinal CSF leak.

All of this will help us address the most persistent questions about spinal CSF leak, from diagnosis to treatment and beyond. And most importantly, it will help us make a profound, lasting, and measurable difference in patients' lives.



our programs

COMMUNITY SUPPORT & ADVOCACY

online support

Our online support community at Inspire has over 10,000 members. Inspire's robust privacy controls protect sensitive health information as people connect with one another and share their experiences.



We have a team of volunteers who act as community leaders, monitoring discussion, and participating and providing quality information as needed. This past year, our team of community leaders worked together to create a messaging library to help coordinate

responses and ensure that the information, links, and other helpful resources we share is accurate and up-to-date. We also formalized a process for attending to the needs of our community in a way that supports the community leaders who do such important, emotional work. With community-building plans in mind, we look forward to continuing to nurture and build a sense of togetherness within our community as it continues to grow.

email support

People reach out to us with questions or requests via email. Whether they are looking for physicians, specialists, or simply need to connect with someone, we respond to each email promptly—within a day in almost all cases. Currently, our Board Secretary is handling the majority of this correspondence, with occasional help from other Board Members and the Executive Director. In tandem with supporting our Inspire team of volunteers, we have developed a response database/messaging library to assist us in replying to these email requests.

our programs

COMMUNITY SUPPORT & ADVOCACY

other support

Spinal CSF leak can be a challenging, lonely experience. To help support our community, we created several mental health features and resources to address this.

During Mental Health Awareness Month, we asked Dr. Melissa Geraghty to share her presentation on coping with medical gaslighting. In her video, Dr. Geraghty discusses the all-too-common experience of gaslighting and shares concepts patients can use to both cope with and respond to it.



Suffering for any period of time with a spinal CSF leak is a distinctly unforgettable experience with remarkable psychological impact.

Jodi Blaszyk, PsyD
Spinal CSF leak patient and clinical psychologist

ADAPT: [Introduction](#) | [Acceptance](#) | [Diagnosis](#) | [Advocate & educate](#) | [Plan](#) | [Thrive](#)

We also invited Jodi Blaszyk, PsyD, a spinal CSF leak patient and clinical psychologist, to share a mental health concept she coined for support in living with spinal CSF leak called ADAPT. Her series of articles, each expounding on a different letter in the acronym, explores the grief and pain of coping with a spinal CSF leak—and also offers a path towards radical acceptance, compassion, and finding small moments in which to thrive. Here's what some readers had to say:

“Great appreciation for ADAPT series. As a newly diagnosed patient and clinical counsellor I am completely surprised by the magnitude of the emotional toll and how often it’s not included in the symptom list. Thank you for making transparent this very real part of the spinal CSF leak journey.”

“The conclusion of ADAPT series seriously spoke to me. I’m so glad something like this has been written. Giving voice to the often silent suffering that goes on, these type of resources are effective in helping people manage their experience better! I love it and I’m just grateful those words are there to articulate some of my experience.”

our programs

COMMUNITY SUPPORT & ADVOCACY

physician directory

We maintain an internal referral directory to assist those seeking care on a case-by-case basis.

We plan to make this resource public in the next fiscal year.

advocacy

We are members of Alliance for Headache Disorders Advocacy, National Organization for Rare Disorders, and Rare Foundation Alliance (Global Genes). These organizations are skilled at advocacy and provide opportunities to contribute our voices on a range of issues relevant to intracranial hypotension patients, such as insurance, disability coverage, and research funding.

This year we added our voice to NORD's efforts in a letter urging state governors to maintain or expand licensure flexibilities for care across state lines during the ongoing pandemic. And we sent several volunteers to Headache on the Hill, the annual advocacy event organized by the Alliance for Headache Disorders Advocacy. One of our attendees [shared her experience as a first-time advocate with us here](#).

We are currently in the process of establishing an Advocacy team to create curriculum, training, and resources for patients interested in advocacy. The goals of this are ultimately for patients to be viewed as equal partners in care and for patients to have the tools to advocate for their own care; for physicians to be educated through our advocacy work to recognize and diagnose the often complex but not necessarily rare symptoms of a spinal CSF leak with either the knowledge to treat or properly refer; and for all patients to be treated promptly, appropriately, with positive long-term outcomes.

2021-2022

FINANCIAL REPORT

For fiscal year ending June 30, 2022

Total Assets Beginning Fiscal Year	218,356
Total Revenue	215,464
Expenses	
Programs	111,449
Education	6,557
Research	58,968
Advocacy	2,475
Administrative	17,320
Fundraising	18,573
Total Expenses	147,342
Excess	68,122
Total Assets Year-End	286,478