

2019-2020

Annual Report

SPINAL CSF LEAK FOUNDATION

FISCAL YEAR JULY 1, 2019 TO JUNE 30, 2020



spinal csf leak

F O U N D A T I O N

because your dura matters®

Spinal CSF Leak Foundation
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Executive Summary

Spinal CSF Leak Foundation was established as a 501(c)3 non-profit organization in 2014 by individuals affected with intracranial hypotension or spinal cerebrospinal fluid (CSF) leaks. Our mission is to reduce the suffering of persons affected by intracranial hypotension or spinal cerebrospinal fluid leak. We strive to close gaps, to raise awareness, to educate both medical professionals and laypersons, and to stimulate and fund research 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.

All of our board members are affected by this disorder, and remain moderately to profoundly disabled. Connie Deline, the physician co-founder, chairs the medical advisory board comprised of a diverse group of physician experts. Teams include board members and volunteers, all affected by the disorder in some way and therefore invested in the mission.

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

Under the category of education and awareness, we target both laypersons and medical professionals. We have garnered a reputation as the leading voice for up-to-date and reliable information. 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 called “leakweek” effectively engages our patient community and beyond. We anticipate adding a webinar series and regular podcasts to our range of educational offerings.

In addition to funding research, we have engaged a diverse group of clinicians and researchers representing several subspecialties and academic institutions to develop guidelines for the diagnosis and treatment of spontaneous intracranial hypotension. We led a group of key opinion leaders through the process for the October 1, 2020, implementation of specific ICD-10 diagnostic codes for intracranial hypotension and CSF leaks, essential for both accuracy of medical records as well as insurance reimbursement for testing and treatments, and critical for research. With the engagement of clinicians, researchers, and patients, we are building the infrastructure for a collaborative research network to accelerate advances in this field and improve patient outcomes.

Executive Summary

High-quality compassionate informational and emotional support is essential for persons affected by intracranial hypotension or spinal CSF leak. By partnering with other organizations and networking with organizations representing related disorders, our advocacy efforts are more powerful and effective.

Our mission drives our specific activities within each program category. Over the next year and beyond, we will continue 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.

Organizational Profile

Spinal CSF Leak Foundation has 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 no paid staff and limited contract help, and is powered primarily by volunteers.

BOARD OF DIRECTORS

The current board of directors includes
Andrea J. Buchanan; Amanda J. Pickard, PhD;
and two members with significant disability who wish to remain anonymous.

MEDICAL ADVISORY BOARD

Timothy J. Amrhein, MD

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

Ian Carroll, MD, MS

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

Jeremy Cutsforth-Gregory, MD

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

Connie Deline, MD

Chair, Medical Advisory Board
Spinal CSF Leak Foundation
Camp Hill, PA

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

Organizational Profile

Deborah Friedman, MD, MPH

Professor of Neurology and Ophthalmology
Department of Neurology and
Neurotherapeutics
Founding Director of Headache and Facial
Pain Program
UT Southwestern Medical Center, Dallas, TX

Linda Gray Leithe, MD

Associate Professor
Division of Neuroradiology
Department of Radiology
Duke University Medical Center,
Durham, NC
Chair, Special Interest Group on CSF
Pressure Disorders, American Headache
Society

Peter G. Kranz, MD

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

Charles Louy, PhD, MD, MBA

Professor of Anesthesiology
Medical Director, Inpatient Pain Service
Associate Program Director, Pain
Management Fellowship
Department of Anesthesiology
Cedars-Sinai, Los Angeles, CA

M. Marcel Maya, MD

Co-chair, Department of Imaging
S. Mark Taper Foundation Imaging Center
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

Simy Parikh, MD

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

Jill Rau, MD, PhD

Neurologist- Headache Specialist
HonorHealth Neuroscience Institute,
Scottsdale, AZ

Wouter I. Schievink, MD

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

Stephen Silberstein, MD

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

About the Disorder

Spinal cerebrospinal fluid (CSF) leak is an important and underdiagnosed cause of new-onset headache that is treatable. 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 or tear, the cerebrospinal fluid (CSF) leaks out of this compartment. These defects can be small or large and 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 a number of symptoms, the most common symptom is an “upright headache,” that is, a headache that is worse after minutes to hours upright, improved when lying flat, or a headache that is less obviously positional but gets worse as the day goes on. Most of the time, this is mistaken as 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 can be life-threatening.

Spinal CSF leak is a diagnosis that tends to be missed when it occurs out of the blue, 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, it 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. Prognosis is generally good with the correct diagnosis and treatment, 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, about CSF dynamics, complications and long-term outcomes.

Mission, Vision, Values, and Goals

MISSION STATEMENT

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

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.

