



## **IDIOPATHIC INTRACRANIAL HYPERTENSION UK (IIH UK)**

### **TRUSTEES' ANNUAL REPORT AND ACCOUNTS 2023-24**

(Registered Charity Number – England & Wales 1143522, Scotland SC043294)

#### **Charity Trustees during the report period**

1. The following represented IIH UK as trustees during the report period 1 July 2023 to 30 June 2024:

Michelle Williamson	Chair
Clare Parr	Information Rep
Betsy Clark	Treasurer
Amanda Denton	Research Rep
Kerryann Chalmers-Worth	Secretary

#### **Structure, Governance and Management**

2. IIH UK was founded in 2008 and established as a registered charity in England and Wales in 2011 and in Scotland in 2012. It is governed by its founding constitution, as subsequently amended on 12 May 2012, 21 June 2014 and 13<sup>th</sup> July 2019. The charity is constituted by association.
3. All trustees have given their time voluntarily during 2023-24 and have not received remuneration or any other benefits in undertaking their duties. Trustees and Representatives are permitted to claim expenses to ensure they are not out of pocket whilst undertaking their volunteer responsibilities. (E.g., travel and accommodation.) Following endorsement by the 2014 Annual General Meeting (AGM), trustees are elected for a period of 3 years and remain empowered to appoint new trustees in-year by extraordinary trustee meeting, although trustees appointed in this way must seek re-election at the following AGM.
4. IIH UK is a member of the National Council for Voluntary Organisations (NCVO), Rare Disease UK, the Neurological Alliance, the Health and Social Care Alliance Scotland, Genetic Alliance, Benefits and Work and an affiliate of the James Lind Alliance. We also support the Brain and Spine Foundation and hold a lotteries license with Sunderland City Council.
5. We became General Data Protection Regulation (GDPR) compliant in March 2018.
6. We bank with the National Westminster Bank. Facebook (Fb) has become our main platform for donations. Just Giving is our main platform for fundraising.
7. At the year-end, our team members are: Shelly Williamson, Trustee. Clare Parr, Trustee. Betsy Clarke, Trustee. Amanda Denton, Trustee. Kerry Ann Chalmers-Worth, Trustee. Nisha Sedani,

IIH UK ANNUAL REPORT AND ACCOUNTS 2023-24 Website [www.iih.org.uk](http://www.iih.org.uk); X @IIHUK

E-mail [info@iih.org.uk](mailto:info@iih.org.uk) Facebook [www.facebook.com/IIHUKCharity](https://www.facebook.com/IIHUKCharity)

Research Rep. Katie Williamson, Shop Rep. Mellissa Monsoon, Arts and Culture Rep. Lisa Whelan, Publicity Rep. Lizzie Davies, Newsletter Rep. Kirsty Robertson, Fundraising Rep.

### **Charity Objects**

8. The charity's objects as amended on 13 June 2019 are as follows:
  - a. To provide the best possible support and advice network for people with Idiopathic Intracranial Hypertension (hereafter referred to as IIH) and their families.
  - b. To advance the education of the public in general, people with IIH and the medical community in particular on the subject of IIH.
  - c. To promote and support research for the public benefit on all aspects of the condition IIH and to publish the useful results.
  - d. To raise the profile of the charity IIH UK.

### **Summary of main activities undertaken by IIH UK for the public benefit in relation to the objects**

9. IIH UK would not be able to exist without the small number of dedicated volunteers who freely give their time; many of whom have IIH themselves. They assist with the day- to-day running of the charity in areas such as fundraising, membership, publicity, merchandise, newsletter production. In planning and undertaking the activities during the report period, IIH UK trustees were cognisant of the Charity Commission's guidance on public benefit. With the objectives in mind, the Charity's key activities fall into 4 main areas: to provide an excellent support network for people with IIH and their families/friends/carers; to educate the public and the medical community in particular about IIH; to support and promote research into the condition, and finally, to raise the profile of IIH UK.

