



HEADS UP! - September 2022 - Edition 33



AGM

Annual General Meeting

Join us online for our Annual General Meeting
Sunday 6th November 7:30 PM

Register Here:

<https://us06web.zoom.us/meeting/register/tZAuf-yuqzgoGNegmSeY4ysvtas20QPareGH>

How to Help

Find out some free ways you can support us on Page 16

Membership Renewal

Don't forget that membership can now be renewed online.

https://www.iih.org.uk/product/107/7/membership_renewal



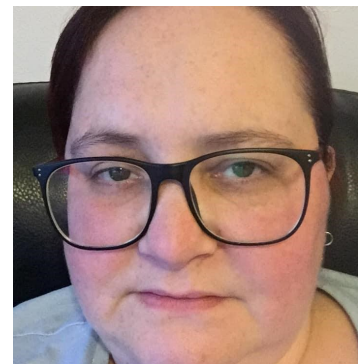
The HOPE Program

Read all about the HOPE program and how it's helping patients and their families on Page 7

Meet others and rediscover your strengths. Whatever challenges you are facing - you are not alone.



Share your Story



This edition Clare shares her IIH story on page 12. If you would like to share your story with other members please send it to newsletter@iih.org.uk

To open the hyperlinks in this newsletter from your lap top/PC simply hold down the ctrl key then left click the link or just tap the link from your smart phone.

Recent news from Birmingham University.

Tests showed women with Idiopathic Intracranial Hypertension had a distinct metabolic profile, but weight loss programmes had positive effect on results. The below link takes you to an article written by Birmingham University on the findings of the academic paper.

https://www.birmingham.ac.uk/news/2022/metabolic-markers-could-give-clues-for-brain-hypertension?fbclid=IwAR2nm9ljewONYsvy2X7gWA-P0HlwCkO7Mu8wGAXbD00YjSfnjl2vG1U_O5Q

You can read the paper here:

<https://n.neurology.org/content/early/2022/09/08/WNL.0000000000201007?fbclid=IwAR00u5DHNeDyYpyG7XMr814lyUHsIWQ1DfW2uMAIDQiiltg5Elpq9kHh5E8>

Clinical Drug Trial Update

The effect of GLP-1RA exenatide on Idiopathic Intracranial Hypertension: Randomised Clinical Trial' This research has now been published and can be read here:

<https://www.medrxiv.org/content/10.1101/2022.05.24.22275518v2?fbclid=IwAR1sXmrh3-8biZo-jaAHrzu7XzKBwZJb3R70S7MRSZBXnFX0U7LuiXV9sMQ>

This is the small trial to test if Exenatide was effective at reducing ICP and headache.

You can read about the phase 3 trial named 'IIH Evolve' on the next page. This is a big step forward for an exclusive treatment specifically for IIH. IIH will have a medication to treat it rather than the current drugs used off label. It will be an international trial with newly diagnosed patients recruited from the UK, Europe, USA, Australia and New Zealand.

IIH EVOLVE

A PHASE III CLINICAL TRIAL FOR IDIOPATHIC INTRACRANIAL HYPERTENSION (IIH)

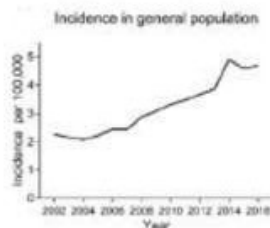


www.invextherapeutics.com

ABOUT IIH

Idiopathic intracranial hypertension (IIH) happens when high pressure around the brain causes symptoms like vision changes and headaches. The high brain pressure likely results from an imbalance in brain fluid (cerebrospinal fluid (CSF)). This increases pressure in the brain ("intracranial pressure or ICP") and on the nerve in the back of the eye, called the optic nerve. There is no known cause ("idiopathic"). IIH is predominately associated with females of child bearing age (>90% of cases), but men can be affected as well.

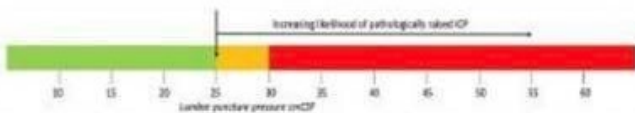
IIH causes disabling long term headaches. Additionally, as fluid builds up around the nerve at the back of the eye, this can cause compression and damage to the optic nerve and if left untreated can lead to permanent blindness. There are a number of other features of the disease, which can be very disabling for example: ringing in the ears, neck and back pain and impaired cognition. Although previously thought to be rare, the number of patients with IIH is increasing each year (the incidence has increased by more than 350% in the last 10 years). For most, unfortunately IIH is a chronic condition and many patients have long term symptoms of disease.



DIAGNOSIS OF IIH

The majority of patients presenting with IIH have symptoms that include a headache that is progressively more severe and frequent. IIH is diagnosed based on the patient's clinical features (Box A) followed by a defined set of criteria (Box B).