VALUES

- **Compassion.** Our compassion for affected individuals fuels our efforts.
- **Inclusiveness.** We honor and respect the diversity of our community.
- **Integrity.** Everything we do is with the utmost integrity.
- **Hopefulness.** We maintain hope for the future despite the challenges.

GOALS

- **Elevate awareness**
We seek to raise the level of awareness of intracranial hypotension or spinal CSF leak among laypersons and health professionals.
- **Educate**
We support and provide professional education on all clinical aspects of intracranial hypotension or spinal CSF leak.
- **Support**
We provide each person affected by intracranial hypotension or 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 intracranial hypotension or spinal CSF leak.

Programs

EDUCATION AND AWARENESS

WEBSITE AND SOCIAL MEDIA. We post frequent content on our website as well as on social media, including Facebook, Twitter, and Instagram. Our YouTube channel has a growing library of videos. We also update our subscribers via e-news.

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. <https://rarediseases.org/rare-diseases/spontaneous-intracranial-hypotension/>

MEDICAL EDUCATION. We support intracranial hypotension medical education with planning support, promotion, and/or educational grants. The third annual Cedars-Sinai Intracranial Hypotension Symposium was held on February 8, 2020, in partnership with the Foundation. Medical professionals, patients, and laypersons attended. Video replays were added to our educational library for those unable to attend in person, and we filmed physicians, patients, and caregivers for use in later educational videos. Planning is underway for the next Symposium in October 2021.

PATIENT STORIES. Our library of video and narrative format patient stories is growing with the efforts of the Patient Storytelling team formed in 2019. In February of 2020, we filmed five new patient stories, bringing our total number of stories to 13 video stories with accompanying narrative and ten narrative-only stories. Our goal is for the diversity of patient stories to reflect the broad range of affected individuals, clinical presentations, clinical courses, and outcomes.

EXPLAINER VIDEOS. We produced the animated “Upright Headache” video in 2017 which has now been viewed over 63,000 times. Additional explainer videos are being planned.

LEAKWEEK. Our 2020 #leakweek has been rescheduled for June 2021. We hope to replicate the success of our third annual #leakweek, which was held June 3-8, 2019, and featured six new patient stories, Ask the Expert sessions on Facebook LIVE, and our first annual #duradash virtual race encouraging patients and supporters to participate in activities suitable to their circumstances.

Programs

RESEARCH

SPONTANEOUS INTRACRANIAL HYPOTENSION GUIDELINES PROJECT. This ambitious project was initiated under the umbrella of the American Headache Society with a team gathered by our Medical Advisory Board. The panelists 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 the project. The Foundation has been funding meeting expenses.

ICD-10 CODING PROPOSAL. The Spinal CSF Leak Foundation medical advisory board organized a team of experts and key opinion leaders to review the current ICD-10 coding and submit a proposal for the addition of a specific code for spontaneous intracranial hypotension along with several related codes. The ICD-10 Coordination and Maintenance Committee approved the proposed new and revised codes related to intracranial hypotension and CSF leaks for implementation 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 at <https://spinalcsfleak.org/diagnostic-coding/>

RESEARCH GRANTS. Two research grants were awarded during the 2019–2020 fiscal year. To date we have awarded five research grants.

RESEARCH NETWORK. We have engaged our medical advisors in discussion regarding the formation of a research network and registry. Grant funding is being pursued to support the infrastructure for this project.

PATIENT REGISTRY PROJECT. We have been evaluating patient registry platforms and will lead the development of common data elements (CDEs) on spontaneous intracranial hypotension, which will be needed for a registry. This will require broad engagement across a number of subspecialties and institutions, staffing, and significant monetary resources.

EDS COMORBIDITY COALITION. Dr. Connie Deline and one board member participated in this ongoing collaboration between several organizations and stakeholders.

Programs

COMMUNITY SUPPORT AND ADVOCACY

ONLINE SUPPORT. Our online support community with Inspire has robust privacy controls to protect sensitive health information. We do not encourage the use of insecure platforms.

<https://www.inspire.com/groups/spinal-csf-leak/>

EMAIL SUPPORT. Responses to email queries occur within a day in almost all cases. Our capacity for telephone support is currently limited.

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

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. Headache on the Hill is an annual event held in February, organized by the Alliance for Headache Disorders Advocacy.

Financial Report

FOR FISCAL YEAR-END JUNE 30, 2020

| | |
|---------------------------------------|---------|
| Total Assets Beginning of Fiscal Year | 140,253 |
| Total Revenue | 135,408 |
| Expenses | |
| Programs | 93,839 |
| Education | 44,802 |
| Research | 46,363 |
| Advocacy | 2,674 |
| Administrative | 17,326 |
| Fundraising | 12,216 |
| Total Expenses | 123,381 |
| Excess | 12,027 |
| Total Assets Year-End | 152,280 |