### **Summary of IIH UK's achievements during 2023-24**

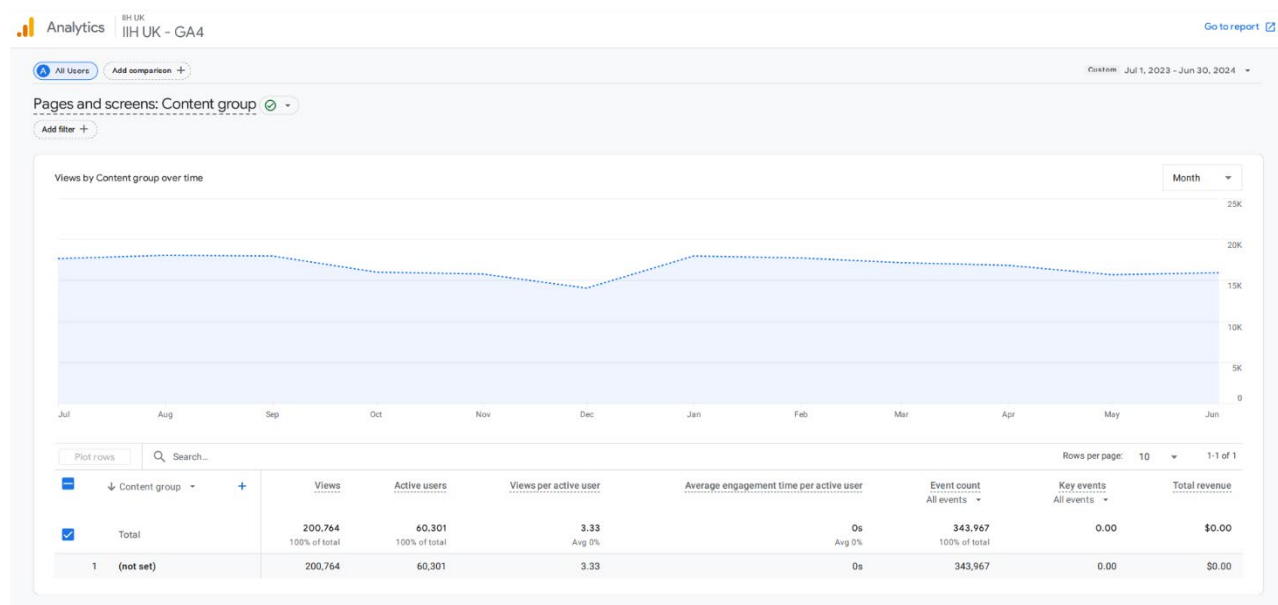
IIH UK has been very proactive throughout the year, as shown below:

#### **Support**

- a. **IIH UK website.** The Charity's website traffic at [www.iih.org.uk](http://www.iih.org.uk) continues to increase. During this financial year 200,764 pages were viewed by over 60,000 users. The website is maintained by FAT Promotions and is kept up to date by both FAT and some of our volunteers.

Our website was launched during 2021. The members only area has proved popular, it is an area where members can view current and past newsletters, download benefit information guides and find the latest AGM news as it is announced.

## Website statistics.



b. We will continue to offer our support and the latest medical and research information on our website [www.iih.org.uk](http://www.iih.org.uk), on Facebook IIH UK National Charity, X @IIHUK in our members newsletters and via our patient leaflets and patient conference/webinar.

### c. HOPE project.

Our HOPE project created a virtual self-management programme and support community for people with IIH and parents of children with IIH from around the UK. We held a 'live' discussion about the project on our page Facebook page in September.

The Hope Project has provided the people we support with the knowledge, skills and confidence to cope with many of life's challenges, frustrations, fears and isolation. To help people reach their potential by supporting them at the earliest possible stage, Coventry University's evaluation of the HOPE Programme has shown that people are emotionally and psychologically healthier and more resilient in the face of ongoing stress. Further, the course improves people's quality of life through teaching important life skills such as goal setting, relaxation and stress management. It builds strong relationships in and across community, people who attend HOPE courses often remain in touch with each other after the course ends and provide each other with ongoing peer- support and encouragement. This is important in a rare condition as many people do not know anyone else with their condition. Online delivery will support the further development of an IIH peer support community across the UK.

You can read about the HOPE programme here: <https://www.h4c.org.uk/hope-programme>

To date 527 people have participated on our HOPE programme (25 parents and 502 people living with IIH.) HOPE is a 6-week online course available 24/7 on any device. Covering things like

mindfulness, stress management, dealing with setbacks and fatigue management amongst other things. Here is what people who have done the course are saying.

'It really does give you a better understanding and has helped me explain better to others about what I can and can't do but also be more acceptance to help.'

'I did turn up later to start the course, but I picked everything up just fine. I think having someone to talk to you about your goals and discussion topics is really key. The isolation that comes with the condition has a real negative impact, so it is good have someone there to give feedback.'

'I have enjoyed the fact that it is an online course but yet interactive and with the opportunity for live video chat.'

'I have enjoyed all of it, loved the cafes being able to meet others and listen to how to manage experiences and be able to offer support. Loved the mindfulness exercise of leaves on the stream found that very helpful.'

