About the Spinal CSF Leak Foundation

spinal csf leak FOUNDATION
because your dura maters®

HISTORY

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, a rare and often misdiagnosed condition that, according to published estimates, affects 5 per 100,000 people per year. Our mission is to reduce the suffering of persons affected by intracranial hypotension or spinal CSF leak, and we do this through education and awareness-raising, community support and advocacy, and the funding of research.

OUR MISSION

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OUR PROGRAMS

Education and Awareness

We want to make sure everyone has accurate and reliable information about spinal CSF leak, and we share that information via our website and social media platforms. We organize and support events where doctors, patients, and caregivers can learn from each other. We also use stories and videos—from people sharing their personal experiences, to doctors presenting at medical conferences—to help people understand the condition. We have an annual awareness week each June, along with a virtual activity challenge, which is a fantastic opportunity for our community be engaged in not only supporting one another but educating others about what it means to live with spinal CSF leak.

Research

We provide research grants to studies that advance understanding of the field, so that we can improve treatments and help more people. Our multidisciplinary medical advisory board comprises experts who are actively involved in educational and research activities. We helped created relevant ICD-10 codes to accurately classify spontaneous intracranial hypotension (SIH) caused by spinal CSF leak, thus enabling comprehensive research, critical epidemiological studies, and improved patient care. Our latest efforts include creating a patient advisory panel for research and putting together an international multidisciplinary team to develop much-needed diagnostic and treatment guidelines.

Community Support and Advocacy

We recognize that spinal CSF leak can significantly impact the well-being of individuals and their families. Hence, we prioritize offering high-quality, empathetic, and informative support to those affected by this disorder, whether through email correspondence or through the work we do in our support community on Inspire. We also collaborate with other organizations focused on related disorders to enhance our advocacy efforts.