A	B
IIH symptoms <ul style="list-style-type: none">• Headache (increasingly severe and frequent) (76-94%)• Visual obscurator's (darkening of the vision) (68-72%)• Pulsatile tinnitus (52-61%)• Back pain (53%)• Dizziness (52%)• Neck pain (42%)• Blurred vision (32%)• Cognitive disturbance (20%)• Radicular pain (19%)• Diplopia (typically horizontal) (18%)	IIH Diagnostic criteria <ol style="list-style-type: none">A. PapilloedemaB. Normal neurological examination (except sixth cranial nerve palsy)C. Neuroimaging: normal brain parenchyma (no hydrocephalus, mass, structural lesion or meningeal enhancement). Venous thrombosis excluded in all.D. Normal CSF constituentsE. Elevated lumbar puncture pressure ≥ 25cmCSF



Mollan et al., Idiopathic intracranial hypertension: consensus guidelines on management. *J Neurol Neurosurg Psychiatry*. 2018 Oct;89(10):1088-1100.

Investigation and management depend on symptoms and signs and requires an interdisciplinary team approach. There are clear diagnostic criteria and consensus treatment guidelines (2018), and as a result the awareness of IIH is growing and standardization of care is anticipated to improve.

Current treatments include weight loss management and medical therapies such as acetazolamide, although these are all unlicensed for IIH and have side effects which can be intolerable for patients. For those at risk of irreversible visual loss, urgent neurosurgery / ophthalmic surgery (e.g., CSF shunting) is required to reduce the ICP and preserve vision. There is a need for new safe and effective treatments for IIH. Invex is developing a once per week injectable formulation of Exenatide to treat IIH.

ABOUT PRESENDIN

Presendin is a sustained release (SR) formulation of Exenatide in a biodegradable poly (lactic-co-glycolic acid) microsphere (PLGA) delivered via a once per week, sub-cutaneous injection, and moving into Phase III development. This injection would be done at home by the patient (or care giver) once training has taken place. Exenatide is a small peptide and a synthetic version of the GLP-1 agonist exendin-4, which is currently approved for the treatment of type 2 diabetes (but does not cause dangerous lowering of blood sugar levels). Exenatide has been licensed for use in type 2 diabetes since 2005 so there is a wealth of knowledge about the drug safety. Common side effects of Exenatide include nausea, loss of appetite and dizziness, which are typically short lived. Most of these side effects tend to go away within a few days or a couple of weeks and serious side effects are uncommon. Exenatide can also cause weight loss.

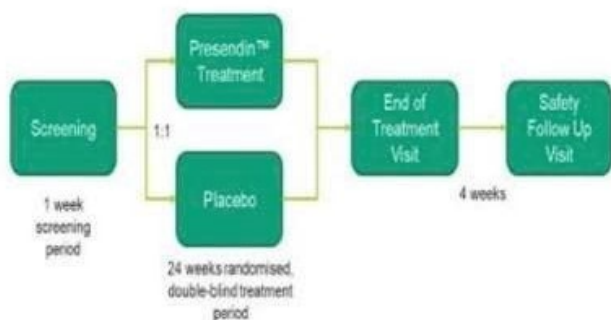
ABOUT IIH EVOLVE

IIH EVOLVE is a randomised, placebo-controlled, double-blind Phase III clinical trial that will randomise 240 adult patients with **newly diagnosed IIH with papilloedema** to determine the efficacy and safety of Presendin versus placebo, administered once weekly over 24 weeks. The primary endpoint of IIH EVOLVE will assess efficacy of Presendin to reduce ICP over 24 weeks compared to those on placebo.

Secondary endpoints will assess changes in vision (the visual field: Perimetric Mean Deviation (PMD) and papilloedema) and headache measures (such as Monthly Headache Days (MHD) over 24 weeks). Invex intends to open up to 40 clinical sites across the UK, Europe, Australia, Israel, New Zealand and the USA. Information on the trial is available at clinicaltrials.gov under Identifier **NCT05347147**.



IIH EVOLVE has been designed to meet the requirements for market approval of Presendin for the treatment of IIH in Europe, UK and Australia and to further inform the Food and Drug Administration (FDA) on future drug registration initiatives for the USA market.



GLOBALLY THERE ARE NO CURRENT REGULATORY APPROVED TREATMENTS IN IIH

There are currently no approved drug therapies utilized in the treatment of IIH. Importantly, diagnostic criteria for IIH are well defined and treatment guidelines available. Consensus guidelines co-authored by Prof. Alexandra Sinclair highlight the urgent need for new therapeutic agents, with current methods of treating more severe cases reliant on medical device/surgical interventions with high failure rates and poor outcomes.



GLOBALLY RECOGNISED EXPERT INPUT & INVOLVEMENT

Trial Steering Group Chairperson – Professor Michael Wall - Dr Wall is a Professor of Ophthalmology and Neurology at the University of Iowa College of Medicine and Director of the Iowa Visual Field Reading Center. He is considered a global key opinion leader in IIH, having made a significant contribution to the clinical and scientific literature pertaining to the diagnosis, treatment and management of this disease and has led a significant number of important IIH clinical trials.

Trial Steering Group Member – Associate Professor Clare Fraser – Dr Fraser is a Consultant Neuro-Ophthalmologist, consultant Visiting Medical Officer at both Sydney Eye Hospital and Liverpool Hospital and is also in private practice in Sydney. Dr Fraser served as Vice President of The Neuro-Ophthalmology Society of Australia, is Chair of the North American Neuro-Ophthalmology Society International Committee and is on the committee for the Neuro-Ophthalmology Virtual Education Library and on the editorial boards for several high impact ophthalmology journals.