You can sign up for the next course here: <https://www.h4c.org.uk/courses-all/iih-110324>

#### Statistics for IIH Hope Courses during the financial year.

	Date of Course	Enrolled	Not active	Completed Course
Parent	14/09/2023	4	2	2
Adult	14/09/2023	56	14	42
Parents	11/03/2024	5	0	5
Adult	11/03/2024	62	14	48

- d. **X.** We have now been on twitter/X for 13 years @IIH UK. Unlike Facebook many clinicians are on X whom you are able to follow, ask questions etc. X has lost its popularity with the people we support since the takeover, and many have left the platform. Our followers fell to 2574 down 68 on the previous year.

- e. **Instagram.**

We created an Instagram account in March 2021. Although slow to take off we are slowly building our followers and now have 862, up 178 on the previous year.

- f. **Facebook.**

Facebook continues to be our most popular social platform, and we now have over 10 thousand followers.

#### Education.

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E-mail [info@iih.org.uk](mailto:info@iih.org.uk) Facebook [www.facebook.com/IIHUKCharity](https://www.facebook.com/IIHUKCharity)

- g. **Leaflets.** You will find the following leaflets on our website.

What is IIH

What is IIH without Papilloedema (IIHWOP)

Optic Nerve Sheath Fenestration

IIH and Weight

Headache Acetazolamide

Information for friends, family and carers ICP Monitoring

IIH and Education Benefits information Employment with IIH

Medication Overuse Headache in IIH Shunts and IIH

Stents and IIH Topiramate

Visual Problems in IIH

When I go to the Eye Clinic

- h. We became an official seller of IIH UK branded 'Hidden Disabilities' lanyards which are available in our online shop.



- i. In February we joined [1FitLife](#) at their studio in Christchurch for a day of filming for an exciting new project!

We chose 'World Brain Day' today to launch our IIH Activity Programme. Recorded at 1FitLife studios in Christchurch.

Working with FitLife and physiotherapist Nuala Donovan we put together a series of videos which have been added to our YouTube Channel. The activity programme was based on the results of an IIH UK research grant given to Nuala in 2022/23

<https://www.youtube.com/channel/UCEpwmNOMWtQ-6hRSL4A1Vpw>

From mindfulness to a full body workout you are sure to find something to suit how you are feeling on a day-to-day basis. They are perfect for anyone living with IIH who has not been able to exercise, done in both sitting or standing at a tempo that you yourself set we hope that you have as much fun doing them as we did making them. We suggest you first watch them in this order before deciding your own road to improved fitness.

1. Introduction to Nuala. <https://youtu.be/ryZ6uEjRPB4>
2. Introduction to the IIH Activity Programme. <https://youtu.be/ELnF9OiCLnk>
3. Structure of the IIH Activity Programme. <https://youtu.be/LzyXbHMTh-c>
4. IIH Activity Programme options. <https://youtu.be/Fw-4AN78UEY>
5. Warm up. <https://youtu.be/ptUqhKJHP1g>
6. Balance. <https://youtu.be/wXLpNRw8d48>
7. Cardio. <https://youtu.be/UyUQc4qgft0>
8. Strength. <https://youtu.be/E-13AM9qtgs>
9. Combined. [https://youtu.be/jq-v7HYDM\\_k](https://youtu.be/jq-v7HYDM_k)
10. Cool down. [https://youtu.be/Fj\\_KvcTJN-g](https://youtu.be/Fj_KvcTJN-g)

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11. Mind mapping - mindfulness. <https://youtu.be/CRqd90dYH70>

Note: To cover all body types we had planned on having four people with IIH take part in the video's but as often happens when living with IIH two people were unable to attend on the day so our Trustee Amanda and Shop Rep Katie stepped up and took turns in the recording of the video's.

- j. We continue to sponsor the **Paediatric IIH Special Interest Group (SIG)**, led by Dr Krishnakumar - Addenbrookes, Cambridge. Our Chair Shelly Williamson, HOPE facilitator Laura Kerbey and Research Rep Nisha Sedani are members of this SIG. There were no face-to-face meetings during the year and all discussions done via email.

## **Research**

- k. Our Obesity Stigma in IIH research was published.  
Titled: **Weight management communications in idiopathic intracranial hypertension: challenges and recommendations from the patients' perspective**. You can read the paper here:  
<https://neurologyopen.bmj.com/content/5/2/e000527>
- l. We continue to fund the travelling expenses for the Birmingham Trials which enables IIH Patients from further afield to take part via a research grant to University Hospitals Birmingham. We are committed to fund the IIH: Life registry at a cost of £5,000 per annum.
- m. **IIH Life Registry**. The IIH Life registry has been developed by Professor Alex Sinclair and captures routine clinical data from neurologists/ophthalmologists/ neuro-ophthalmologists and orthoptic led clinics that management IIH patients around the United Kingdom.

