

HEADS UP! - April 2022 - Edition 32

HOPE
PROGRAMME
FOR PEOPLE
LIVING WITH IIH

FREE SELF-MANAGEMENT
COURSE



ARE YOU LIVING WITH IDIOPATHIC INTRACRANIAL HYPERTENSION ?

Do you want to rediscover
your strengths and
increase your ability to
cope and live well?

Meet others in the same
situation and take control
of your health.

This 6 session ONLINE course
covers topics such as:

- Managing stress, fatigue and getting better sleep
- Mindfulness
- Dealing with setbacks
- Communication and relationships
- Getting active, creative and eating well
- Using your strengths to make you happier

BOOK NOW
WWW.H4C.ORG.UK/COURSES
EMAIL: HOPE@H4C.ORG.UK
OR PHONE: 024 7736 0153



START DATES
22.03.2022
12.05.2022
08.09.2022

There are still places left on our May and September courses. Note: As this first round of courses is funded by the UK Lotteries community fund we can only allow people from the UK to take part. Next year we will be funding this ourselves, it can then be rolled out to our members worldwide.

Meet our new Patron

Dr Sui Wong
Page 2

Membership Renewal

Membership renewal reminders are sent automatically, if you have recently renewed and receive a reminder, please ignore it.

[https://www.iih.org.uk/
product/32/7/membership](https://www.iih.org.uk/product/32/7/membership)



Plain English Summaries

People often find that online medical papers are extremely difficult to understand. This is why we have established a dedicated page on our website for Plain English Summaries, We now have 5 easy to understand versions which you can find here:

[https://www.iih.org.uk/
product/102/5/
plain_english_summaries](https://www.iih.org.uk/product/102/5/plain_english_summaries)

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.

Meet our New Patron



Dr Sui H. Wong is a consultant neurologist and neuro-ophthalmologist in London with NHS practices based at Moorfields Eye Hospital and Guy's & St Thomas' Hospitals NHS Foundation Trusts. She is privileged to have set up and works with an amazing multidisciplinary team, to deliver a multi-award-winning patient-centred service in Idiopathic Intracranial Hypertension, developed in partnership with people with IIH. Dr Wong is also certified in Lifestyle Medicine and encourages lifestyle approaches for the health and wellbeing of her patients, and where possible ways to manage their condition through lifestyle measures. She is also active in neuroscience and neuro-ophthalmology research, including the clinical applications of lifestyle and mindfulness interventions.

Dr Wong is passionate about supporting and empowering people with IIH and is incredibly honoured to become the Patron for IIH UK charity.

Upcoming Events

In recent years Trustees and Team Members have been unable to attend face to face events due to COVID. Thankfully this is now changing and we have two events coming up which we are co-sponsoring and will have a stand showcasing the work that we do.

4th July - CSF Disorders day. Edgbaston Hotel and Conference centre. Birmingham University.

20-23rd June - European Neuro-ophthalmology Society Conference (EUNOS) - Great Hall, Aston Web Building, Birmingham University.

We have decided not to hold a face to face conference this year; COVID is still prevalent and we do not want to take the risk of cross infection. Instead we will hold our AGM on line as we did last year and organise a conference webinar which will take place sometime during September Awareness Month. All being well we will all get together once more during 2023.

We will announce details of our AGM and Webinar nearer the time.

Benefits and Work Guides you can trust



Did you know we have a subscription with Benefits & Work which allows our members to access their range of publications. The informative guides cover a range of issues relating to disability and benefits. These guides are available free of charge and are available for download in the member area of the website.

Everyone who works for IIH UK gives their time voluntarily, they either have IIH or care for someone who has IIH. Having no paid staff enables us to spend our funds on achieving our objectives as set out in our constitution:

Can you spare a couple of hours a week? We currently have two vacancies.

1. Secretary - This is a Trustee position, this work includes taking minutes at meetings and sourcing a venue for our Annual Patient Conference and AGM.
2. Fundraising Rep - This role includes thanking fundraisers on our social media, sending thankyou certificates and letters. Organising our online raffles.
3. Newsletter Assistant - This role includes sourcing articles for our newsletter, creation of the newsletter using publisher and distribution of the newsletter to members.

Email shellywilliamson@iih.org.uk for more information.

IIH discussion in the USA



The Aerospace Medical Association (AsMA) is meeting 22nd - 26th May in Reno, USA and we have funded a travel grant to enable PhD student Olivia Grech and Dr James Mitchell to attend. Along with other Birmingham IIH Team members they have submitted a suite of their work. Idiopathic intracranial hypertension (IIH) shares similar features to Spaceflight Associated Neuro-ocular Syndrome (SANS):

1. IIH:Pressure (Phase 2 RCT - exenatide v placebo) - Major Mitchell, MRCP
2. IIH: Physiology (Novel insights into 24 hour ICP changes utilising telemetric intracranial pressure monitors in idiopathic intracranial hypertension) -Professor Sinclair, PhD
3. IIH:Pressure Med (which is the best at reducing ICP? acetazolamide v amiloride v furosemide v spironolactone v topiramate) -Professor Mollan, FRCOphth
4. IIH:Pressure cognitive evaluation utilising the validated NIH Toolbox Cognitive Battery (v1.11). (How ICP reduction improves cognitive function immediately!) - Ms Olivia Grech, MRES
5. Use of Optical Coherence Tomography in detecting the earliest minimal change (microns) for a diagnosis of papilloedema and the ability to predict intracranial pressure. -Professor Mollan, FRCOphth.

(AmMA is organized exclusively for charitable, educational, and scientific purposes. It is the largest, most-representative professional membership organization in the fields of aerospace medicine and human performance.)

We chose to offer this travel grant after discussion with the Birmingham team about the importance of IIH being discussed on an international stage and will have our logo included on relevant presentation slides as an acknowledgement/advertisement.

Meet your team



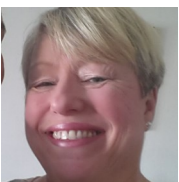
Chair - Shelly Williamson. My daughter was diagnosed with IIH in 2007 at the age of 13. When my daughter was diagnosed with IIH I asked the consultant for information about IIH and was told there is none and to google it when I got home. I did just that and found the former IIH Support forum where I volunteered and became a moderator. Soon after, I was invited to join the team and was instrumental in getting the IIH UK Charity off the ground.



