



IDIOPATHIC INTRACRANIAL HYPERTENSION UK (IIH UK)

TRUSTEES' ANNUAL REPORT AND ACCOUNTS 2021-22

(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 2021 to 30 June 2022:

Michelle Williamson	Chair
Clare Parr	Acting Secretary
Betsy Clark	Treasurer
Amanda Denton	Research Rep

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 13th July 2019. The charity is constituted by association.
3. All trustees have given their time voluntarily during 2021-22 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. We also accept donations via the Charities Aid Foundation. (See item **z** below.)
7. At the year-end our team members are: Shelly Williamson, Trustee. Clare Parr, Trustee. Betsy Clark, Trustee. Amanda Denton, Trustee. Krystal Kirkby, Research Rep. Nisha Sedani, Research Rep. Katie Williamson, Shop Rep. Mellissa Fisher, Arts and Culture Rep. We currently have several positions open; these include Trustee/Secretary, Fundraising Rep, Newsletter Rep. Please email info@iih.org.uk if interested in finding out more about these positions.

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

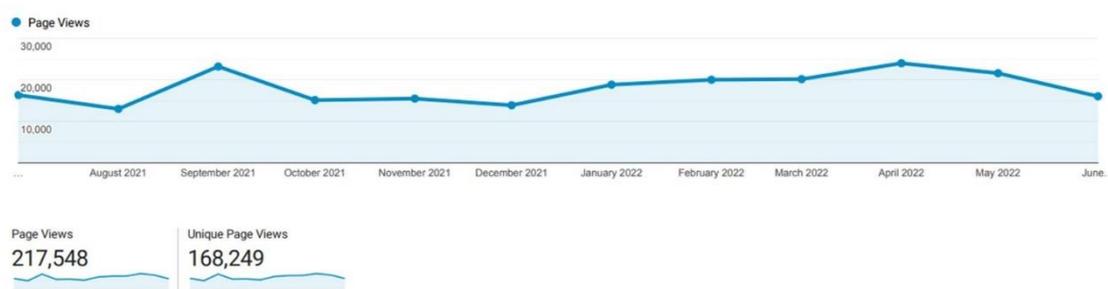
9. IIH UK would not be able to exist without the small number of dedicated volunteers who freely give their time; many of whom have IIH themselves. They assist with the day-to-day running of the charity in areas such as fundraising, membership, publicity, merchandise, newsletter production. In planning 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 2021-22

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 continues to increase. During this financial year 217,548 pages were viewed, 53,155 more than last year. The website is maintained by FAT Promotions and is kept up to date by both FAT and some of our volunteers. Our new 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.



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

c. **HOPE project.**

We secured funding from the National Lotteries Community fund to fund this project for adults with IIH. During the year we also ran a HOPE programme for parents of children with IIH which we self-funded.

Our HOPE project created a virtual support community for people with IIH around the UK. Following stakeholder involvement in the development of the bespoke programme for IIH including focus groups, surveys and a steering group. In addition, participants have the opportunity to become facilitators of the HOPE programme and become involved in delivering the HOPE programme to future cohorts. If you have taken part in the HOPE programme and would like to know more about becoming a facilitator please get in touch.

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.

There are currently two programmes: 1. For adults with IIH. 2. For parents of children with IIH.

We are amalgamating the courses in 2023.

You can read about the HOPE programme here:

<https://www.h4c.org.uk/hope-programme>

Statistics for IIH Hope Courses.

	Date of Course	Enrolled	Not active	Completed Course
Parent	20/09/2021	23	6	17
Adult	22/03/2022	71	18	53
Adult	22/03/2022	69	22	47
Adult	12/05/2022	83	22	61
Parent	08/06/2022	13	2	11

- d. **Twitter.** We have now been on twitter for 11 years @IIH UK. A lot of clinicians are on Twitter whom you are able to follow, ask questions etc. We have 2548 followers on twitter, up 197 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.
- f. **COVID-19.** We don't hear much on the news outlets about Coronavirus (COVID-19) any more but it is still very much with us. As the situation continues to affect the people we support, our top priority at IIH UK was supporting people living with Idiopathic Intracranial Hypertension (IIH) which is why we gathered the latest facts and guidance which we shared on our website and social media sites. In light of the ongoing uncertainties IIH UK ran its annual members conference as a virtual event.

Education

- g. **Leaflets.** Several years ago, we commissioned Professor Sinclair and her team at University Hospitals Birmingham to re-write some of our information leaflets in collaboration with some of our volunteers. All leaflets were reviewed during the year and amended if necessary. 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

Leaflets coming soon:
 Lumbar Puncture
 Pappilloedema
 Pregnancy and Family Planning with IIH
 IIH and Flying

Greater Occipital Nerve Block (GON)
BOTOX/ Calcitonin Gene-Related Peptide (CGRP)

- h. We continue to sponsor the **Paediatric IIH Special Interest Group (SIG)**, led by Dr Krishnakumar - Addenbrookes, Cambridge. Our Chair Shelly Williamson and HOPE facilitator Laura Kerbey are members of this SIG. (both have children with IIH) also, Nisha Ravel, our Research Rep joined the SIG in February 2021. There was no face to face meetings during the year and all discussions done via email. We hope to update about this soon.
- i. During the course of the year, we developed IIH information packs for clinicians. These were launched at the European Neuro-ophthalmology Society conference which we attended in June 2022. This was attended by neuro-ophthalmologists from all over the world. The packs contained information about IIH UK and our website, samples of our information leaflets, of our medical/shunt info cards, HOPE programme poster and IIH consensus guidelines poster. They were very well received by delegates.
- j. In July and August 2021 our Arts and Culture Rep Melissa held 4 Visualising Physical Pain through art workshops via Zoom, teaching attendees drawing techniques whilst having a discussion about how pain is communicated and how chronic illnesses are perceived by medical professionals and in society. Mellissa shared her artistic practice and works about the invisible symptoms of IIH.
- k. **N-CODE**
In 2022 IIH UK was delighted to be invited to be a partner for a bid to support a 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 EPSRC. You can follow N-Code on Twitter: @ncode_network

Information on N Code: EPSRC-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 EPSRC for 3 years and will launch on 10th October 2022. The 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.