The IIH Life Registry is an excellent resource being used by the Birmingham team since 2013. It enables the IIH team to record information including: visual test results, Quality of Life measures, headaches, medication usage, related conditions, heights and weights. The benefits for this including being able to link changes between these markers to show how they affect each other and also the impact that IIH is having on a person's life.

- n. **IIH Intervention Trial**. #10 of our Top ten areas for IIH research is 'What is the best type of intervention to treat IIH'. We do not yet know which of the current available treatments is the best to treat IIH and were delighted to be invited to the steering group to discuss the development of a new Stent v Shunt trial. We found out in March 22 that Prof Sinclair was chosen to lead this research which aims to establish the best surgical intervention (shunt V stent) in people with IIH to prevent blindness. Finding out the most effective method of surgery is vital to improve the management and quality of life of people with IIH.

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 engaged 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.

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.’

During the year we became aware that the IIH Intervention trial has not recruited as many patients as it needs and faced closure if recruitment did not pick up. This would be a disaster as we really need this research trial to answer an especially important question.

IIH is under-researched, and a 2015 Cochrane review found insufficient evidence to recommend or reject any current treatments used for treating people with IIH. In 2017 we collaborated with the James Lind Alliance to find the top 10 research priorities in IIH. By creating this priority setting partnership we aimed to identify the top 10 research priorities identified not just by doctors but by people with IIH and their carers.

IIH UK’s hope for the research priorities was to ensure that future research in IIH focused on questions and outcomes important to individuals with IIH and those treating them and ensure funding is allocated to these areas.

#10 of the top ten research priorities is ‘Which is the best type of intervention to treat IIH and when should surgery be performed?’. This brings us back to the IIH Intervention trial.

The question posed in this trial is “Which is better to save vision in those with sight threatening IIH? CSF shunting or venous stenting?

There are many centres around the world doing both of these procedures but there has NEVER EVER been a robust randomised trial comparing the procedures based on outcomes important to people with IIH. From listening to the people we support we know that it can be a postcode

lottery, at the moment doctors do not know which is the best intervention, shunt or stent, and sometimes it can be down to the doctors or hospitals preference. IIH UK supported the grant application for this trial because we know that having high quality research evidence is vital to decide which intervention is best for people with IIH based on research, not preference. On completion of this trial we will know which is the best procedure to save vision and ALSO which has the least risks and complications.

IIH is a rare disease and getting funding from national agencies to do research is extremely difficult. Clinical trials typically cost > £1.5 Million to conduct. To get research funding, the research idea has to compete in front of leading international scientists in a 'dragons' den' like situation with other diseases like cancer, dementia etc. The University of Birmingham led by Professor Sinclair have the funds for this trial and it would be a terrible waste for it to fail because of a recruitment issue. If the trial does not recruit it may force closure, it will also affect other future research bids in the area of IIH.

If you would like to take part in this research trial you can look at the eligibility criteria here <https://www.isrctn.com/ISRCTN57142415> to see if you are eligible. If you are eligible and are interested in taking part, please contact your IIH doctor and ask to be put forward to the trial.

- o. This year we were in a position to offer **two research grants**. The successful applicants of the two grants on offer were:

1. Dr Suzanne Hagan, Dept. of Vision Sciences, School of Health and Life Sciences, Glasgow Caledonian University (GCU) **£10,000**

Titled - Tear Fluid Cytokines and Metabolic Proteins as Novel, Non-Invasive Biomarkers of Idiopathic Intracranial Hypertension (IIH). 'Evidence suggests that inflammatory and metabolic irregularities may influence IIH pathology. Studies have shown changes to inflammatory cytokines in the serum and cerebrospinal fluid (CSF) of people with IIH. Moreover, IIH studies have also shown changes to metabolic proteins, including leptin and insulin. Together, these studies indicate that cytokines and metabolic proteins may be biomarkers of IIH, with the cytokines IL-1 $\beta$ , IL-8 and TNF- $\alpha$  being potential relapse markers.

Additionally, research has shown differential changes to cytokine levels between IIH patients and those with other neurological conditions, i.e. multiple sclerosis Taken together, the evidence suggests that inflammatory and metabolic irregularities may influence IIH pathology.