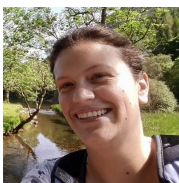
Clare Parr - Liaison Rep and Acting Secretary. I was diagnosed with IIH in 2005 and found a small UK based support forum created by a nurse whose Mum had IIH. This was invaluable for me as so much was unknown. I found support and friends for life. A small group of us felt we needed more support and focus on IIH in the UK, by 2008 IIH UK had its first conference and AGM.



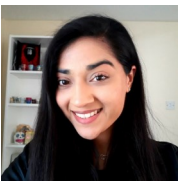
Amanda Denton - Research Rep. I was diagnosed with IIH in 2014 and found the lack of information and awareness was a barrier to mine and my families learning to live with this condition. I was a lecturer in Physiotherapy at Plymouth University and lead a MSc in Neurological Rehabilitation. I am a Trustee and Research Rep for IIH UK.



Betsy Clarke - Treasurer. I joined the IIH UK Team when my daughter Hollie (who is a secondary school maths teacher), was diagnosed with IIH in 2018. I wanted to help raise awareness and support for this terribly under-mentioned and under-funded condition. I began volunteering as Accounts Representative at the 2019 AGM and I am now Treasurer.



Krystal Kirkby - Research Rep. I was a lecturer in Biomedical Science and Public Health at the University of Derby and have research interests in molecular nutrition. I was diagnosed with IIH in 2014 and was shocked by how little was known about the condition. I officially took the position of research representative for IIHUK in 2016. In this role I work closely with clinicians at University Hospitals Birmingham on various projects, as well as conducting patient centred research through the charity.



Nisha Sedani - Research Rep. I suffered from IIH as a young adult and it was during this time that I was extremely frustrated at not being able to express my overwhelming pain, frustration and confusion. By joining the team at IIH UK, I feel that I am able to bring my experience to enable us to gain a better understanding of the causes and treatments for IIH. I am excited to be part of the team

at IIH UK, working together to enable further awareness and campaigning for improvement for the lives of patients and families affected by IIH.



Letty Jones - Publicity/ Newsletter Rep. I was diagnosed with IIH in 2015 and had a shunt fitted a year later. I have a few other conditions including Lupus and Ehlers-Danlos Syndrome. (I know it sounds like a superhero name... it kind of is! I'm super bendy!) I'm the world's biggest clutz! If something is breakable, you can be sure I'll probably break it. This includes myself! I'm pretty shy until you get to know me and then I don't shut up... I'm also autistic and like to spew reams of information at people. Ask me anything; just be prepared for the long answer!



Katie Williamson - Shop Representative. I was diagnosed with IIH in 2007 when I was 13. I was quite poorly the first 6 years or so after my diagnosis but have now been fairly stable since 2016. I run the shop here at IIH UK. I am autistic with PDA and as well as IIH I also have epilepsy, asthma and IBS. I don't let my illnesses rule my life though and love to ride horses. I ride at my local RDA centre and dressage is my passion.



Mellissa Fisher - Arts and Culture Representative. I am a British artist whose work explores the relationships between nature and the self. Past works have involved using casts of my own body and the bacteria that live on it to visualise the invisible world on our skin. I have undertaken major commissions for the Eden Project and the BBC. In 2016 I was commissioned by the BBC to create a large-scale microbial sculpture which formed a central theme of the documentary "Michael Mosely verses the Superbugs", My most recent works are surrounding invisible illness and Idiopathic Intracranial Hypertension (IIH) which I was diagnosed with in 2018. www.mellissafisher.com@mellissafisherartist.

HOPE Programme Round up



HOPE for Adults with IIH - Free online self-management course for members of IIH UK

IIH UK received funding from the National Lottery in 2021 to fund the co-creation of an online self management programme. People with IIH and professionals working with IIH took part in co-creation sessions with researchers from HOPE to ensure that the contents of the programme will meet the needs of people with IIH. There has been a phenomenal response when dates for the courses were released and the first course starting on the 23rd March was so oversubscribed IIH UK are funding a parallel delivery. We look forward to the feedback from the first cohort and to continuing to develop the course. If you haven't signed up information and a link is below:

Are you living with IIH?

Would you like to cope better, feel more in control of your emotions and be more resilient?

It is important for people living with IIH to stay connected. We are offering *free online Hope Programme, a 6-week group self-management programme for people living with IIH to feel more in control and more resilient.*

Each week the course covers topics like: • managing stress • smarter goal setting • gratitude • character strengths • physical activity • eating well • coping with fatigue • practicing mindfulness • communication and relationships

The course includes quizzes, worksheets, audio and video materials, interactive activities and social networking via email and forums. Participants are supported throughout by trained facilitators. Weekly Zoom meetings will also bring the group together at set times.

The course can be accessed from PC, laptop, tablet or smartphone. It takes up to 2 hours to complete each weekly session, which you can complete at any time which is convenient for you.

Many parents and carers have already benefitted from the programme and found the course helped them to feel better with their child's diagnosis and family life.

If you're interested or want to find out more about the program bit.ly/IIH2022.

Dates for 2022 are on the web pages and link above.

IIHUK
Idiopathic Intracranial Hypertension

Feedback from the HOPE Programme for parents 2021

"The Hope course is really practical and relatable for parents. It's made a difference to give me a chance to reflect, create a breathing space in my head. I realise that I can't pour from an empty jug."

hope
for the
community

Registered Charity in England and Wales: 1143522 and Scotland SC043294

IIHUK
Idiopathic Intracranial Hypertension

Feedback from the HOPE Programme for parents 2021

"It's good to feel connected to others in the same situation. Help to cope."

