2018-2019
Annual Report
SPINAL CSF LEAK FOUNDATION
FISCAL YEAR JULY 1, 2018 TO JUNE 30, 2019

Spinal CSF Leak Foundation
707 W. Main Ave. Suite B1 PMB103
Spokane WA 99201
spinalcsfleak.org
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Spinal CSF Leak Foundation was established as a 501(c)3 non-profit organization in 2014 by individuals affected with 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 with intracranial hypotension or spinal CSF leak will experience shorter diagnostic delays, receive more timely and appropriate testing and treatments, and have better outcomes.

Three of our board members are moderately to profoundly disabled by this disorder, one has recovered, while two have spouses with spontaneous intracranial hypotension (SIH). Connie Deline is the physician co-founder who chairs the medical advisory board composed of a diverse group of physician experts. Teams include board members and volunteers, all impacted 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. 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 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.

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 to propose specific ICD-10 diagnostic codes, essential for accuracy of medical records, insurance reimbursement for testing and treatments, as well as critical for research. With the engagement of clinicians, researchers, and patients, we are now well-positioned to develop a research network to accelerate advances in this field and improve patient outcomes.

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 / spinal CSF leak will experience shorter diagnostic delays, receive more timely and appropriate diagnostic testing and treatments, and have better outcomes.
Spinal CSF Leak Foundation was established as a 501(c)3 non-profit organization in 2014 by individuals affected with intracranial hypotension. We strive to close gaps, to raise awareness, to educate both medical professionals and lay persons, to stimulate and fund research such that persons affected with intracranial hypotension / spinal CSF leak will experience shorter diagnostic delays, receive more timely and appropriate diagnostic testing and treatments, and have better long-term outcomes.

**BOARD OF DIRECTORS**

Rich Alfieri  
Jayne Barsic, DPT  
Andrea Buchanan  
Connie Deline, MD  
   Vice-President and Secretary  
Michael Zetz, DDS  
   President and Treasurer  

One board member wishes 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**  
VP, Board of Directors  
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

MEDICAL ADVISORY BOARD, cont'd

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
Board of Directors, American Headache Society

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
Honor Health 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

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
Board of Directors, American Headache Society

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
**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 are associated 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 Statement

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

Goals

Education of general public: Raise the level of awareness of spinal CSF leaks, diagnostic challenges, and treatment options.

Education of health care professionals: support and provide professional education on all clinical aspects of spinal CSF leak.

Support those affected by spinal CSF leaks: Provide every person with a spinal CSF leak and their families/caregivers access to compassionate, high quality, and consistent informational and emotional support.

Empower the spinal CSF leak community: Position the Spinal CSF Leak Foundation as the leading voice and most trusted source of information about the condition. Inspire volunteer engagement.

Make research happen: Fund research and facilitate collaboration of researchers / NIH / institutions / industry to increase research on the epidemiology, causes, diagnostic testing, treatments and outcomes of spinal CSF leak.
Programs

EDUCATION AND AWARENESS

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

RARE DISEASE DATABASE REPORT. This summary was co-authored by Dr. Wouter Schievink and Dr. Connie Deline and is an excellent introduction 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 Second Annual Cedars-Sinai Intracranial Hypotension Symposium was held on October 13, 2018, 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. Dr. Connie Deline was on the planning committee for the standing-room-only half-day pre-conference held at the Scottsdale Headache Symposium held in November 2018. The Third Annual Cedars-Sinai Intracranial Hypotension Symposium, held in partnership with the Foundation, will be February 8, 2020.

PATIENT STORIES. Our library of video and narrative format patient stories is growing with the efforts of the Patient Storytelling team formed in 2019. Over time, the diversity of patient stories will 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 43,000 times. Additional explainer videos are being planned.

LEAKWEEK. Our third annual #leakweek was held June 3-8, 2019. Six new patient stories were released. The first annual #duradash virtual race engaged patients and supporters to participate in activities suitable to their circumstances. We hosted additional Ask-the-Expert sessions on Facebook LIVE which are available for replay.
Programs

RESEARCH

SPONTANEOUS INTRACRANIAL HYPOTENSION GUIDELINES PROJECT. This ambitious project was initiated by Dr. Connie Deline, Dr. Stephen Silberstein, and Dr. Wouter Schievink and is being done under the umbrella of the American Headache Society. 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 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. We gathered a group of Key Opinion Leaders to work on a proposal for the addition of a specific code for spontaneous intracranial hypotension along with related codes. This started in the spring of 2017. A proposal was presented to the ICD-10 Coordination and Maintenance Committee on March 6, 2019. A decision on this proposal is pending. This is critical for accuracy of medical records, insurance reimbursement of testing and treatments, disability benefits and research. If approved, we will provide a summary to health professionals on implementation of coding.

RESEARCH GRANTS. Three research grants were awarded in 2018. A Request for Proposals was posted on June 8, 2019 for the cycle of grants to be awarded during the 2019-2020 fiscal year.

RESEARCH NETWORK. We have engaged our medical advisors in discussion regarding the formation of a research network and anticipate the successful recruitment of most panelists on the guidelines project and others involved in treating patients. 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 as well as significant monetary resources.

EDS COMORBIDITY COALITION. Connie Deline, MD, and another board member are participating in this ongoing collaboration between several organizations and stakeholders.
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, 2019**

<table>
<thead>
<tr>
<th>Description</th>
<th>Amount</th>
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<tr>
<td>Total Assets Beginning of Fiscal Year</td>
<td>96,888</td>
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<td>Total Revenue</td>
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<td>Expenses</td>
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<td>Programs</td>
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<td>Research</td>
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<td>Total Expenses</td>
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<td>Excess</td>
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<td>Total Assets Fiscal Year-end</td>
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