Trial Steering Group Member – Professor Susan Mollan – Dr Mollan is a consultant Neuro-Ophthalmologist at University Hospital Birmingham. She is the Director of Ophthalmic Research at University Hospital Birmingham and Director of the Ocular Reading Centre. She has published widely on IIH and is a key contributor to current consensus treatment guidelines for IIH.

Trial Steering Group Member – Professor Helen Danesh-Meyer – Dr Danesh-Meyer is Professor, Faculty of Medical and Health Sciences, Ophthalmology and holds the Sir William and Lady Stevenson Chair in Ophthalmology and Head of Academic Neuro-ophthalmology and Glaucoma, University of Auckland and Director of the Eye Institute. Dr Danesh-Meyer is an international authority in glaucoma and neuro-ophthalmology.

Trial Steering Group Member – Professor Dr Wolf Lagrèze – Dr Lagrèze is Professor of Ophthalmology at the University Medical Center Freiburg, Germany, where he holds the Chair of Neuro-ophthalmology and Pediatric Ophthalmology. Dr Lagrèze directs the Interdisciplinary Center for Orbital Diseases at the same institution and has a strong research interest in pediatric ophthalmology, neuro-ophthalmology and orbital diseases.

Trial Steering Group Member – Professor Patricia Pozo-Rosich – Dr Pozo-Rosich is Head of Section in the Neurology Department at Vall d'Hebron University Hospital in Barcelona and Director of the Migraine Adaptive Brain Centre. Dr Pozo-Rosich is also Coordinator of the Brain, Mind & Behaviour eCORE and in charge of the Headache Research Laboratory at the Vall d'Hebron Institute of Research. Dr Pozo-Rosich is the Honorary Secretary of the International Headache Society.

A SIGNIFICANT & COSTLY BURDEN OF ILLNESS

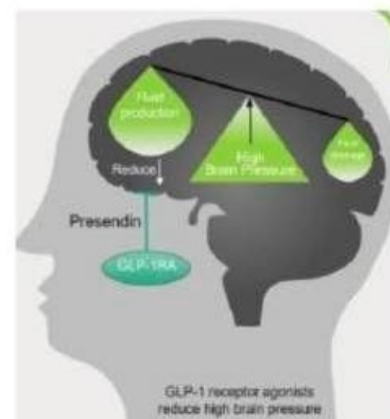
IIH is a rapidly growing disease driven by changing demographics, with incidence growth of 5.2% 2002-2016. By 2030 IIH is projected to cost hospitals in England alone +£400m p.a, with a similar trend in USA.

A key cost driver is an estimated 40% of IIH patients have repeat hospital admissions and an average length of stay being 2.7 days. >90% of patients suffer headaches that are progressively more severe and frequent: major cause of morbidity and up to 25% suffer permanent vision loss due to the elevated intracranial pressure (ICP) effect on optic nerve function.

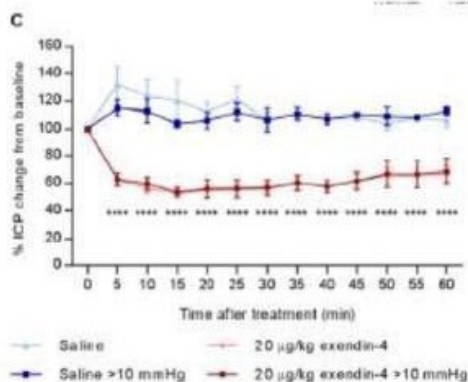
IIH EVOLVE is therefore an important and timely clinical trial to understand the clinical efficacy and safety of the once per week IIH treatment Presendin in newly diagnosed IIH patients.

THE EVIDENCE FOR EXENATIDE IN IIH

Prof. Alex Sinclair Invex Executive Director and Chief Scientific Officer and Clinician Scientist and Neurology Consultant in the Metabolic Neurology Group at the Institute of Metabolism and Systems Research, College of Medical and Dental Sciences, The University of Birmingham was the first to demonstrate glucagon like peptide 1 (GLP-1) receptor agonists commonly used in diabetes treatment (Exenatide formulated as Byetta® or Bydureon®) act on the choroid plexus in the brain to lower cerebral spinal fluid secretion and consequently, intracranial pressure (ICP). Exenatide has a well-defined mechanism of action.



