why do we need your help?

- Greater awareness and education is needed to improve familiarity of intracranial hypotension and spinal CSF leak among health care professionals and the general public. This will help to shorten delays to diagnosis and treatment.

- The full range of specialized diagnostic imaging is not available in all centers and even in expert hands may still fail to identify a leak.

- While a cure is possible, many patients suffer for years despite currently available treatments.

- More research is needed to advance our understanding of all aspects of the disorder and to improve testing and treatments.

how can you help?

Get Involved
spinalcsfleak.org/get-involved

Volunteer
volunteer@spinalcsfleak.org

Donate
spinalcsfleak.org/donate

Fundraise
spinalcsfleak.org/get-involved/fundraise

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a patient’s guide to SPONTANEOUS INTRACRANIAL HYPOTENSION due to SPINAL CSF LEAK

who we are

Spinal CSF Leak Foundation is a 501(c)(3) non-profit health advocacy organization. Our mission is to reduce the suffering of persons affected by intracranial hypotension or spinal CSF leak.
**what causes spinal CSF leak?**

**Medical Procedures**
- Lumbar puncture (spinal tap)
- Epidural injection (spinal injection)
- Spinal or other surgery

**Injuries**
- Fall
- Motor vehicle accident

**Spontaneous**
There are several types of spontaneous spinal CSF leaks:
- Dural tears can be caused by spinal bone spur or calcified disc.
- Meningeal diverticula are often associated with abnormally thin or weak dura, as may be seen with a number of genetic connective tissue disorders, such as Marfan syndrome or Ehlers-Danlos syndrome.
- CSF-venous fistula is an abnormal connection between the normal CSF space and veins outside the dura mater. Why these develop is not yet understood.

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**what is a spinal CSF leak?**

Spinal cerebrospinal fluid (CSF) leak is an important and under-diagnosed cause of new onset headache that is treatable. Cerebrospinal fluid (CSF) bathes and supports the brain and spinal cord. When the connective tissue known as dura mater that holds CSF in around the spinal cord has a hole or tear, the result is a loss of CSF volume, known as intracranial hypotension.

The most common symptom is a positional headache that is worse after minutes to hours upright and improved when lying down, but there are many other neurologic signs and symptoms. Headache severity varies enormously from mild to severe and may not correlate well with findings on imaging. Patients may be quite disabled by their inability to be functional while upright. Recognition of the headache pattern and other symptoms is important in leading physicians to suspect the diagnosis of intracranial hypotension.

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**how is a spinal CSF leak diagnosed?**

**Symptoms**
The diagnosis is suspected on the basis of the patient’s symptoms.

**Brain imaging**
MRI of the head without and with contrast should be performed in most cases. There are several typical findings seen in about 80% of cases although normal imaging does not rule out the diagnosis.

**Spinal imaging**
Specialized spinal imaging is used to locate the CSF leak. MRI, CT and digital subtraction imaging are used.

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**how is a spinal CSF leak treated?**

**Initial treatment**
Bedrest, fluids and extra caffeine may allow some cases to resolve without any further treatment.

**Spinal Injection Procedures**
For those that require treatment, a type of spinal injection procedure called epidural patching is commonly performed. This can be repeated a number of times.

**Surgery**
Some patients require surgical repair by a neurosurgeon. A few patients will require a number of procedures.