



# Patient Advisory Panel for Research on Intracranial Hypotension for Spinal CSF Leak Foundation

## Role Description

### TITLE

Patient Representative – Patient Advisory Panel for Research on Intracranial Hypotension

### SUMMARY

Each patient panel member will participate in regular meetings to add their perspective to research initiatives on the topic of intracranial hypotension. The panel member should be an individual affected by intracranial hypotension as a patient, family member or caregiver who can provide critical and constructive feedback to the Medical Advisory Board of Spinal CSF Leak Foundation, the Board of Directors, and/or to the Steering Committee for the Intracranial Hypotension Research Network as requested. Principal investigators of studies may request input from the panel on study design as well.

### TIME COMMITMENT

In addition to online orientation and training sessions, there will be at least two meetings per year, and up to four meetings per year, held by web-conference. Preparation for meetings will include review of documentation for several hours before each meeting. Additional time may be needed to respond to online surveys for study input between meetings.

### TERM

The term of the appointment is two years, with eligibility for reappointment.

### HONORARIA & EXPENSES

This is a volunteer role; there is no honorarium for panel members. While travel for in-person meetings is not anticipated, travel and hotel expenses will be reimbursed when appropriate according to the policies of Spinal CSF Leak Foundation.



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## SKILLS & EXPERIENCE

Patient advisory panel members should:

- have experience of intracranial hypotension either as a patient, caregiver, or relative
- have basic familiarity with medical terminology associated with spinal CSF leak
- have a basic understanding or knowledge of the research process and interest in learning more
- be able to provide critical and constructive feedback
- have good analytical and networking skills
- have confidence to voice your own opinions clearly and participate in group discussion
- be willing to listen and respect differing opinions
- have an awareness of equality and diversity
- be able to meet the time commitment

## ROLES

- Attend online orientation and training sessions in addition to working meetings.
- Prepare for web-conference meetings by reviewing any materials in advance.
- Be available to complete online surveys on short notice as needed.
- Share your perspectives on research priorities where appropriate.
- Ensure that discussions consider how the work fits with our research strategy and objectives to help drive patient benefit.
- Review and evaluate research proposals as requested.
- Provide feedback on study design.
- Provide feedback on ongoing research studies where appropriate.
- Respect the viewpoints of others in the group.
- Identify opportunities for wider patient involvement in research studies.

## HOW TO APPLY

- Go to <https://spinalcsfleak.org/patient-advisory-panel> to complete the online application by July 1, 2021 at 5 pm ET.
- You will be notified of shortlisting outcome on or before August 2, 2021.
- Interviews will take place until September 30, 2021.
- Notification shall occur on or before November 1, 2021.
- The panel members will start to receive communications starting in the fall of 2021.