IIHUK

Idiopathic Intracranial Hypertension

Wednesday 10th July 2025

Amanda Denton

IIH UK Trustee and Research Representative

IIHUK
Idiopathic Intracranial Hypertension

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IIH UK Patron

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IIH UK Trustee
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IIH UK Trustee
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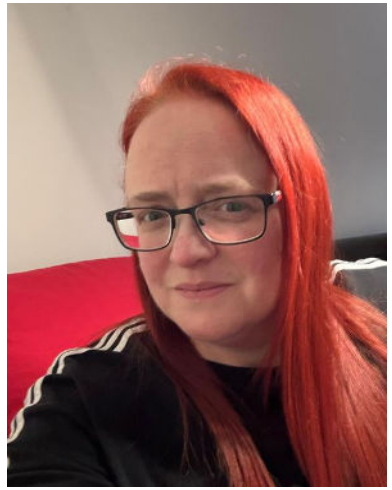

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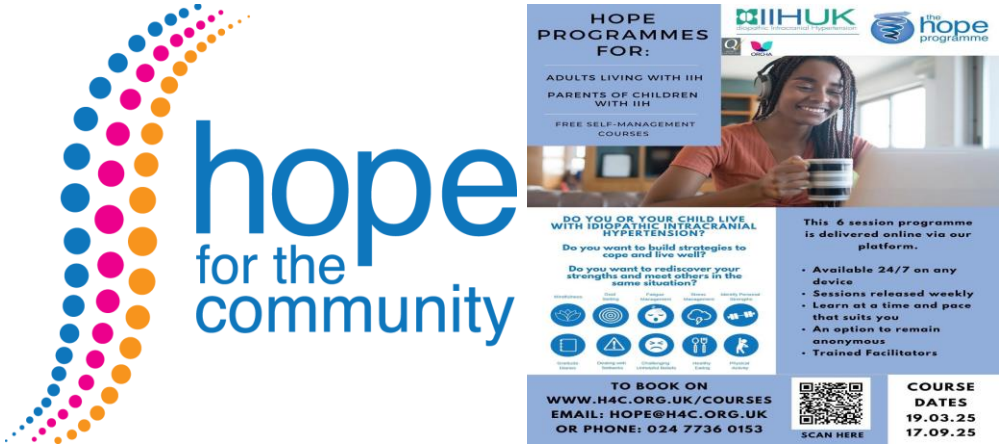
IIHUK
Idiopathic Intracranial Hypertension

IIH UK OBJECTIVES:

- To provide the best possible **support and advice** for people with Idiopathic Intracranial Hypertension and their families
- To **advance the education** of the public in general, people with IIH and the medical community in particular on the subject of IIH
- To **promote and support research** for the public benefit on all aspects of the condition IIH and to publish the useful results
- To **raise the profile of the charity IIH UK**.

Objectives: Support and Advice, Education www.iih.org.uk

Downloadable leaflets:
Leaflets | IIH UK - (Idiopathic intracranial hypertension)



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Idiopathic Intracranial Hypertension

Objective: Research

IDIOPATHIC INTRACRANIAL HYPERTENSION PRIORITY SETTING PARTNERSHIP

Top 10 Priorities for IIH Research

1 ADDRESSING THE CAUSES, SYMPTOMS AND PROGRESSION
In the individual with IIH; what causes the disease, the symptoms and the progression of the disease?

2 BIOLOGICAL MECHANISMS OF HEADACHE
What are the biological mechanisms of headache in IIH and why in some do headaches continue even after papilloedema has resolved?

3 SAFE TREATMENTS
Can new therapies for IIH be developed which are effective, safe, and tolerable and potentially help with weight loss as well as reducing brain pressure?

4 PREDICTING VISUAL LOSS
What is the biological explanation for the differences between rapid visual loss compared with gradual visual loss in IIH and how can this be predicted?

5 MONITORING VISUAL FUNCTION
What are the best ways to monitor visual function?

6 IIH BIOMARKERS
Can IIH biomarkers (tests in body fluids for example urine, saliva, blood, or brain scans) help diagnosis, predict the risk and guide therapy decisions in IIH?