Aims and Objectives of this project aims to identify novel tear fluid biomarkers in patients with IIH, which may serve as future non-invasive diagnostic and/or therapeutic tools. The objectives are to assess tear fluids from IIH patients (versus healthy controls) for panels of inflammatory cytokines and metabolic proteins, alongside other clinical parameters. For example, this will include Optical Coherence Tomography (OCT) measures of optic disc swelling (papilloedema) and/or retinal vasculature changes (both common clinical presentations of IIH), body mass index (BMI), glycated haemoglobin levels (HbA1c), visual acuity, ocular surface health and patient quality of life (QoL). If significant tear fluid protein changes are identified, this may

create a novel method to diagnose ocular pathological changes in people with IIH, which will help in the development of new diagnostic/therapeutic tools.' We are excited to see the results of this research project.

2. Professor Susan Mollan. Honorary Professor, University of Birmingham. Queen Elizabeth Hospital. **£9294.71**

Titled - How do PHOMS affect the vision in IIH? 'We do not yet know which people living with IIH lose vision over time. Loss of vision is not related to how high the brain pressure goes. Optical coherence tomography (OCT) scans of the eye are helpful in clinic. In this study we propose a deep analysis of these OCT images. One structure that was recently described on OCT in people living with IIH is called PHOMS. PHOMS stands for peripapillary hyperreflective ovoid mass structures. PHOMS are deposits underneath the optic nerve in people who have papilloedema. PHOMS cause the optic nerve to look elevated. We do not know what impact the size of a PHOM has on the vision.

This study would create a secure dataset to analyse clinical characteristics of people living with IIH alongside their OCT scans. At University Hospitals Birmingham we have a dedicated team who can construct this dataset and then analyse it. We wish to know what happens to PHOMS overtime, with treatment and what factors influence them. Importantly we want to know if PHOMS cause late visual loss.

Once our study is complete, we wish for this anonymised dataset to be made available to other researchers. The hospital has a secure data platform to do this. Researchers would apply to a patient and public committee for access to this dataset. This would increase the research footprint for this small grant, as researchers from around the world could apply for the dataset.'

#### **Other IIH Research published during the year.**

- p. **Asymptomatic idiopathic intracranial hypertension: Prevalence and prognosis**  
<https://onlinelibrary.wiley.com/doi/10.1111/ceo.14256>
- q. **Current and emerging diagnostic and management approaches for idiopathic intracranial hypertension.**  
<https://www.tandfonline.com/doi/abs/10.1080/14737175.2023.2206567>
- r. **IIH: A step change in understanding disease mechanisms.**  
This Review summarises evidence suggesting that IIH is not idiopathic, but is instead related to systemic metabolic and hormonal perturbations, and should be considered a metabolic disease.  
<https://www.nature.com/articles/s41582-023-00893-0.epdf>
- s. **Weight Management Interventions for Adults with Idiopathic Intracranial Hypertension. A Systematic Review and Practice Recommendations**  
<https://www.neurology.org/doi/full/10.1212/WNL.0000000000207866>

## **Raising the Profile of IIH**

- t. September saw us at Birmingham University Hospital Medical School to meet the Translational Brain Science Research Group for the unveiling of the winning artwork from our 2020 Art Competition. (COVID delayed this event).

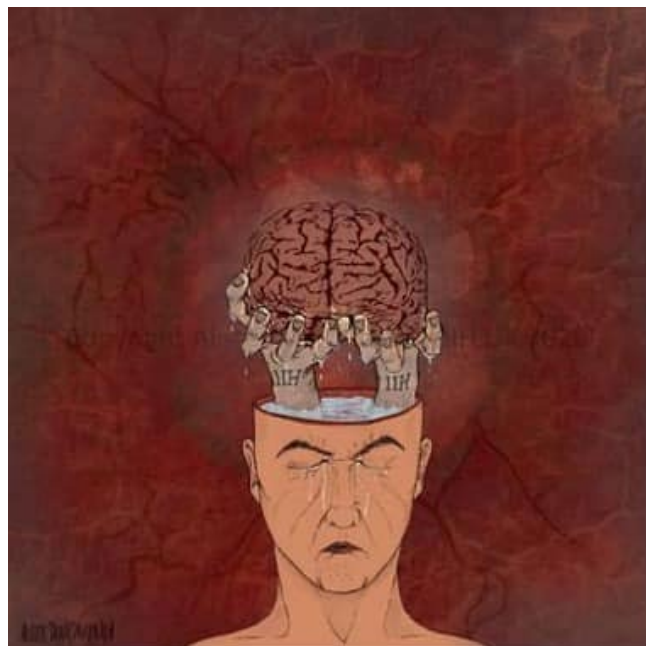
The winner of the adult category was Alistair McCracken whose mother has IIH. His prize was to have his artwork hanging on the wall in the medical school and a tour of the IIH Laboratories.