hope
for the
community

Registered Charity in England and Wales: 1143522 and Scotland SC043294

IIHUK
Idiopathic Intracranial Hypertension

Feedback from the HOPE Programme for parents 2021

"Loving learning and being inspired and not feeling so alone in this new journey"

hope
for the
community

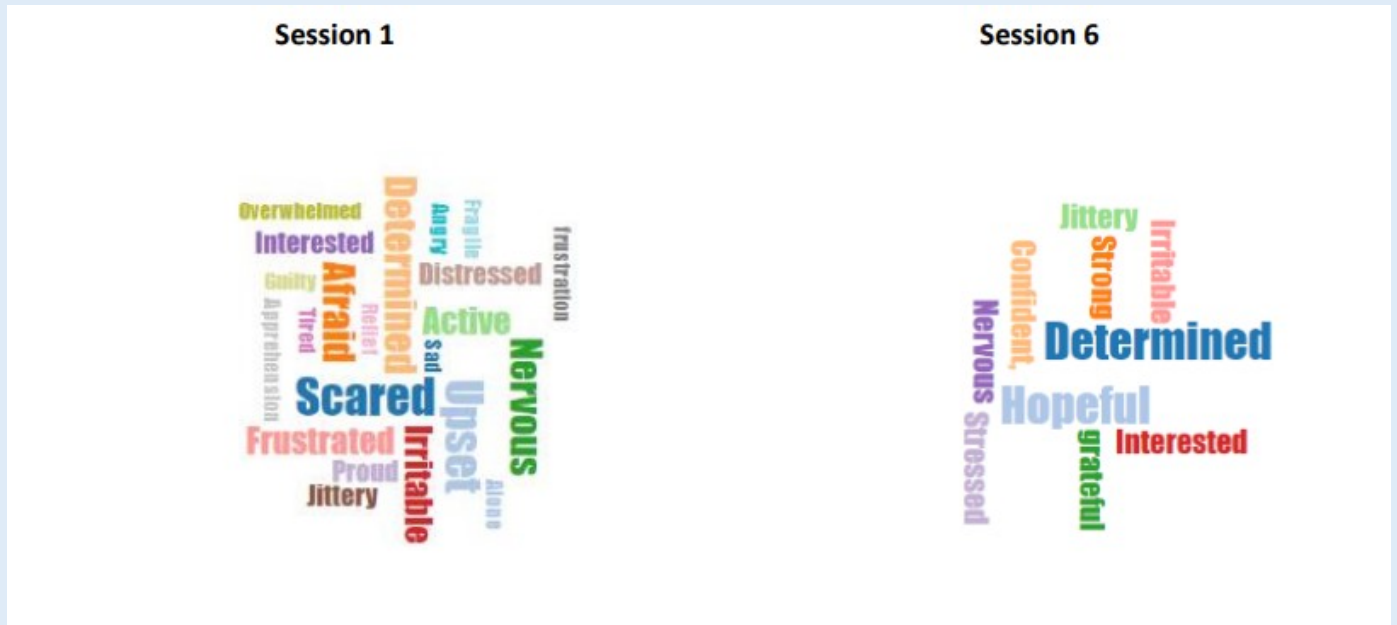
Registered Charity in England and Wales: 1143522 and Scotland SC043294

Becky's HOPE story



HOPE courses for parents of children with IIH

IIH UK has also partnered with HOPE to run a separate HOPE course for parents of children who have IIH. This first course ran in the winter of 2021. Word clouds from the course for parents show the improvements in well being experienced by participants.



A case study from a parent from the first cohort details their experience

Becky has a child with IIH (Idiopathic intracranial hypertension).

Before she went on the online Hope course for Parents of children with IIH, Becky says she was “struggling with hospitals, medications, constantly - hour-by-hour, day-by-day. It’s hard to plan things. It was getting me down.”

She found out about the course on the IIH UK National Charity’s Facebook page and put her name down. “I approached it with an open mind and I loved it!” Becky says. “I liked the way you could pick it up and drop it, if life got in the way. I could do 5 minutes, or 20 minutes. It gave me some time for me.” She liked the online format of the course, too: “It was really user-friendly. It felt good to see how many pages I’d done each week, and how many I had left.” Becky liked the fact that she could bookmark the most relevant pages, including some of the videos.

The parts of the course where she learned about Gratitude appealed to Becky. “I really enjoyed the positivity of the course. Being grateful for the small things, looking at that side of life – it’s so important. It’s easy to get too caught up with everything else that’s going on in life to notice. It’s let me balance that seesaw.”

And is there anything that Becky has carried on doing, since the Hope course finished? “The goal setting. Just little things that I wasn’t making time for. I’ve written a Christmas list. I’ve been on a diet but I didn’t have time to look at recipe books, so I made that one of my goals. And I set myself a daily goal to drink more water, for my health! I’m definitely still doing that, keeping hydrated.”

In summary, Becky says “The Hope course is really practical and relatable for parents. It’s made a difference to give me a chance to reflect, create a breathing space in my head. I realise that I can’t pour from an empty jug.”

Upcoming HOPE Programme for Parents

HOPE PROGRAMME FOR PARENTS OF CHILDREN WITH IIH

FREE SELF-MANAGEMENT COURSE

"Really practical and relatable for parents. It has made a difference and given me a chance to reflect and create a breathing space in my head."

IIHUK
idiopathic Intracranial Hypertension



ARE YOU CARING FOR A CHILD WITH IIH?

Would you like to learn tips to help manage and cope?



This 6 session programme is delivered online via our platform.

- Available 24/7 on any device
- Sessions released weekly
- Learn at a time and pace that suits you
- An option to remain anonymous
- Trained Facilitators

BOOK NOW

WWW.H4C.ORG.UK/COURSES

EMAIL: HOPE@H4C.ORG.UK

OR PHONE: 024 7736 0153



START DATES

08.06.22

01.11.22

Discussing weight with people with Idiopathic Intracranial Hypertension, Results of an online survey: Stigma, support and changing the dialogue.

Authors: Amanda Denton, Melissa Fisher and Shelly Williamson

Summary

Key messages

People with IIH (pwIIH) are experiencing weight stigma with 86% believing that IIH is their fault because of their weight

93% of pwIIH were NOT asked permission to discuss their weight with them

78% of people with IIH who were advised to lose weight were NOT offered support in achieving this

84% of the 22% offered support with losing weight did not find the support offered helpful and appropriate

Background

Weight discussions occur in consultations between health professionals and pwIIH because of the established links between obesity and outcomes in this condition. IIH UK responded to perceived concerns from IIH UK members about the weight related dialogue they were having with their health care professionals. International guidance shows that the way health professionals engage with people living with obesity impacts on engagement, motivation and relationships.

IIH UK members were also raising concerns about a perceived lack of support for management of their weight.

