spinal csf leak FOUNDATION

because your dura maters®

OUR PROGRAMS

EDUCATION AND AWARENESS

website and social media

Our website is recognized as the single most reliable source of information on intracranial hypotension, from symptoms, diagnostic and treatment information, to selected publication links, to our video library.

rare disease database report

This NORD Rare Disease Database report, co-authored by Dr. Connie Deline, is an overview suitable for newly diagnosed patients. https://rarediseases.org/rare-diseases/spontaneous-intracranial-hypotension/

medical education

We support intracranial hypotension medical education with planning support and educational grants. The upcoming 2023 Intracranial Hypotension Conference will be held on July 8-9. Video replays from all previous conferences are available on our website.

patient stories

We have a growing library of stories in video and narrative format. Our goal is for the diversity of these stories to reflect the broad range of affected individuals, clinical presentations, clinical courses, and outcomes.

explainer videos

Our animated “Upright Headache” video, produced in 2017, has now been viewed over 100,000 times.

duradash® and leakweek

This year, our annual awareness week will take place June 1-10, 2023, alongside duradash®, a virtual activity challenge from May 28 through June 10 that encourages patients and supporters to participate in activities suitable to their circumstances.

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OUR PROGRAMS

RESEARCH / ADVOCACY

spontaneous intracranial hypotension guidelines project

Initiated under the umbrella of the American Headache Society with a team gathered by our Medical Advisory Board, 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. The systematic literature reviews will facilitate the prioritization of collaborative research efforts.

research network and registry

Our Medical Advisory Board is actively working on the formation of a collaborative research network to accelerate research in this field. A shared registry will complement these efforts.

research grants

To date, we have awarded six research grants. You can find out more about the research we fund by visiting our website.

icd-10 codes

The Spinal CSF Leak Foundation Medical Advisory Board organized a team of experts and to propose specific new and revised codes for spontaneous intracranial hypotension. The ICD-10 Coordination and Maintenance Committee approved these codes for implementation on October 1, 2020, in the United States. A summary of these codes is available at https://spinalcsfleak.org/diagnostic-coding/

community support and advocacy

We network with other organizations representing related disorders to provide high-quality information and emotional support. We partner with Inspire for our online support community, and this year, five advocates from the Foundation attended Headache on the Hill, an annual advocacy event in Washington DC organized by the Alliance for Headache Disorders Advocacy (AHDA).