On hearing of his win Alistair said:

“It really meant a lot for me as a budding artist to enter this competition because my mother, Fern McCracken, has suffered from IIH most of her life. She struggles with the condition every day, but her strength and willpower to push through always astounds and inspires me, and I always do my best to help and support her as much as I can.

The main inspiration behind my piece is the nature of IIH itself. As IIH is what I would consider a “hidden” condition, I wanted to create a piece of art that could metaphorically portray the effects IIH has on an individual that no one sees on the surface level, such as the stress put on the brain by excess fluid. This concept is even more present in the artwork’s background, which is designed to replicate the inside of an eye with Papilledema, one of the symptoms used to identify IIH”

Alistair’s winning artwork.



- u. We celebrated National Volunteers Day. IIH UK are reliant on our volunteers for everything

that we do, without their hard work and dedication we would not be able to continue our life-changing work. So thank you to each and every one of our volunteers, past and present.

- v. Our online shop has lots of items to help raise awareness of IIH.  
[https://www.iih.org.uk/section/7/1/online\\_shop](https://www.iih.org.uk/section/7/1/online_shop)
- w. We want everyone affected by neurological conditions to have access to high quality, joined up care and support to meet their needs whoever they are, whenever they need it and wherever they live. Getting the right care, treatment and support at the right time can make a lifechanging difference when you have IIH. But there are huge variations across the UK – not everyone with a neurological condition in the UK has access to the same high quality, joined up care and support so we partnered with the Neurological Alliance to help spread word of their **My Neuro survey**, by sharing their experiences the people we support will help to gather the evidence to make the case for change.
- x. Trustees/Team members attended the following events during the year.

**Publication of the Obesity Stigma article discussion.** July 23 - online

**Launch of IIH Research grant awards meeting.** Sept. 23 – online

**Genetic Alliance Members Meeting** Sept. 23 - Online

**Translational Brain Science Research Group meeting and Lab tour.** Sept. 23 - Birmingham

**Sense of Symptoms exhibition.** Oct. 23. Brighton.

**IIH Intervention trial steering group meeting.** Oct. 23 – online

**1 Fitlife shoot planning meeting.** Nov. 23 - online

**Neurological Alliance Members meeting.** Nov. 23 – Online

**HOPE planning meeting.** Dec. 23 – online

**1 Fitlife filming shoot.** Feb 24 – Christchurch

**PPIE Focus group meeting** to support Grant application for weight management research in IIH. Feb 25 – online

**Meeting with 23-24 Research Grant winner Dr Hagan** re support for ethics. Mar 24. – Online

**PPIE meeting with Prof Sinclair** to support recruitment for IIH Intervention Trial. June 24. - online.

Attending other organisations' conferences/meetings whether face to face or online provides an opportunity for Trustees and Team Members to meet other attendees and develop friendships with other likeminded organisations enabling us to raise the profile of IIH.

- y. **Brain Awareness Week (BAW)** is the global campaign to increase public awareness of the progress and benefits of brain research. This financial year we celebrated it from 11<sup>th</sup> -17<sup>th</sup> March.
- z. **September Awareness Month.** Provides an opportunity for people with IIH to get involved with raising awareness of IIH. Throughout the month of September, we posted daily on our Fb Charity page and Twitter. From interesting facts to supporters fundraising, the month of September was once again a tremendous success due to the shares and retweets the posts received.

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- i. **Rare Disease Day** takes place on the last day of February each year. This year our Trustee Shelly created profile photos for everyone to add to their profile photo on Facebook. The theme for this year was 'Rare is strong, rare is many, rare is proud.' Overall, it was a perfect day spent spreading awareness and raising the profile of Idiopathic Intracranial Hypertension.
- ii. As a Charity run solely by Volunteers, we just had to celebrate **International Volunteers week** 1<sup>st</sup> – 7<sup>th</sup> June.
- iii. On 18<sup>th</sup> October we celebrated World Menopause Day. There is little information about IIH and Menopause so we shared our video where Professor Sinclair talks about IIH, hormones and mentions taking HRT whilst living with IIH.