The aims of this survey were to gather information about weight related discussions between health care professionals and pwIIH and how this dialogue impacted on them. Secondary aims were to gather information on weight management support for pwIIH.

Methods

This study was an anonymous online survey using Survey Monkey™. The questions in the survey were piloted with pwIIH and professionals working with pwIIH. The finalised survey was emailed to members of IIH UK. The survey was also shared on social media groups for people with IIH and IIH UK Facebook and Twitter sites.

Results

IIH UK received a phenomenal response to the survey and in one week over 500 responses were received. The survey remained open for a further two weeks. 625 pwIIH completed the survey after any incomplete submissions were removed. The results are summarized below and the questions from the survey are used for structure and context.



Who is advising people with IIH that they need to lose weight? (n=617)

A range of professionals are discussing weight with pwIIH and for many people this dialogue is being repeated with more than one:

Neurologist: 88%

Neurosurgeon:17%

Ophthalmologist: 50%

GP: 44%

Nurse: 21%

Were you asked permission to discuss your weight? (n=625)

A staggering 92% of pwIIH were not asked permission to discuss their weight with them.

How did the person who advised you to lose weight raise this with you? (n=615)

PwIIH free wrote responses to the question and examples below highlight that the way that weight was raised varied considerably. Sadly, the majority of comments were negative but it is important to recognize that there were a minority of people with IIH who had a positive experience.

The Good

“Weight gain can be a cause for iih, weightloss can help symptoms. Do you need support with this?”

“The,matter of factly, told me to lose weight as it would improve my symptoms, I wasn't offended by it, I appreciated that wasn't patronising me”

The Bad

“Told me lose weight and it would go away...haha”

"To help yourself you need to lose weight, you will not get rid of this until you have"

The Ugly

“You need to lose weight or go blind. That's your choice”

“I have one thing to say “slimming world”

‘This happens to people who like too much cake’

“If you weren't fat and had some control you wouldn't be here”

“There's no way you eat what you say you do, do the exercise you say you do and are as fat as you are”

How did being advised to lose weight make you feel? (n=623)

A wordle diagram on the next page uses common words from responses to represent. It is evident that the dialogue was predominantly perceived negatively.



Did you find the person who advised you to lose weight empathetic and supportive? (n=624)

79% of pwIIH did not find the person discussing weight empathetic or supportive.

Examples of supporting responses to this yes/ no question are given below:

“No support, no sympathy, no understanding of life and living with IIH”

“My calls and emails went unanswered. I tend to deprioritize myself as it is but I feel as though my doctors also make me a very low priority. IIH effects my everyday and I feel lost and unsupported most days.”

“I know it’s hard but you have to make yourself lose weight” while I was dieting and not losing “you have to exercise” while not taking into account what I’ve told her about constant pain/other conditions”

“Very black and white. Lose weight. Get out of my office, I can’t help you.”

“He just said I know its really difficult “

“They are busy and need to get me out quick, the info is delivered matter of fact and as medical information, forgetting that there is feeling attached to the words loose weight, and many of us are fat due to feelings. So just telling us “you need to lose weight” then moving on to the next item of business is not supportive at all”

“They just seem rude and unsympathetic. I have tried to explain that I do exercise as much as I can but I am in pain but they don't seem to care”

Were you happy with how the topic of weight was raised with you? (n=619)

79% of pwIIH were not happy with how the topic was raised with them.

Examples of the full responses to justify their yes/no answer are given below:

“It was just thrown in! No “have you ever considered...?” Or approaching it in a manner considering the emotional impact”

“Not a single person asked permission to discuss the topic with me. I would've said yes but that's besides the point I could've explained that it's a sensitive subject or that previous medical professionals have left me quite nervous about this topic. It could've helped the way the conversation was had.”

“It came out of nowhere. And I was (still am) a healthy bmi”

“I felt like I was being put in a one size fits all basket, rather than my individual health needs and history being taken seriously”

“Just told me to lose weight, no explanation, no help with weightloss”



Are there any words or language that you would prefer medical professionals to use if they need to discuss your weight with you? (n=571)

A wordle is used below to summarise responses to this question.

Figure 2. Words or language that pwIIH would like professionals to use in weight dialogues: a wordle summary (n=571 pwIIH).



How could the experience of being advised to lose weight have been improved? (n=585)

Examples of the responses to this question are given below:

“Is it okay if we can discuss the topic of your weight?” “Are you sure?”

“Let’s explore options to assist you in weight loss and see how this will impact your symptoms and condition”

“Take blame out of it. Approach it as you would any other medical condition. Here is the problem, here are ways to treat it, here are people/resources that can help you”

“Overweight is always nicer than obese but understand that is the true medical term on the scale”

“I wish they’d ditch the “morbidly” or “extremely” as it’s dehumanizing”

“I think that if it's going to be considered such a crucial part of treating the condition, then doctors should take more time to understand potential issues around weight rather than assuming it's a simple case of losing”

“I would rather they listen to me. I am desperately trying to lose weight and maybe I need help to manage it? I must do, I am fat. But provide support not judgement.”



Do you feel that you have had less favourable treatment because of the link between IIH and obesity? (n=621)

67% felt that they had less favorable treatment because of their obesity.

Examples of the full answers people gave to justify the yes/no answer to this question are given below.

“Drs see IIH on my notes and then see me a ‘fat’ person and almost immediately most drs go straight in with loose weight eat healthy (which I do) and there’s a disconnect to how they treat me”

“I think obesity is negatively viewed any way and just perceived to be people who are lazy or lack will power and lots of other negative views by everyone. Support medically is lacking and so is the treatment very narrow and treats the symptoms not the cause. So we blame ourselves and doctors blame us which only makes us eat more.”

“I kept being told to lose weight for 5 years because it would cure me. I had weight loss surgery and am now underweight and luckily for me my IIH is in remission. I now get praised and got discharged. When my symptoms flared last year I got told I couldn’t possibly have it anymore and it was just a migraine. They aren’t interested anymore because they can’t blame my weight.”

