

NATIONAL INSTITUTE FOR HEALTH AND CARE EXCELLENCE

Interventional procedures

Patient Organisation Submission

IP1996 Transvenous embolisation for treating cerebrospinal fluid venous fistula associated with spontaneous intracranial hypotension

Thank you for agreeing to give us your views on this procedure or operation and how it could be used in the NHS.

When we are developing interventional procedures guidance we are looking at how well a procedure or operation works and how safe it is for patients to have.

Patient and carer organisations can provide a unique perspective on conditions and their treatment that is not typically available from other sources. We are interested in hearing about:

- the experience of having the condition or caring for someone with the condition
- the experience of having the procedure or operation
- the outcomes of the procedure or operation that are important to patients or carers (which might differ from those measured in clinical studies, and including health-related quality of life)
- the impact of the procedure or operation on patients and carers. (What are the benefits to patients and their families, how does it affect quality of life, and what are the side effects after the procedure or operation.)
- the expectations about the risks and benefits of the procedure or operation.

To help you give your views, we have provided this template, and ask if you would like to attend as a patient expert at the bottom of the form. You do not have to answer every question – they are there as prompts. The text boxes will expand as you type, the length of your response should not normally exceed 10 pages.

Please note, all submissions will be published on the NICE website alongside all evidence the committee reviewed. Identifiable information will be redacted.

About you	
1. Your name	Bernadette Hard
2. Name of organisation	The CFS Leak Association
3. Job title or position	Trustee
4. Brief description of the organisation (e.g. who funds the organisation? How many members does the organisation have?)	<p>We are a charity funded through donations and membership. We have 171 members.</p> <p>Our core aims are to raise awareness of CSF leaks and support those affected to secure accurate diagnosis and evidence based treatment</p>
<p>5. How did you gather the information about the experiences of patients and carers to help your submission?</p> <p>Information was gathered from direct experience of members, of both SIH and specifically TVE to treat CSF- Venus fistula.</p> <p>Published research studies were also taken into account in both SIH and the specific intervention to be considered</p>	

Living with the condition

6. What is it like to live with the condition or what do carers experience when caring for someone with the condition?

Living with a cerebrospinal fluid (CSF) leak is profoundly disabling. The condition causes constant, debilitating headaches that worsen when upright, alongside dizziness, visual and hearing problems, cognitive impairment, and overwhelming fatigue. Many patients are unable to work, drive, or carry out basic daily activities, leaving them isolated and dependent on others for support. Because CSF leaks are poorly recognised and often misdiagnosed, patients can spend years seeking answers, enduring both the physical toll of untreated symptoms and the psychological strain of not being believed. The impact reaches far beyond health — it affects identity, independence, employment, and family life.

this place a heavy burden on families and carers. Loved ones often take on roles as full-time carers, managing daily tasks, providing emotional support, and coping with the frustration of limited treatment options. This can lead to financial strain, social isolation, and significant emotional stress, as carers witness the person they support living with relentless, life-limiting symptoms.

Advantages of the procedure or operation

7. What do patients (or carers) think the advantages of the procedure or operation are? Why do you consider it to be innovative?

Although numbers are small, some patients have experienced immediate and complete resolution of symptoms of SIH following TVE

8. Does this procedure have the potential to change the current pathway or patient outcomes? Could it lead, for example, to improved outcomes, fewer hospital visits or less invasive treatment?

Yes. The alternative is invasive spinal neurosurgery, which has higher risk of complications, longer stay in hospital and higher procedural risks associated

Disadvantages of the procedure or operation

9. What do patients (or carers) think the disadvantages of the procedure or operation are?

I am not aware of specific disadvantages compared with the alternatives which are continued SIH or invasive spinal neurosurgery

Patient population
<p>10. Are there any groups of patients who might benefit either more or less from the procedure or operation than others? If so, please describe them and explain why.</p> <p>This is a very specific procedure for patients who's SIH is related to a CSF to venous fistula</p>
Safety and efficacy
<p>11. What are the uncertainties about how well this procedure works and how safe it is?</p> <p>The evidence base is limited and comes from case series, but early results suggest it to be safer than surgery, and possibly more efficacious</p>
Equality
<p>10. Are there any potential equality issues that should be taken into account when considering this topic?</p> <p>I am not aware that access to TVE is discriminatory based on protected characteristics, however more broadly there is a significant gap in access to expert care based on where patients live.</p>
Other issues
<p>11. Are there any other issues that you would like the Committee to consider?</p> <p>We value any investigation into an evidence-based treatment for SIH. Specifically in relation to TVE, a challenge will be access to MDT's for diagnostic evaluation, and availability of practitioners who are highly skilled in the procedure</p>
Key messages

12. In no more than 5 bullet points, please summarise the key messages of your submission.

1. SIH is an under recognised, under treated and highly disability condition
2. Patients need access to evaluation by a specialist CSF leak MDT
3. HCP's need access to high quality training in the diagnosis and treatment of this condition
4. The UK would benefit from a database of patients with SIH to allow the collection and evaluation of good quality outcome data
5. We welcome the availability of effective and minimally invasive treatments for SIH where appropriate

Committee meeting

13. Would you be willing to attend the interventional procedures committee meeting to provide the view from your organisation in person?

Yes

Thank you for your time.

Please return your completed submission to helen.crosbie@nice.org.uk and ip@nice.org.uk.