ABOUT SPINAL CSF LEAK FOUNDATION

HISTORY
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) leak. We strive to close information 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.

OUR MISSION
Our mission is to reduce the suffering of persons affected by intracranial hypotension or spinal CSF leak.

OUR PROGRAMS

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 effectively engages our patient community and beyond.

Research
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 of successfully establishing specific ICD-10 diagnostic codes, 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.

Community Support and Advocacy
High-quality compassionate informational and emotional support is essential for persons affected by intracranial hypotension or spinal CSF leak. We partner and network with other organizations representing related disorders to make our advocacy efforts even more effective.