“I have lost 7 stone and since losing the weight my treatment has been significantly better. When I was overweight my treatment was not as good. When I was overweight my IIH was “blamed” on my weight. Now the health professionals cannot blame the weight, I definitely receive better treatment and am taken more seriously”

“Because it’s all they focus on”

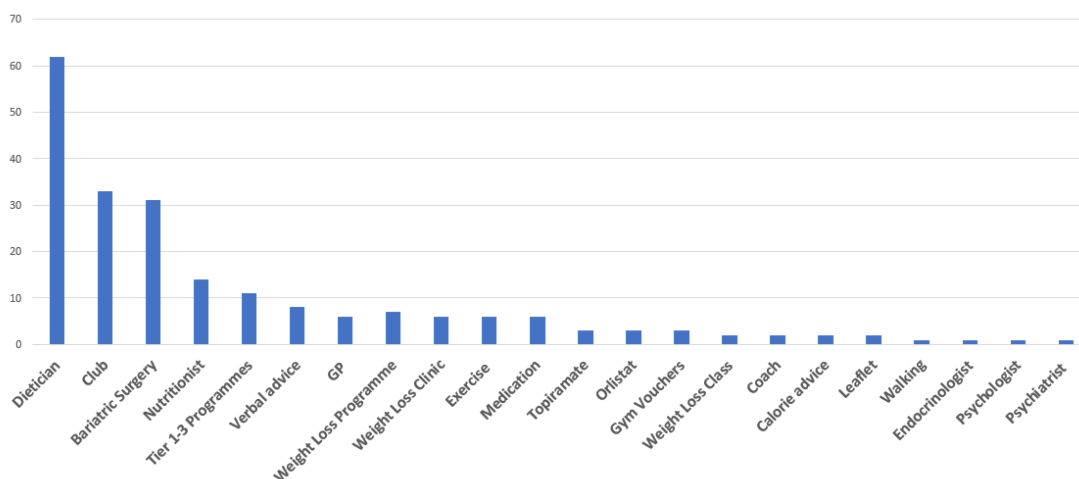
When you were advised to lose weight, were you offered support to do this? (n=624)

78% of pwIIH were not offered support to lose weight.

If you were offered support to lose weight; please detail the support that you were offered? (n=478)

The graph below shows the breadth of support that the 22% of pwIIH who were offered support with weight loss were offered.

Figure 3: Support offered to pwIIH to help them manage their weight (n=478)





Examples of the supporting information to this question are detailed below:

“I was put on a tier 3 program and am yet to have them engage with me on it, I still call them every month 19 months after the acceptance on to tier 3 support”

“I have had to fight to get support. I am under a mental health team and have had to have them email my GP digging that they refer me to a complex weight management team for them to even consider it.”

“Consultant told me to exercise more eat less”

“referral to medical dieticians. More paper information such as leaflets etc. at our appointments.”

“I was sent to a dietitian but when I attended the appointment she had a quick chat about food swaps, gave me a food wheel leaflet and that was it. No further appointments, no support, no targets, nothing to work to. No follow up”.

“Slimming world/weight watchers. I was diagnosed during COVID-19 so it was harder to access these groups” I wasn’t. I was told to eat less and move more and “ignore the cravings”

“The neurologist said she would get in touch with a dietician I never heard from one though”.

“Tier 3 weight management which I agreed too, and was never sent anything about it. No idea what I’m meant to do”

Was the support offered helpful and appropriate?

84% of people with IIH did not find the support offered helpful or appropriate.

Examples of responses to this question are detailed below:

“Referral to a nutritionist by my neurologist. My GP offered 12 weeks of Weight Watchers/Slimming World yet again - I detest those groups, they're like cults”

“A nutritionist with the hospital. They took 2-3 months to write out to me with a leaflet on healthy choices. There was no follow up from them once this was received.”

“I was offered 5 appointments with a Dietician, she suggested weight loss surgery, I then had to do all the research, my GP isn't very knowledgeable with IIH and struggles helping me with things, so anything I do I have to research myself.”

“I did go a weight loss weekly thing but they kept talking about me having gastric surgery which scared and upset me”

“The reasons for this related to not being referred or not able to access due to covid – such as clubs”

“Expense, affordability issues”

“I was told I would be given help to lose weight: for example weight management classes, appointments with a nutritionists and I am still waiting for this after 1 year. I felt like I just got the blame and shunned”

“Waiting lists.....”



If you were advised to lose weight were you given a weight loss goal? (n=610)

70% of people with IIH were not given a weight loss goal when advised to lose weight.

Examples of responses to this question are detailed below:

“At first it was 5% body fat but this changed to 10% once I achieved the goal so I feel he wouldn't have stopped with new targets and no improvement to symptoms”

“It was realistic goal each week to achieve”

“I got told to lose half my body weight”

“I was told even losing 10% of my body weight would be a massive help”

“It sounded like a big number. 13% of your body weight sounds huge.”

“I was told to lose 75 pounds”

If you were given a weight loss goal did this feel achievable for you? (n=412)

Of the 30% of people given a weight loss goal 76% did not feel that the goal was achievable for them.

Examples of the supporting information for this question are given below:

“Got told to lose 15 stone I am no good with massive goals like that”

“Having pressure to hit a weight target quite often has the opposite effect. Doctors should be breaking it down into achievable goals.”

“Only they kept moving it 5%, 6% 10% 12%, then I didn't lose it fast enough.”

“I was told to lose between 8 and 10 stone within 6 months. I was never given a goal, just to lose weight so my pressure would go down. I felt overly pressured to reach this "ideal" goal and no matter what I did, it didn't work, so it felt very unachievable.”

“5% and it made no difference. Then he said 100lbs. I've gone from 98kg to 58kg”

“10st is just so huge, it feels like a mountain I can't climb. I have issues with my relationship with food. I can't exercise as this instantly gives me a headache. So how am I supposed to loose weight?”

“It was the lowest end of healthy bmi and it just seemed impossible that my body would ever be that small”

“It sounded like a big number. 13% of your body weight sounds huge”

Discussion

Stigma can be defined as ' a strong feeling of disapproval from most people in a society about something, especially when this disapproval is unfair' Albury et al 2020. It is evident from the responses by pwIIH to this survey that obesity (weight based) stigma is being experienced during their consultations with health care professionals.