**Fundraising** – We use the following platforms to raise funds.

1. **Just Giving:** provides us with our main source of income from fundraising.
2. **Membership fees:** email [membership@iih.org.uk](mailto:membership@iih.org.uk) to become a member.
3. **IIH UK online awareness merchandise sales:** [www.iihukshop.moonfruit.com/](http://www.iihukshop.moonfruit.com/)
4. **Easyfundraising:** [www.easyfundraising.org.uk/causes/iihuk/](http://www.easyfundraising.org.uk/causes/iihuk/)
5. **The Weather Lottery:**  
[www.theweatherlottery.com/charitiesHomepage.php?client=IIHUK](http://www.theweatherlottery.com/charitiesHomepage.php?client=IIHUK)
6. **The Charities Aid Foundation:** [www.cafonline.org/system/charity-search-results](http://www.cafonline.org/system/charity-search-results)
7. **Facebook:** provides us with our main source of income from donations.  
[www.facebook.com/fund/IIHUKCharity/](http://www.facebook.com/fund/IIHUKCharity/)
8. **PayPal Giving:** [www.paypal.com/uk/fundraiser/charity/49628](http://www.paypal.com/uk/fundraiser/charity/49628)
9. **eBay for Charities:** [www.charity.ebay.co.uk/charity/IIH-UK/49628](http://www.charity.ebay.co.uk/charity/IIH-UK/49628)
10. **Teespring:** [www.teespring.com/en-GB/stores/iih-uk](http://www.teespring.com/en-GB/stores/iih-uk)
11. **DONATE:** <https://platform.nationalfundingscheme.org/idiopathic-intracranial-hypertension-united-kingdom-/HOPE>
12. **Charity Choice:** [www.charitychoice.co.uk/idiopathic-intracranial-hypertension-united-kingdom-18148](http://www.charitychoice.co.uk/idiopathic-intracranial-hypertension-united-kingdom-18148)

**Donations received during the 23-24 financial year:** £500 – Winner Winner Chicken Dinner Ltd.  
£1000 – Benefact Group

Michelle Williamson. Chair

*Michelle Williamson*



## Receipts and payments accounts

CC16a

For the period  
from

Period start date  
01/07/2023

To

Period end date  
30/06/2024

### Section A Receipts and payments

	Unrestricted funds	Restricted funds	Endowment funds	Total funds	Last year
	to the nearest £	to the nearest £	to the nearest £	to the nearest £	to the nearest £
<b>A1 Receipts</b>					
Donations & Fundraising	967	-	-	967	£ 2,216.07
Just Giving	5,585	-	-	5,585	£ 4,964.86
Facebook	379	-	-	379	£ 4,397.31
Paypal Giving Fund	3,513	-	-	3,513	£ 6,779.50
Other	2,666	-	-	2,666	£ 10,475.90
Membership Fees	2,115	-	-	2,115	£ 2,142.00
Conference Tickets	-	-	-	-	
Merchandise	1,628	-	-	1,628	£ 3,242.08
Bank Interest	267	-	-	267	£ 123.74
Refunds	-	-	-	-	£ -
	-	-	-	-	-
<b>Sub total(Gross income for AR)</b>	<b>17,119</b>	<b>-</b>	<b>-</b>	<b>17,119</b>	<b>34,341</b>
<b>A2 Asset and investment sales, (see table).</b>					
	-	-	-	-	
	-	-	-	-	-
<b>Sub total</b>	<b>-</b>	<b>-</b>	<b>-</b>	<b>-</b>	<b>-</b>
<b>Total receipts</b>	<b>17,119</b>	<b>-</b>	<b>-</b>	<b>17,119</b>	<b>34,341</b>

<b>A3 Payments</b>					
Governance	£ -	-	-	-	£ -
IT	£ 3,098.75	-	-	3,099	£ 1,925.77
Merchandise (Stock Purchase)	£ 210.00	-	-	210	£ 430.50
Paypal Fees	£ 141.03	-	-	141	£ 131.08
Postage & Packaging	£ 794.03	-	-	794	£ 461.83
Printing & Stationery	£ 142.17	-	-	142	£ 605.87
Transport	£ 76.46	-	-	76	£ -
Misc	£ -	-	-	-	£ -
Refunds	£ 19.50	-	-	20	£ -
Justgiving Membership	£ 216.00	-	-	216	£ 216.00
Other Membership	£ 101.00	-	-	101	£ 121.00
AGM/Patient Conf		-	-	-	£ -
Symposium/Conference		-	-	-	£ -
Partnership Donations	£ 6,000.00	-	-	6,000	£ 2,000.00
Education	£ 19,050.00	-	-	19,050	£ -
Research & Alliance	£ 10,000.00	-	-	10,000	£ 4,343.50
Surveys		-	-	-	£ -
Representatives & Trustee Expenses	£ 2,135.87	-	-	2,136	£ 1,255.33
Publicity and Profile		-	-	-	£ -
Focus Meetinsg		-	-	-	£ -
Life Registry		-	-	-	£ -
Hope Program Child	£ 3,368.00	-	-	3,368	£ 1,350.00
Hope Prgram - Adult Donation	£ 1,680.00	-	-	1,680	£ 5,700.00
Events	£ -	-	-	-	
	£ -	-	-	-	£ -
	£ -	-	-	-	£ -
	£ -	-	-	-	£ -
<b>Sub total</b>	<b>47,033</b>	<b>-</b>	<b>-</b>	<b>47,033</b>	<b>18,541</b>