7 HORMONES
What are the hormonal causes for IIH and why is IIH primarily associated with female sex?

8 SAFE AND EFFECTIVE MEDICATIONS
What medications are effective and safe to treat IIH headaches?

9 WEIGHT LOSS
With regard to weight loss in IIH: how much is needed to treat IIH and how quickly does it work? What is the best, safest and most acceptable method to achieve this in the short and long term? Additionally, does the initial Body Mass Index (BMI) of the patient have an effect?

10 BEST TYPE OF INTERVENTION
Which is the best type of intervention to treat IIH and when should surgery be performed?

IIHUK Idiopathic Intracranial Hypertension · James Lind Alliance Priority Setting Partnerships · IIH Patients and Professionals Setting Research Priorities

General neurology

OPEN ACCESS

REVIEW

Idiopathic intracranial hypertension: consensus guidelines on management

Susan P Mollan,[1,2] Brendan Davies,[3] Nick C Silver,[4] Simon Shaw,[5] Conor L Mallucci,[6,7] Benjamin R Wakerley,[8,9] Anita Krishnan,[4] Swarupsinh V Chavda,[10] Satheesh Ramalingam,[10] Julie Edwards,[11,12] Krystal Hemmings,[13] Michelle Williamson,[13] Michael A Burdon,[2] Ghaniah Hassan-Smith,[1,12] Kathleen Digre,[14] Grant T Liu,[15] Rigmor Højland Jensen,[16] Alexandra J Sinclair[1,2,12,17]

► Additional material is published online only. To view please visit the journal online (http://dx.doi.org/10.1136/jnnp-2017-317440).

For numbered affiliations see end of article.

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ABSTRACT
The aim was to capture interdisciplinary expertise from a large group of clinicians, reflecting practice from across the UK and further, to inform subsequent development of a national consensus guidance for optimal management of idiopathic intracranial hypertension (IIH).
Methods Between September 2015 and October 2017, a specialist interest group including neurology, neurosurgery, neuroradiology, ophthalmology, nursing, primary care doctors and patient representatives met. An initial UK survey of attitudes and practice in IIH was sent to a wide group of physicians and surgeons who investigate and manage IIH regularly. A comprehensive systematic literature review was performed to assemble the foundations of the statements. An international panel along with four national professional bodies, namely the Association of British Neurologists, British Association for the Study of Headache, the Society of British Neurological Surgeons and the Royal College of Ophthalmologists critically reviewed the statements.
Results Over 20 questions were constructed: one based on the diagnostic principles for optimal investigation contains information that will be of interest to those in primary care and other healthcare professionals.

The increasing economic burden of IIH has been highlighted by a number of groups.[1 2] Clear guidance will help educate the attending doctors to manage these patients appropriately. This will help reduce the repeat unsolicited emergency hospital attendances and reduce IIH-related disability. There are a number of ongoing clinical trials in IIH (https://www.clinicaltrials.gov/) and as evidence for medical and surgical management evolves in IIH this document will require timely updates.

BACKGROUND
IIH occurs predominantly in women and although the underlying pathogenesis is not fully understood, it has a striking association with obesity.[1] The combination of raised intracranial pressure, without hydrocephalus or mass lesion, normal cerebrospinal fluid (CSF) composition and where no underlying aetiology is found are accepted criteria for the diagnosis of IIH.[4] The overall age-adjusted