Why is how you are advised to lose weight important? Research evidence shows that, adults who experience weight-based stigma are more likely to avoid exercise and physical activity, and to engage in unhealthy diets and sedentary behaviors that increase the risk of worsening obesity *International Consensus Statement on Obesity Stigma 2020*. Therefore, the consultation could be having the opposite effect to that intended and actually exacerbating the condition.

National guidance from Albury et al 2020 propose that weight stigma can trigger physiological and behavioural changes that themselves contribute to poor metabolic health and further weight gain. These changes include increased eating, reduced self-control, a 2-5 times increased likelihood of mood and anxiety disorders, stimulation of cortisol, itself an obesogenic hormone and avoidance of exercise.

The potential mechanisms are summarized in figure 5 below.

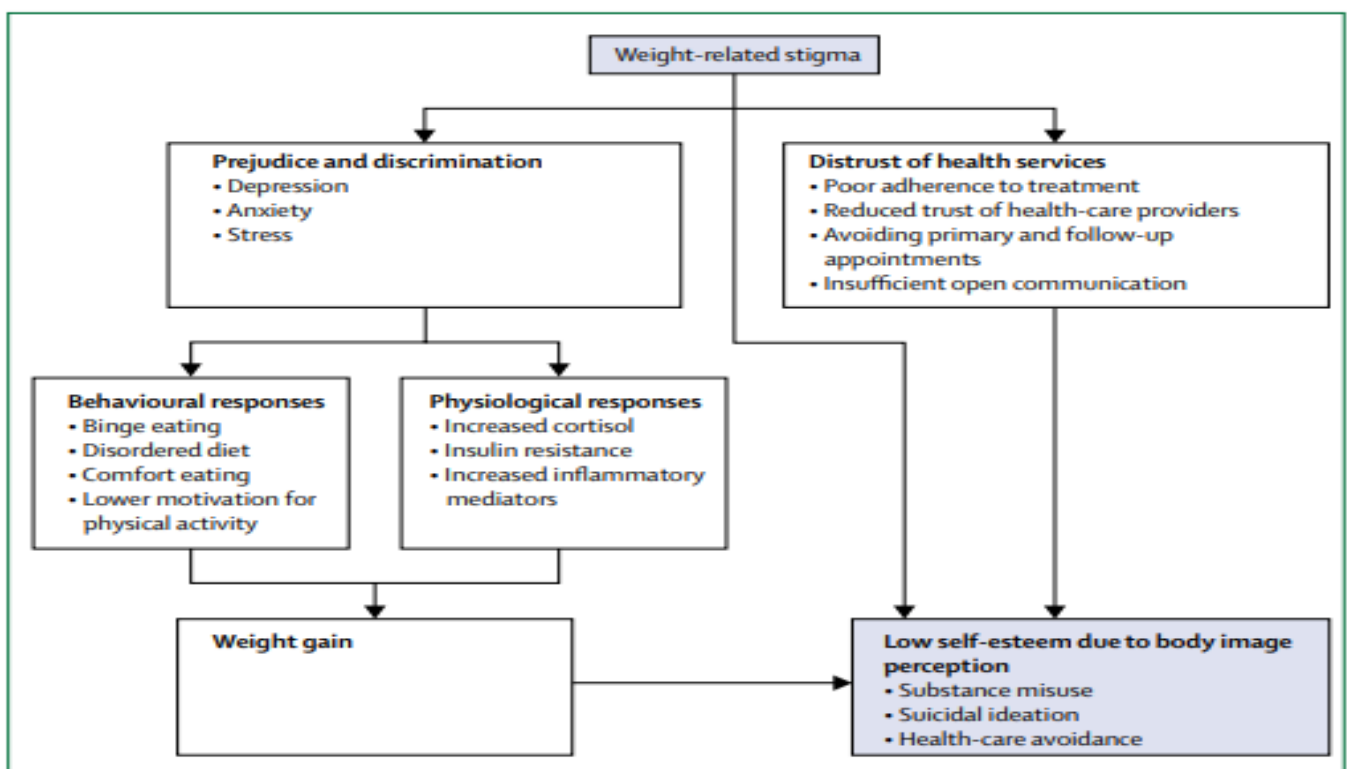


Figure: Potential mechanisms by which weight-related stigma might perpetuate obesity and contribute to the adverse health outcomes associated with obesity

Brown and Flint 2020 propose that the way health care professionals communicate with people living with obesity impacts engagement motivation and the patient-practitioner relationship. They further discuss that terminology is important such as the term obese have negative emotional effects on the person. This is supported by the results of this survey and pwIIH would prefer that this terminology is not used in their consultations. It is clear from the responses to this survey that improvements are needed in consultations regarding weight with pwIIH.

The results of this survey suggest that education is needed with health care professionals to promote improvements in language and dialogue in their consultations with pwIIH about weight. Albury et al 2020 propose the following principles should be used in communication about weight.



Figure 5 Albury et al 2020

Panel: General principles* for communication between a health-care practitioner and a person living with obesity to reduce stigma and improve the individual's wellbeing

Be positive

- Focus on the gains that might be accomplished by weight management, rather than the potential negative effects of failing to address obesity

Be helpful and supportive

- Offer specific help and advice where appropriate
- Signpost and guide people towards more information and local services
- Acknowledge that there are many routes to lose weight and that what works for one might not work for all

Be aware of non-verbal communication

- Talking about obesity is difficult; ensure that body language recognises this difficulty by engaging in a way that would be deemed appropriate for any other medical condition

Be collaborative

- Whenever possible, build meaningful and specific goals together
- Percentage change in weight or even weight neutrality should not be used as a goal, but rather a step towards reaching a meaningful person-centred outcome

Be understanding

- Up to 80% of obesity might be genetically determined
- Ensure not to attribute blame, but to acknowledge the difficulties faced by the person

Be environmentally aware

- Chairs with arms and weight limits can be restrictive
- Tight spaces with back-to-back chairs can be hard to navigate
- Appropriate medical equipment should be available, including scales that weigh up to 150 kg in a private space and a range of different sized cuffs to measure blood pressure

*Adapted from the NHS England guide by Partha Kar.⁴²

What needs to happen in response to this survey?

In response to this survey there are key areas that pwIIH would like to be addressed and key actions that IIH UK plans to take.

What would people with IIH like to change in response to this survey?