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STRONG AND SUPPORTIVE PHASE II CLINICAL DATA

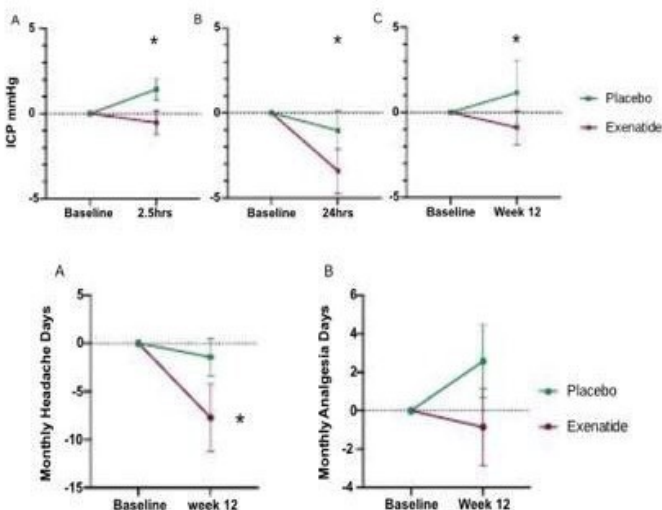
In May 2020, Invex released Phase II trial results in IIH patients. The purpose of the trial, known as the PRESSURE Trial, was to obtain first clinical proof of concept for Exenatide in IIH and provide a basis to move into a pivotal Phase III trial. The design of IIH Pressure was a double blind, placebo-controlled trial of 16 IIH patients randomised to either placebo or Exenatide over 12 weeks.

The results were positive.

Primary Endpoint (reduction in ICP) - statistically significant reduction in ICP across three-time points (2.5 hours, 24 hours and 12 weeks post dose).

Secondary Endpoint – statistically significant reduction in headache days (7.7 day reduction p/m).

Secondary Endpoint (Vision) – statistically significant improvement in visual acuity (1 line on the vision chart (LogMar)).



IIH PRESSURE: SAFETY & ADVERSE EVENTS

No serious adverse events (AE) were observed related to the use of Exenatide. Overall, adverse events were relatively low, with nausea (which settled in the first week) the most common AE seen in >85% of patients treated with Exenatide. Nausea is a known and the most frequent AE of sub-cutaneous administration of this formulation of Exenatide (Byetta®).

Event	Number & Arms*	Description
Serious Adverse Events (SAE)	1, P	Thyroiditis (unrelated, participant continued in study)
Adverse Events (AE)	3, E	Nausea - required treatment
	4, E	Nausea - mild
	1, E 2, P	Minor wound infection (unrelated, participant continued in study)
	1, P	Post-operative swelling

* P = Placebo group, E = Exenatide Group



The results of the PRESSURE trial have been presented at major, relevant medical conferences including at the Annual Meetings for the North American Neuro-Ophthalmology Society (NANOS), The Australian New Zealand Headache Society, European Headache Federation (EHF), the European Neuro-Ophthalmology Society (EUNOS) and the Aerospace Medical Association.

ABOUT INVEX

Invex Therapeutics (Invex) is an Australian Securities Exchange (ASX)-listed biopharmaceutical company focused on the repurposing of an already approved drug, Exenatide, for efficacious treatment of neurological conditions involving raised intracranial pressure. Invex's primary focus is on the disease Idiopathic Intracranial Hypertension (IIH), a condition with no regulatory approved treatments to date. Invex has trademarked its repurposed Exenatide as Presendin.



CONTACT INFORMATION

IIHEVOLVE@invextherapeutics.com. This email address should be used by healthcare professionals either with an interest in or already working on Invex's Phase III IIH-EVOLVE clinical study or for charities seeking further information. Please note that all information on ongoing clinical trials including eligibility criteria and contact information is posted on the <https://clinicaltrials.gov/> website under ClinicalTrials.gov Identifier: NCT05347147.

For Further IIH Information:

UK – <https://www.iih.org.uk/>
 For Australia – <https://headacheaustralia.org.au> or <http://www.iihaustralia.org.au>

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N-CODE

In 2022 IIH UK was delighted to be invited to be a partner for a bid to support a new research network called N- CODE. IIH UK were delighted to hear that the bid led by researchers at Birmingham University was successful and has received funding from the ESRC. You can follow N-Code on Twitter: @ncode_network

Information on N Code is below:

ESRC-funded Network+: Neurotechnology for enabling community based diagnosis and care – to be known as N-CODE.

The N-CODE network has been funded by the ESRC for 3 years was launched on 10th October. Our focus is the development of technologies that shift the emphasis of diagnosis and management of neurological conditions from hospital to the community. We will work with partners and stakeholders to develop digital solutions built around neural interfacing, signal processing, machine learning and mathematical modelling as enabling technologies. These offer significant potential for addressing many challenges currently faced by people with neurological conditions and those responsible for their care. We will work with people with lived experience and their communities to address these challenges together.

IIH Intervention Trial

IIH UK was consulted and involved in a successful research bid (National Institute for Health Research NIHR) led by Birmingham University to investigate Shunt and Stent interventions in people with IIH. IIH UK were involved in the grant bid and are continuing to be involved in reviewing trial documentation etc to ensure that it is easy to understand for people with IIH. IIH UK will be part of future steering group meetings (Dec2022)

Birmingham University have the following to say about the IIH Interventions trial and why it is important.

‘IIH Intervention Trial is a randomised clinical trial that will compare two interventions for patients with Idiopathic Intracranial Hypertension (IIH) and progressive visual loss: Cerebrospinal fluid (CSF) shunting and Dural venous sinus stenting (DVSS).