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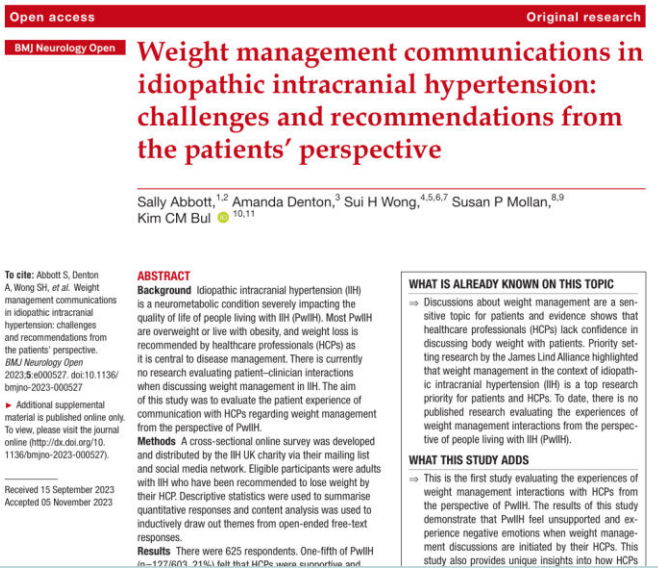
Open access Original research

BMJ Neurology Open

Weight management communications in idiopathic intracranial hypertension: challenges and recommendations from the patients' perspective

Sally Abbott,[1,2] Amanda Denton,[3] Sui H Wong,[4,5,6,7] Susan P Mollan,[8,9] Kim CM Bul [10,11]

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ABSTRACT
Background Idiopathic intracranial hypertension (IIH) is a neurometabolic condition severely impacting the quality of life of people living with IIH (PwIIH). Most PwIIH are overweight or live with obesity, and weight loss is recommended by healthcare professionals (HCPs) as it is central to disease management. There is currently no research evaluating patient–clinician interactions when discussing weight management in IIH. The aim of this study was to evaluate the patient experience of communication with HCPs regarding weight management from the perspective of PwIIH.
Methods A cross-sectional online survey was developed and distributed by the IIH UK charity via their mailing list and social media network. Eligible participants were adults with IIH who have been recommended to lose weight by their HCP. Descriptive statistics were used to summarise quantitative responses and content analysis was used to inductively draw out themes from open-ended free-text responses.
Results There were 625 respondents. One-fifth of PwIIH (n=127/603, 21%) felt that HCPs were supportive and

WHAT IS ALREADY KNOWN ON THIS TOPIC
⇒ Discussions about weight management are a sensitive topic for patients and evidence shows that healthcare professionals (HCPs) lack confidence in discussing body weight with patients. Priority setting research by the James Lind Alliance highlighted that weight management in the context of idiopathic intracranial hypertension (IIH) is a top research priority for patients and HCPs. To date, there is no published research evaluating the experiences of weight management interactions from the perspective of people living with IIH (PwIIH).

WHAT THIS STUDY ADDS
⇒ This is the first study evaluating the experiences of weight management interactions with HCPs from the perspective of PwIIH. The results of this study demonstrate that PwIIH feel unsupported and experience negative emotions when weight management discussions are initiated by their HCPs. This study also provides unique insights into how HCPs

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Objectives: Support, Advice, Education, Research and Profile