PwIIH request that health care professionals ask first if it is ok to discuss weight with them

PwIIH acknowledge that weight MAY be one of the factors but they do not want this to be the sole focus of their interactions with health care professionals

PwIIH would like support with weight loss that is evidence based from a multidisciplinary team who are specialized in weight loss and have knowledge of the specific needs of people with IIH.



PwIIH want weight management options that are affordable, supported and manageable within the context of living with one or more long term conditions.

PwIIH asked if weight loss is a goal then they need regular reviews of their weight with realistic short term goals

Actions from IIH UK to address weight stigma in pwIIH?

Information on weight stigma experienced by people with IIH will be included in information packs sent to health care professionals.

IIH UK will circulate a Top 10 tips for having a conversation about weight with people with IIH developed in collaboration with people with IIH to include in information packs sent to health care professionals.

IIH UK will develop infographics focused on addressing weight stigma experienced by people with IIH to share with professional bodies and on social media.

A new self-management programme: HOPE for people with IIH will be co-designed, developed and delivered to people with IIH supported by National Lottery Funding (starting march 2022)

IIH UK will join the All Parliamentary Group on Obesity and will represent the views of pwIIH at national policy level.

IIH UK will register as stakeholders for the proposed NICE guidance on obesity management

IIH UK will engage with organisations addressing weight stigma such as Obesity UK.

IIH UK will disseminate the results of this survey at relevant conferences for health care professionals working with pwIIH.

IIH UK will publish this survey summary on their webpages to share with pwIIH.

Conclusions

PwIIH are experiencing obesity stigma during consultations with health professionals. Education about conducting a weight related dialogue is needed for professionals engaging with pwIIH. This survey also showed a lack of accessible and appropriate support to achieve weight loss despite the known links to improvement in outcomes for people with IIH.

Help us raise funds!



Did you know that you can use the following platforms to raise funds for us.

JustGiving - Donate or set up a fundraising page at www.justgiving.com/iihuk

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

Donate via **Charity Choice** - www.charitychoice.co.uk/idiopathic-intracranial-hypertension-united-kingdom-181486

We'd love to know what you think about our newsletters. Please offer your feedback by emailing info@iih.org.uk



More stock arriving soon. **We have teamed up with GantMicrobes.com**

Brain



Neuron



Headache



Visit our Teespring Store for clothing, mugs, bags and more



www.teespring.com/en-GB/stores/iih-uk

Social Media

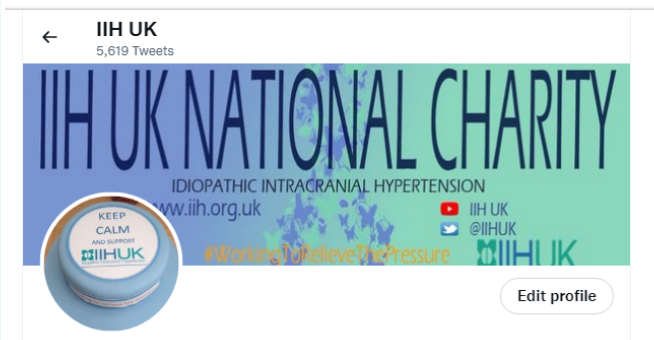
Facebook [IIH UK National Charity](#)



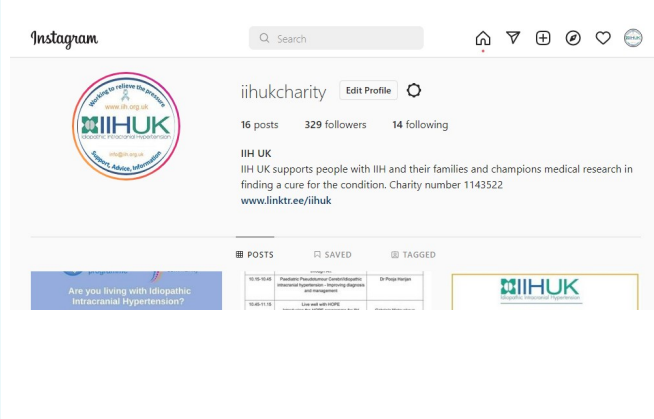
Website: www.iih.org.uk



Twitter [@IIHUK](#)



Instagram [@iihukcharity](#)



[YouTube](#)

Please subscribe to our YouTube channel which you will find at:

<https://www.youtube.com/c/IIHUKNationalCharity>

or search for IIH UK. Tick the bell you will get a notification anytime we add a video.

We have highlighted some of our video's here:

[IIH Priority Setting Partnership.](#)

[What is IIH?](#)

[What are the Symptoms of IIH?](#)

[What is the underlying cause of IIH?](#)

[What is papilloedema?](#)

[What is IIH without papilloedema? \(IIHWOP\)](#)

[How is IIH treated?](#)

[Why is lumbar puncture needed?](#)

[How is IIH linked with weight?](#)

[How is IIH affected by pregnancy and hormones?](#)

[How are headaches treated in IIH?](#)

[When I come to the IIH Clinic.](#)

[IIH Weight Trial](#)

[Paediatric IIH - Improving diagnosis](#)

[Latest Research in IIH—2021](#)

[About the HOPE Programme](#)

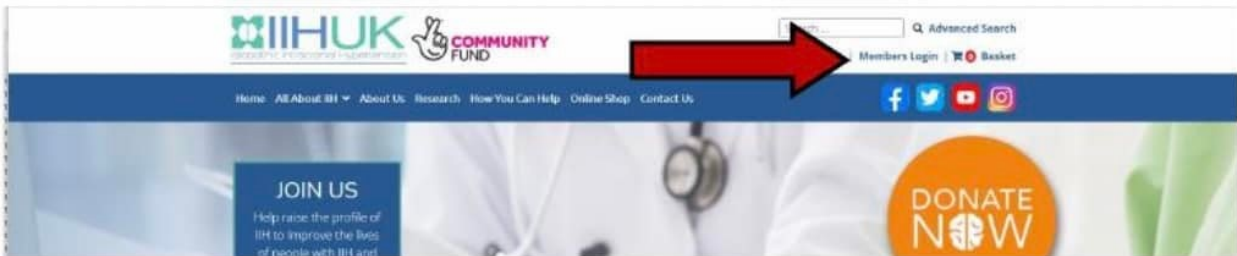
[IIH UK Webinar—2021](#)