Both interventions reduce intracranial pressure and preserve vision, but there has been no direct comparison between them and we still do not know which one is more effective. This is an important clinical question and the trial will change practice at national and international level. We have engaged patient groups (IIH UK) and opinion leaders from across the country in order to design high-quality research methodology, while providing our study participants with an exceptional research experience. The trial will enrol 138 patients from 15 UK hospitals who will be randomly allocated to one of the two interventions. We will assess which one is better at preserving vision, more cost-effective, their possible complications, and their impact on headaches and on quality of life. The trial will last for 5 years and we commit to delivering patient-centred scientific research with integrity and strong ethics. Our vision is to advance knowledge, develop treatments and improve the care of patients with IIH.’

Systematic review of interventions for weight management in IIH

In June 2022 IIH UK took part in a meeting and working group putting together a systematic review of interventions for weight management. This systematic review is being led by Dr Sally Abbott a dietician with a special interest in weight management. IIH UK joined a team of experts in managing people with IIH from across the country to discuss this important area for people with IIH. The systematic review is in progress and we look forward to seeing the outcomes and future work in this area.

In 2021 IIH UK applied for and successfully received a £10,000 grant from The National Lottery Community fund to co-create the first self management programme for adults with IIH. Over the course of 2021 many people with IIH and health care professionals worked with The HOPE programme [HOPE PROGRAMME — Hope For The Community CIC \(h4c.org.uk\)](https://www.h4c.org.uk) to develop the course.

The new HOPE programme was launched in march 2022 and we were overwhelmed with applicants for the online programme so much so that a parallel course was set up. IIH UK also funded a parent carers course for parents of children with IIH.

Over the last 12 months over 200 people with IIH and parents of children with IIH have taken part from across the UK:



Praise and feedback for the HOPE programme include:

"It has given me a good insight into how others with the same condition manage on a daily basis. It has changed my way of thinking about living with the condition entirely."

"The programme has been a breath of fresh air and a place to explore the condition safely and confidently. The tasks, videos and information were really engaging and relevant. Thank you."

"The course has allowed me to reflect on my strengths and use those strengths to be a more productive and happy person; instead of sulking about the things I may not be able to do anymore, I have been able to begin a process of adapting to my limitations and finding new things to pursue and enjoy."

"This course has helped me to discover that I can still have a happy, hopeful and fulfilling life with my long-term health conditions. I do not have to let my conditions define me, but they are a part of me."

"I am more understanding of my own condition and that the feelings I have of uselessness are unfounded to some extent. I shouldn't beat myself up for not being ok every day. take my time and set myself simpler goals that are achievable."

The Hope Program cont...

One persons HOPE story:

Tünde was diagnosed with Idiopathic intracranial hypertension (IIH) around a year before starting the Hope Programme. She had just been trying to deal with all her symptoms and appointments.

Tünde heard about the course from the IIH Support group *“I wanted to find out what I can do to cope better”* she says. *“How should I do things differently?”*

So what did Tünde learn? *“For me it was really beneficial. How to cope with stress and what to do when I’m feeling over-loaded.”* But the chance to interact with other people who live with IIH was very helpful, too, she explains.

“It was good to see how other people were coping. Learning from people who were doing better than me – and realising that I was doing better than others!” She continues *“It’s just really good to be in touch with other people with IIH. To know that you’re not alone.”*

In 2023 IIH UK and HOPE will bring together the HOPE programmes for adults with IIH and parents of children with IIH. The course will be facilitated by Laura Kerbey who is an experienced online teacher and parent of a child with IIH.

Dates are now available to book at: [COURSES — Hope For The Community CIC \(h4c.org.uk\)](https://www.h4c.org.uk/courses)

To continue to run the HOPE programme in 2023 IIH needs to raise over £6000. The HOPE programme is available exclusively to members of IIH UK.



(We recorded this conference and will put the recordings on our You Tube Channel as soon as the footage is edited. You will appreciate that as volunteers, the team at IIH UK have lives outside of their volunteering responsibilities and sometimes things take a little longer than originally planned.)

IIH UK Members conference Wednesday 14th September 2022

Programme		
9:45	W E L C O M E	
9:45-10.00	Welcome and Housekeeping	Amanda Denton
10.00-10:15	IIH UK Patron	Dr Sui Wong
10.15-10.45	Live Well with HOPE Update on the IIH UK funded Hope Programme for Parents of Children with IIH	Laura Kerbey
10.45-11.15	Live well with HOPE Update on the IIH UK and National Lottery Funded HOPE programme for Adults with IIH	Dr Anna Lynall
11.15-11:30	B R E A K	
11:30-12:00	Cognitive function in people with IIH	Olivia Grech
12.00-12:30	How can Physiotherapy best support people living with IIH? an update on the IIH UK funded research grant.	Fionnuala Donovan
12:30 -1:30	L U N C H	
1:30-2:00	Weight management in people with IIH	Dr Sally Abbott
2:00-2:30	IIH and Fertility	Dr Mark Thaller
2:30-3:00	Round Up and Goodbyes	Amanda Denton

IIH UK held our annual patient conference on September the 14th 2022. This annual event brings together people with IIH, researchers and clinicians to discuss the latest in IIH. The 2022 event was an online webinar format as for 2021 but IIH UK trustees are hopeful that we can restart our popular members conference face to face again next year. Watch the IIH UK social media sites for more information.