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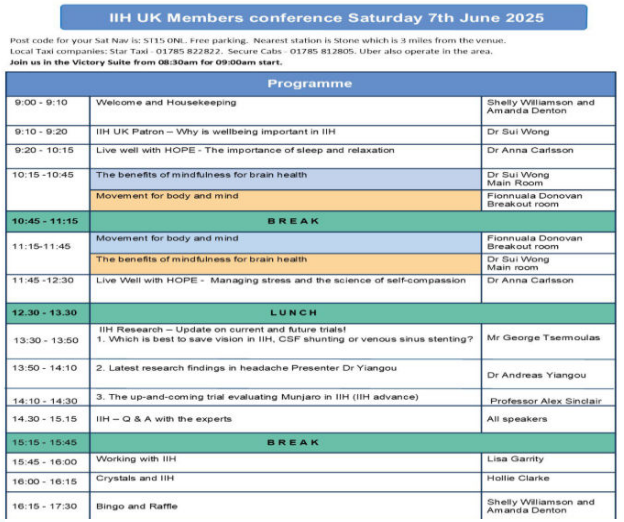
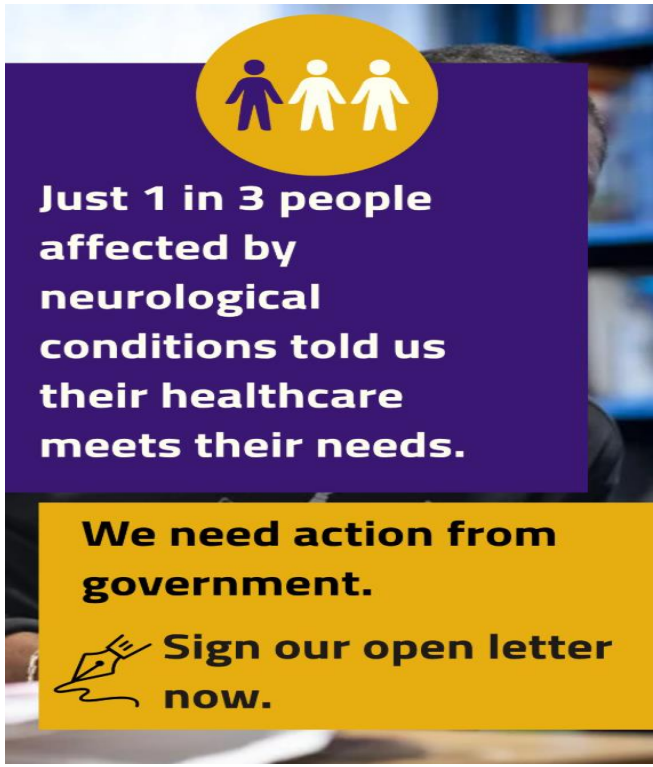


IIH UK Members conference Saturday 7th June 2025

Post code for your Sat Nav is: ST15 0NL. Free parking. Nearest station is Stone which is 3 miles from the venue.
Local Taxi companies: Star Taxi - 01785 822822. Secure Cabs - 01785 812805. Uber also operate in the area.
Join us in the Victory Suite from 08:30am for 09:00am start.

Programme		
9:00 - 9:10	Welcome and Housekeeping	Shelly Williamson and Amanda Denton
9:10 - 9:20	IIH UK Patron – Why is wellbeing important in IIH	Dr Sui Wong
9:20 - 10:15	Live well with HOPE - The importance of sleep and relaxation	Dr Anna Carlsson
10:15 -10:45	The benefits of mindfulness for brain health	Dr Sui Wong Main Room
	Movement for body and mind	Fionnuala Donovan Breakout room
10:45 - 11:15	BREAK	
11:15-11:45	Movement for body and mind	Fionnuala Donovan Breakout room
	The benefits of mindfulness for brain health	Dr Sui Wong Main room
11:45 -12:30	Live Well with HOPE - Managing stress and the science of self-compassion	Dr Anna Carlsson
12.30 - 13.30	LUNCH	
13:30 - 13:50	IIH Research – Update on current and future trials! 1. Which is best to save vision in IIH, CSF shunting or venous sinus stenting?	Mr George Tsermoulas
13:50 - 14:10	2. Latest research findings in headache Presenter Dr Yiangou	Dr Andreas Yiangou
14:10 - 14:30	3. The up-and-coming trial evaluating Munjaro in IIH (IIH advance)	Professor Alex Sinclair
14.30 - 15.15	IIH – Q & A with the experts	All speakers
15:15 - 15:45	BREAK	
15:45 - 16:00	Working with IIH	Lisa Garrity
16:00 - 16:15	Crystals and IIH	Hollie Clarke
16:15 - 17:30	Bingo and Raffle	Shelly Williamson and Amanda Denton



IIH UK is members of the following organisations.

GENETIC ALLIANCE UK | THE NEUROLOGICAL ALLIANCE | James Lind Alliance Priority Setting Partnerships | ALLIANCE | NCVO | RARE DISEASE UK

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Idiopathic Intracranial Hypertension

A really big
THANK YOU!
We couldn't do it without your support

runningBath

All Weathers Lottery

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Thank you for listening today!

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