

## Become a member of IIH UK today!

Being a member of IIH UK not only shows your support but also provides other benefits too! IIH UK is solely funded by fundraising, donations and membership fees and with fees starting at just £5 per year, your membership really does make a difference. Visit the IIH UK website for details.



IIH UK is funding IIH research! We are working with our Patron, Dr Alexandra Sinclair, and her team of clinicians in Birmingham who are undertaking clinical trials. Trial information and research updates can be found on the IIH UK website.



Newly diagnosed with IIH? Ask your Neurologist about the IIH Life research database which is being rolled out to all Neurological hospitals.

This leaflet is provided to assist IIH sufferers and those who care for them to understand their condition, and not to offer medical advice. Always consult your doctor regarding treatment and medical advice.

## Visit our website today! [www.iih.org.uk](http://www.iih.org.uk)

Record your IIH medication and shunt details on a FREE handy Medical Condition Card.



Sign up for our website newsletter to receive information about social gatherings, fundraising activity and the progress of IIH UK.

Our website features links to the:

**International IIH Support Forum**  
**IIH Support UK Facebook group**  
**Weight Loss Support Group**

Visit our online shop for IIH Awareness merchandise, clothing and more!

Read and download medically verified leaflets about IIH for friends and family, IIH symptoms, treatments and much more.

Why not visit our fundraising page for ideas and organize your own fundraiser?

Join an IIH UK Social group in your area through Facebook and meet other people with IIH.



(Previously known as Pseudotumor Cerebri or Benign Intracranial Hypertension)

## WORKING TO RELIEVE THE PRESSURE!

Have you been diagnosed with IIH or care for someone who has? At IIH UK, we understand how overwhelming this can be.

We can help by offering:

- Contact with other sufferers
- Information
- Advice
- Support

**Registered Charity:**  
**England and Wales - 1143522**  
**Scotland - SCO43294**

[www.iih.org.uk](http://www.iih.org.uk)  
[www.iihsupport.org](http://www.iihsupport.org)  
[www.facebook.com/IIHUKCharity](https://www.facebook.com/IIHUKCharity)

## What is Idiopathic Intracranial Hypertension?

Idiopathic Intracranial Hypertension (IIH) is a rare neurological condition; idiopathic means it is of unknown cause, intracranial means within the skull and hypertension means there is too much fluid pressure.

The space surrounding the brain is filled with a water-like fluid called Cerebrospinal Fluid (or CSF) which is produced by the brain to 'clean' and protect it. If, due to a variety of factors, the fluid pressure around the brain rises and cannot drain or be absorbed back into the bloodstream properly, the excessively high pressure produces the symptoms of IIH.

Main symptoms of IIH include:

- severe debilitating headaches
- pulsatile tinnitus (whooshing sound in time with your pulse in one or both ears)
- papilloedema (swelling of the optic disc) **(but not in all cases)**
- nausea and vomiting
- fatigue and memory loss
- problems with balance
- confusion
- blurred vision or black or white out of vision
- seeing flashing lights, colours or 'floating' spots
- double vision, fogging of vision
- a lack of depth perception

**Other neurological and visual symptoms are also experienced by sufferers.**

## Treatments available for IIH

**Medication** - Acetazolamide also known as Diamox®. Furosemide and Topiramate are also used to treat the symptoms of IIH and may reduce the effects of papilloedema (swollen optic discs). When starting any of the above medication, you may have blood tests to ensure that your body is tolerating it well.

**Weight Loss** – Statistically, the majority of patients diagnosed with IIH are overweight. If you are overweight, losing weight has been shown to reduce papilloedema and reduce headaches. Evidence has shown that weight loss can put IIH into remission and, for some people, effectively cure IIH symptoms. We know this is hard and we can help.

**Surgical Options** – A Lumbar Peritoneal (LP) shunt is inserted into the spine and drains into the abdominal cavity. Some of these shunts have an adjustable valve or anti-syphon device attached to prevent over drainage. Alternatively, a Ventricular Peritoneal (VP) shunt is inserted into a ventricle of the brain and drains into the abdominal cavity; it always has a valve. Venous Sinus Stenting can be used if stenosis of the Venous Sinus is evident. Shunts can be necessary to save sight, but unfortunately in the long-term, they often fail.

For more detailed information on medical and surgical treatments offered by your hospital, please speak to your Consultant or GP.

## Living with a diagnosis of IIH

A diagnosis of IIH can come as a shock to both the person diagnosed with the condition and to those who care for them. For some people it can be a life changing condition whilst, for others, medication and, if recommended, weight loss can cause IIH to go into remission or cure.

Some people recover spontaneously after their first lumbar puncture. Some manage well with medical and/or surgical treatments whilst some may go on to suffer chronically even if they have treatments; this can be extremely debilitating for the individual concerned.

IIH is invisible from the outside. It is hard for those watching on to understand what a person with IIH is feeling or experiencing. For those suffering, it is frustrating having to explain how they are feeling as they often look 'well'. Caring for someone with IIH can be demanding and carers will need support as well as those with IIH.

Our International IIH Support Forum is designed for those with IIH and for all who care for them. Run by non-medically qualified volunteer IIH patients and carers, it is a place to exchange experiences, hints and tips on coping with symptoms and to obtain support from those who know what you are going through. Please refer to [www.iihsupport.org](http://www.iihsupport.org)