[Delivering group consultations](#)

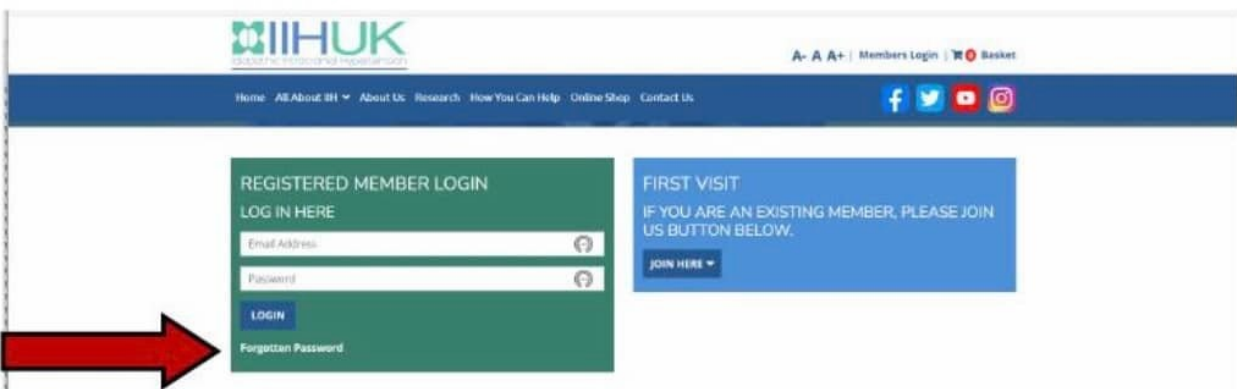
Member login to the members area on the IIH UK Website for the first time.

www.iih.org.uk

Step 1. Click member login



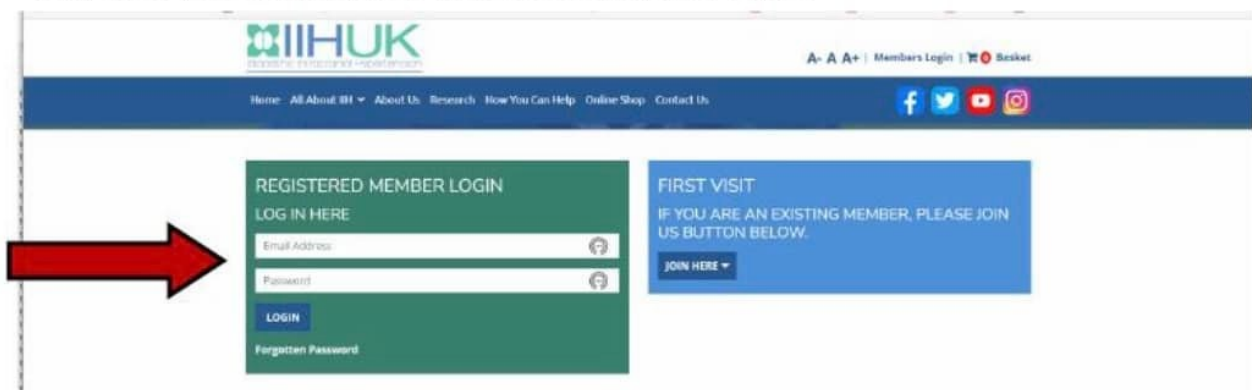
Step 2. Click forgotten password



Step 3. Enter the email address you used when you purchased membership .
And click send new password.

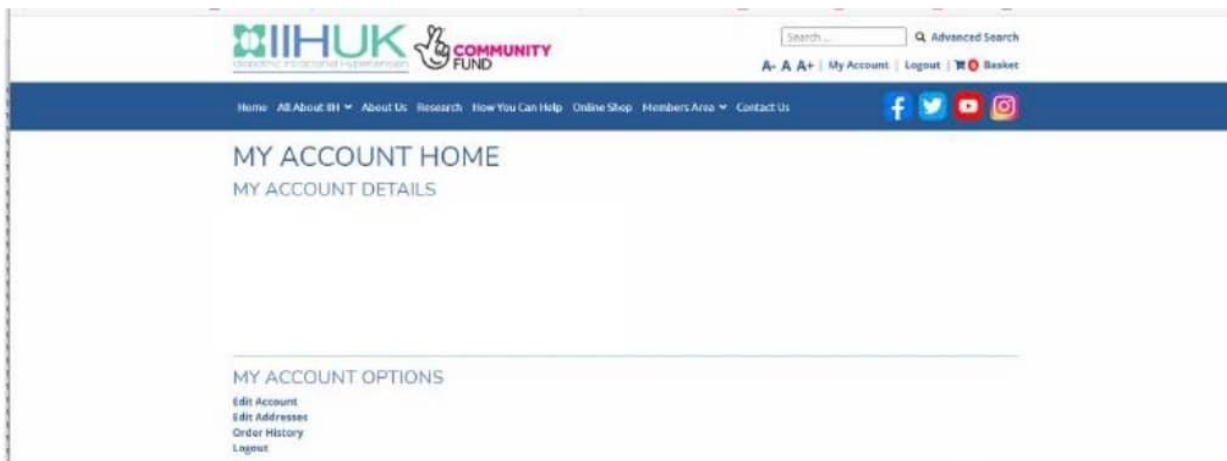



Step 4. Check your mail box and retrieve the new password. (Don't forget to check your spam box) Enter your email address and retrieved password here:





Step 5. You are now logged into the member area and will see this page with your account details. Under account options you can edit your account, address and view your order history if you have made purchases for the shop.



Step 6. Members area now appears in the menu bar or if on a mobile phone click the menu bar  and it will be in the list. Hover your mouse here and a drop down box will appear, you can choose to view the members benefit guides or access the newsletter archive.



The members area is a work in progress and there are still some edits to do to the wording in this area but we hope you enjoy this new member benefit.

Postal Address

IIH UK
19 Woburn
Biddick
Washington
Tyne & Wear
NE38 7JX



Email Address

info@iih.org.uk

shop@iih.org.uk

membership@iih.org.uk

publicity@iih.org.uk



Online

website - www.iih.org.uk

Twitter - @IIHUK

Fb - www.facebook.com/
IIHUKCharity

WWW