<b>A4 Asset and investment purchases. (see table)</b>					
	-	-	-	-	
	-	-	-	-	-
<b>Sub total</b>	<b>-</b>	<b>-</b>	<b>-</b>	<b>-</b>	<b>-</b>

<b>Total payments</b>	47,033	-	-	47,033	18,541
<b>Net of receipts/(payments)</b>	- 29,913	-	-	- 29,913	15,801
A5 Transfers between funds	-	-	-	-	-
A6 Cash funds last year end	67,675	-	-	67,675	51,874
<b>Cash funds this year end</b>	<b>37,762</b>	<b>-</b>	<b>-</b>	<b>37,762</b>	<b>67,675</b>

## Section B Statement of assets and liabilities at the end of the period

Categories	Details	Unrestricted funds to nearest £	Restricted funds to nearest £	Endowment funds to nearest £
<b>B1 Cash funds</b>		-	-	-
		-	-	-
		-	-	-
	<b>Total cash funds</b>	-	-	-
	(agree balances with receipts and payments account(s))	Agreement Error	OK	OK
		Unrestricted funds to nearest £	Restricted funds to nearest £	Endowment funds to nearest £
<b>B2 Other monetary assets</b>		-	-	-
		-	-	-
		-	-	-
		-	-	-
		-	-	-
		-	-	-
		-	-	-
<b>B3 Investment assets</b>		Fund to which asset belongs	Cost (optional)	Current value (optional)
			-	-
			-	-
			-	-
			-	-
			-	-
<b>B4 Assets retained for the charity's own use</b>		Fund to which asset belongs	Cost (optional)	Current value (optional)
			-	-
			-	-
			-	-
			-	-
			-	-
			-	-
			-	-
			-	-
			-	-
<b>B5 Liabilities</b>		Fund to which liability relates	Amount due (optional)	When due (optional)
			-	
			-	
			-	
			-	
			-	

Signed by one or two trustees on behalf of all the trustees

Signature	Print Name	Date of approval



# CHARITY COMMISSION FOR ENGLAND AND WALES

## Independent examiner's report on the accounts

### Section A

### Independent Examiner's Report

Report to the trustees/  
members of

Charity Name  
idiopathic intracranial hypertension

On accounts for the year  
ended

30th June 2024

Charity no  
(if any)

1143522

Set out on pages

1 and 2

*(remember to include the page numbers of additional sheets)*

I report to the trustees on my examination of the accounts of the above charity ("the Trust") for the year ended 30/ 06 / 2024.

Responsibilities and  
basis of report

As the charity trustees of the Trust, you are responsible for the preparation of the accounts in accordance with the requirements of the Charities Act 2011 ("the Act").

I report in respect of my examination of the Trust's accounts carried out under section 145 of the 2011 Act and in carrying out my examination, I have followed the applicable Directions given by the Charity Commission under section 145(5)(b) of the Act.

Independent  
examiner's statement

I have completed my examination. I confirm that no material matters have come to my attention (other than that disclosed below \*) in connection with the examination which gives me cause to believe that in, any material respect:

- accounting records were not kept in accordance with section 130 of the Act or
- the accounts do not accord with the accounting records

I have no concerns and have come across no other matters in connection with the examination to which attention should be drawn in order to enable a proper understanding of the accounts to be reached.

*\* Please delete the words in the brackets if they do not apply.*

Signed:

*Brenda Binnie*

Date:

18/12/24

Name:

Brenda Binnie

Relevant professional  
qualification(s) or body  
(if any):

ACMA

Address:

9 manor close

Droitwich

WR9 8HG

### Section B

### Disclosure

Only complete if the examiner needs to highlight matters of concern (see CC32, Independent examination of charity accounts: directions and guidance for examiners).

**Give here brief details of any items that the examiner wishes to disclose.**