Speakers for 2022 covered a range of topics: The HOPE programme, Cognitive function in people with IIH, Reproductive health in people with IIH, exercise for people with IIH, the latest on weight management an update on the activities of IIH UK over the last 12 months and an update from our new patron Dr Sui Wong.

A short summary of some of the talks are below:

[Fionnuala Donovan](#) - Highly specialist neuro-physiotherapist, Guys and St Thomas NHS Foundation Trust

How can Physiotherapy best support people living with IIH? :an update on the IIH UK funded research grant.

Brief summary: This talk will describe the current research being conducting in the IIH Physiotherapy led clinic at GSTT. This will include: 1. What the current literature says regarding Physical activity and IIH; 2. A summary of the current service and outcomes in the IIH Physiotherapy clinic; 3. A summary of 1:1 interviews conducting with people with IIH who have assessed the IIH clinic at GSTT with particular focus on physical activity and support. 4. Outlines of the next stages of the study including: the development of a larger short answered questionnaire to identify what support people with IIH would like from a physio led IIH clinic (based on the information gained in the 1:1 interviews); distribution of this questionnaire and a summary of the results; implementation of identified service based on questionnaire results; service review of the new service.

[Miss Olivia Grech](#) Institute of Metabolism and Systems Research PhD Student, University of Birmingham

Cognitive Function in people with IIH

Cognition issues have long been noted in Idiopathic Intracranial Hypertension (IIH), however, cognitive function is not widely recognised or addressed in IIH. Researchers performed cognitive tests in 66 IIH participants compared to 25 body mass index-matched control participants to identify impairments in reaction time, memory and executive function. Cognitive performance was also compared at the start of the study, after a lumbar and following 12-months of a weight loss intervention. The researchers demonstrated that executive function and attention is impaired in IIH participants compared to controls at baseline (start of the study with active disease). However, after a lumbar puncture (which temporarily reduced the brain pressure) the measure of attention improved in IIH participants. The cognitive issues identified were reversible, as participants improved in their measures of executive function, sustained attention and memory over 12-months. These improvements were also linked to a reduction in brain pressure. Grech et al, propose that cognitive impairment should be accepted as a clinical feature of IIH and that cognitive deficits can improve over time and with reduction of intracranial pressure.



Laura Kerbey - HOPE programme facilitator

Live Well With HOPE - Update on the IIH UK funded Hope Programme for Parents of Children with IIH. Laura's background as a parent and the impact having a child with IIH had on me and my mental health, family, work etc

Why she wanted to be a facilitator for the HOPE Programme

What was covered in the programme and how this is so beneficial to parents

Benefits of the HOPE Cafes for parent carers

**Dr Anna Lynall, Project Delivery Lead, HOPE for the Community Live well with HOPE
Update on the IIH UK and National Lottery Funded HOPE programme for Adults with IIH**

This session will give an overview of the Hope programme for adults living with IIH that has been co-created with Hope for the Community CIC. Over 200 people living with IIH have now been through the programme and the session will explore the difference that the programme has made to the knowledge, skills and confidence of participants to manage their lives with IIH.

**Dr Mark Thaller, Clinical Lecturer and Neurology Registrar. University of Birmingham
Reproductive health in women with IIH.**

This talk is based on several strands of Dr Thaller's research looking at the impact of an IIH diagnosis on fertility, pregnancy complications of diabetes and pre-eclampsia, type of birth (i.e. caesarean section), practical guidelines for managing IIH in pregnancy and long term outcomes depending on the timing of pregnancy in relation to an IIH diagnosis.

Mark has won 2 awards for his work on IIH and reproductive health; The IIHUK CSF Prize which was awarded at the CSF Symposium back in July and more recently (8th October) The Midland Ophthalmology Society Junior Academic Prize.



Working to relieve the pressure!

I thought my story might be a good one to share as I was diagnosed with IIH WOP and I've always been a WOP'er!

One morning in November 2008, I woke up with such a pain in my head - nothing like the Migraines I'd had since I was a kid or the tension headaches I got with stress (mainly from work) this was totally different, it was like someone had put my head in a vice. At this time I lived and worked in Brighton, I'd woken up to the sound of my alarm clock on my day off (very unusual) but me and my Best Friend had managed to get the day off together and we were heading to London for some shopping and to see the Christmas lights. We arrived at Harrods for Breakfast in Krispy Kreme and whilst Dan went up to get our donuts and coffee my head was getting worse and worse, when he got to the table I rushed off saying I needed the toilet, when I got in the cubicle I was sick - seemed to be the pain making me sick. All day the pain in my head would get worse then ease a little.

As the weeks went on these symptoms never got better; sometimes worse sometimes the same but never letting up - it was there 24/7. After Christmas my parents came down and we went to the Boxing Day sales with Dan. We had just had breakfast when I made the excuse of needing the toilet and disappeared, again being sick from the pain. When I came back and saw my parents faces it was obvious Dan had told them, and I promised I would go to the GP's in the New Year

When I went to see my GP she ended up running every test you can think of, everything came back normal. After the last lot of tests also came back normal, she sat me down and told me the only other thing my symptoms could be was a Brain Tumour and was sending a urgent referral to Neurology - I was upset, scared, frightened and a long way from home/parents but luckily I had Dan who was amazing. Whilst waiting for my Neuro appointment I was having to leave work early and go home ill most days. Eventually I got to see a Neuro at the Royal Sussex in Brighton - she sent me for a MRI due to the symptoms, other than the physical symptoms (my eyes were perfect), and put me on "Depakote". The MRI came back clear and I was back to my GP again - after a few years of going back and fourth my GP said she was going to put me under Endocrinology as this could be a small non-cancerous tumour on my Pituitary Gland. In the meantime I decided to move back to Nottingham after 8 years on the South Coast.

In April 2012 I moved back to Nottingham - still having the same symptoms and being classed as "undiagnosed headaches". I was eventually seen by Endocrinology early January 2013 and sent for an in detail MRI as he too thought this could be a Prolactinoma.

In April 2012 I moved back to Nottingham - still having the same symptoms and being classed as "undiagnosed headaches". I was eventually seen by Endocrinology early January 2013 and sent for an in detail MRI as he too thought this could be a Prolactinoma. 2nd Feb 2013 was a long 17hr day running a work event, I had a little bevvy after work with the guys to say well done and I was absolutely fine.

I woke up on February 3rd 2013 and I didn't feel good at all, as the day went on the worse I felt until it came to the point when I felt like I was going to pass out. My Mum took me to my GP the next day and I was taken straight to the QMC Nottingham for an Emergency Neurology Appointment where the Neurologist was able to check on my recent MRI and said in her opinion this was Idiopathic Intracranial Hypertension but I would need a LP to confirm this. Again nothing wrong with my eyes apart from they were reacting slowly to light. And couldn't believe I had been put on Depakote with no follow up - she

My IIH Story - continued



Working to relieve the pressure!

blamed this for my 7 stone gain.

I had my first Lumbar Puncture a week later. When the Dr realised the pain I was in she stopped and explained to me that LP's should never hurt - if they do, the needle is in the wrong place and needs repositioning! This has always stayed in my head ever since. Once she had repositioned the needle it was more like an uncomfortable feeling rather than pain. My OP came up as just 26 but with the MRI evidence I was diagnosed with IIH WOP (Without Papilloedema).

I saw my first Neurologist 2 weeks later. She had so much knowledge of IIH and IIH WOP it was totally unreal. She was so personable, never treated you as a number, always as the person you are. She tried everything she could think of to help me with my symptoms but nothing worked, so after numerous LP's to relieve the pressure she decided it was time she referred me through to the Neurosurgeons for an LP Shunt. During this time she relocated to a different hospital.

I had to leave work in November 2013, I hadn't been in work since February 2nd and it was now too much to even think about.

I was then put under a new Neuro-ophthalmologist, at my first appointment with him he made it clear (without actually saying so) he was not happy about having to take on someone else's patients.

We had a conversation in which he said he did not believe I had IIH as I did not have papilloedema and my opening pressures are only in the low 20's. I had to tell him they are high 30's now and on checking my notes he saw that I was right. He checked my MRI and saw signs of IIH. I told him that my previous doctor told me I needed urgent Neurosurgeon intervention but he said 'I think you just need to lose weight'. I had previously lost 3 stone in under 2 months but he still wasn't convinced it was IIH. After this appointment I went back to see my GP to ask for a referral to a different Neuro, she looked at his letter and noticed he had actually referred me to the Neurosurgeons after all.

I eventually received an appointment to see a Neurosurgeon who I'm thankfully still under - he is absolutely lovely, he explains everything in depth and makes sure you understand. In May 2015 I got an LP shunt placed, unfortunately it migrated within a year so my Neurosurgeon decided a VP shunt would suit me better, after being lost in the system I got a VP shunt in March 2017. I was also told to take Acetazolamide and Topiramate to help my ongoing IIH symptoms and they did make my symptoms less severe than before.

Since being diagnosed with IIH I've picked up/been diagnosed with a fair few conditions including; Empty Sella Syndrome, Fibromyalgia, Chronic Fatigue Syndrome, Stage 3 Chronic Kidney Disease, Liver issues, FND - Functional Neurological Disease with Non-Epileptic Seizures, Diabetes type II, Lumbar Nerve Damage (from a bodged LP), Chronic Sleep Apnoea, Restless Leg Syndrome, Bursitis in both hips, Depression & Anxiety to name a few.

I find having IIH WOP can mean it's very "hit & miss" with Consultants - especially when I have to go into Ophthalmology.. when I was in that department, I felt like I was banging my head against a brick wall -

My IIH Story - continued



Working to relieve the pressure!

I've only seen one Consultant in this department that I had a positive experience and them NOT saying "well in my opinion I don't think you have IIH because there are no Papilledema present or have there been..." the one positive when I mentioned this to him said "well of course you have IIH, why would they have performed Shunt Surgery twice otherwise?"

I also find it hit and miss with Neurologists too - whereas most Neuro's I've had are completely aware and understand IIH WOP - there are also the ones that like to tell me my IIH symptoms are Migraines. Now considering I've had Migraines since I can remember, I know the difference - I know they can change but surely they can't change into my IIH symptoms? And that's my argument. The Daily Headache I was still having were the same one that started in November 2008 and blew up on February 3rd 2013, it never changed - only the pain level. I have the Headache every single day; from the moment I wake up until the moment I go to sleep again - sometimes the pain levels are around a 5/6 and I can carry on with things and sometimes it's as high as a 8/9 and I am stuck to the spot unable to move but it's definitely my IIH headache and NOT my Migraine Headache that I have daily. I also get Migraines which are complete and utterly different to my IIH Headache,

I have been sent for Botox because my Neuro is convinced I have Migraines. When I spoke with the Consultant giving the Botox and explained my symptoms and she said "These do not sound like Migraines at all, they sound like IIH Headaches" she also told me that she would give me two rounds of Botox but if it is my IIH then the Botox would not work, guess what? Yep, didn't work!

In 2020 things took an amazing direction, I was sent to see the IIH team at the QE Birmingham, they have been like a breath of fresh air! The first time I wasn't told it was all my weight, or that it's not IIH because I don't/have never had Papilloedema. They put me under the Headache Management team and I now have a monthly injection (which hasn't long been out) and Nasal Spray meds for when I have a bad head day - I was having severe pain 16-20 days a month, and now it's around 8-10 days! The team there have given me a new lease of life and hope! I cannot praise them enough!

I read posts from other people who have IIHWOP that are being let down and treated unfairly due to Consultants not seeming to have the knowledge to help them, it's so frustrating but please don't give in - if you feel you're not being treated right, I would suggest you firstly see your GP and ask to be referred to a different Consultant. If that doesn't work or isn't an option then I would speak to PALS (if needed) or find out the head of Neurology and send them a letter outlining your concerns. Remember you deserve to be treated the same way as anyone else.

Sorry it's so long, and thank you for getting to the end - it's hard to condense 9 years down to this lol. It's been an absolute rollercoaster, which I feel like I've been riding too but I couldn't have done it without my parents who are always by my side propping me up and my tight support network of family and true friends. If I can give you just one piece of advice it's live - live your life! Because that cliché of "never knowing what's around the corner" is so true! I've done lots of things and don't let IIHWOP rule my life I have so many memories, which makes it easier now when I'm pretty much house bound. So make sure you can say you've lived your life & Never Ever Give Up! There is always hope, sometimes it's around a different corner to the one you are searching. Thank you for reading and take care xx

Our Fabulous Fundraisers!



Emily Nemeth's son Bert was diagnosed with IIH earlier this year. On Sunday Emily and friends took part in the London to Brighton cycle ride.

They only went and smashed their target!

Their just giving page now stands at £2095.00!! An amazing amount.

Thank you so much! Your fundraising will go a long way to helping us deliver our HOPE Programme for parents of children with IIH.

You can read Bert's story on their just giving page here. <https://www.justgiving.com/fundraising/bertsbabes>



Thankyou to our Facebook birthday fundraisers!

HAPPY BIRTHDAY

Big thanks to Fairy Beautiful with Kerry who's Body Shop event raised £145 as well as goodies for us to raffle! Another event has been set up so you can get ready for Christmas and raise funds for IIH UK too!

Shop here:

<https://consultant.thebodyshop.com/.../kerrya.../event/93235>



September Awareness Month Raffle!

You raised an amazing
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Ways you can support us...



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Set **Easysearch** as your search engine and raise free money every time you search. www.iihuk.easysearch.org.uk

Easyfundraising - shop online at www.easyfundraising.org.uk/causes/iihuk/ and raise funds for us whilst you shop.

The Giving Machine— give as you shop <https://www.thegivingmachine.co.uk/causes/iih-uk/>

Join our lottery and win up to £25,000!
www.theweatherlottery.com/charitiesHomepage.php?client=IIHUK

You can donate at the Charities Aid Foundation - www.cafonline.org/system/charity-search-results

Support us and Raise free funds when you shop at **Amazon** www.smile.amazon.co.uk set IIH UK as your charity

Create a **birthday fundraiser on fb** www.facebook.com/pg/IIHUKCharity/fundraisers/?ref=page_internal

Donate with **PayPal Giving** - www.paypal.com/uk/fundraiser/charity/49628

Selling on eBay? Why not give a percentage to IIH UK via **eBay for Charities** - www.charity.ebay.co.uk/charity/IIH-UK/49628

Buy from our **Teespring store** - www.teespring.com/en-GB/stores/iih-uk

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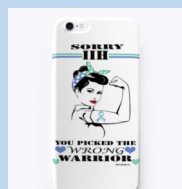
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[IIH UK National Charity](#)

IIH UK National Charity is the main Facebook page for sharing information to everyone on Fb.



[IIH UK on Instagram](#)

We are new to Instagram but are slowly building our followers.



[IIH UK Website](#)

Our website has three areas.

1. People with IIH.
2. Family, friends, carers.
3. Professionals.

It is where you can find all of our information leaflets, research news and members area.



[@IIHUK](#)

@IIH UK is where we share information on Twitter



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Our You Tube Channel is where you will find all of our educational video's and webinars.

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