Research

- 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 have also 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 plans to captures routine clinical data from neurologists/ophthalmologists/

neuro-ophthalmologists and orthoptical clinics that manage 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.

The Birmingham team have used the database for two studies which are both free to read.

One was comparing Birmingham's IIH patients with those in Atlanta, USA
<https://www.nature.com/articles/s41433-019-0359-5>

The other study helped them track trends following COVID-19 pandemic
<https://jnnp.bmj.com/content/early/2020/12/23/jnnp-2020-325519>

Dr Mark Thaller, Clinical Research Fellow at Birmingham, is currently using the rich resource of the IIH Life database for his research into fertility, polycystic ovarian syndrome, Quality of Life and the hormonal basis for IIH. He aims to add to the knowledge base beyond the visual and headache aspects. Dr Thaller has received two awards for his research, the IIH UK CSF award and the Junior Academic Prize from the Midland Ophthalmology Society.

The registry will help future care of IIH patients by researchers being able to use it for their research questions. Roll out to other hospitals was halted due to legal regulations, however they are now in a position to start to build out.

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 that Prof Sinclair was chosen to lead this research which aims to establish the best surgical intervention (shunt vs 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 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.'

o. Physical activity, quality of life and headache impact in people with Idiopathic Intracranial Hypertension survey.

Research Reps Amanda Denton and Dr Krystal Hemmings and a Physiotherapy researcher from Plymouth University Dr Hilary Gunn carried out and analysed this survey. An online survey was sent to people with IIH (pwIIH) to complete. The survey contained measures of physical activity, quality of life and headache impact. 164 people with IIH took part and their information was anonymously analysed. The results showed that pwIIH have low levels of physical activity and take little exercise. Physical activity is related to quality of life in pwIIH. Physical activity was not related to age, current or diagnosis BMI (Body Mass Index) or headache impact score in people with IIH.

The results suggest that improving physical activity in people with IIH could positively impact on quality of life. Ways to increase physical activity such as exercise should be further explored in pwIIH.

Associations between physical activity, quality of life and headache in people with Idiopathic Intracranial Hypertension
Amanda Denton¹, Dr Hilary Gunn² and Dr Krystal Hemmings¹

Physical Activity
Current (hours per week)
Frequency
Work-related

Table 1 Outcome Measures

Measure	Mean (SD)	Range
Age (years)	36.7 (10.2)	18-67
Female (%)	92.7	
Physical Activity (MET)	1.0 (0.4)	0.1-5.0
Quality of Life (SF-36)	48.5 (10.5)	25-75
Headache Impact (HIT-6)	58.5 (10.5)	30-80

Table 2 PASPO Data

Item	Mean (SD)	Range
1. I feel confident about my ability to do the activities	4.2 (1.0)	1-5
2. I feel motivated to do the activities	4.1 (1.0)	1-5
3. I have enough energy to do the activities	3.9 (1.1)	1-5
4. I have enough time to do the activities	3.8 (1.1)	1-5
5. I have enough resources to do the activities	3.7 (1.1)	1-5
6. I have enough information to do the activities	3.6 (1.1)	1-5
7. I have enough support to do the activities	3.5 (1.1)	1-5
8. I have enough encouragement to do the activities	3.4 (1.1)	1-5
9. I have enough knowledge to do the activities	3.3 (1.1)	1-5
10. I have enough skills to do the activities	3.2 (1.1)	1-5
11. I have enough confidence to do the activities	3.1 (1.1)	1-5
12. I have enough resources to do the activities	3.0 (1.1)	1-5
13. I have enough information to do the activities	2.9 (1.1)	1-5
14. I have enough support to do the activities	2.8 (1.1)	1-5
15. I have enough encouragement to do the activities	2.7 (1.1)	1-5
16. I have enough knowledge to do the activities	2.6 (1.1)	1-5
17. I have enough skills to do the activities	2.5 (1.1)	1-5
18. I have enough confidence to do the activities	2.4 (1.1)	1-5
19. I have enough resources to do the activities	2.3 (1.1)	1-5
20. I have enough information to do the activities	2.2 (1.1)	1-5
21. I have enough support to do the activities	2.1 (1.1)	1-5
22. I have enough encouragement to do the activities	2.0 (1.1)	1-5
23. I have enough knowledge to do the activities	1.9 (1.1)	1-5
24. I have enough skills to do the activities	1.8 (1.1)	1-5
25. I have enough confidence to do the activities	1.7 (1.1)	1-5
26. I have enough resources to do the activities	1.6 (1.1)	1-5
27. I have enough information to do the activities	1.5 (1.1)	1-5
28. I have enough support to do the activities	1.4 (1.1)	1-5
29. I have enough encouragement to do the activities	1.3 (1.1)	1-5
30. I have enough knowledge to do the activities	1.2 (1.1)	1-5
31. I have enough skills to do the activities	1.1 (1.1)	1-5
32. I have enough confidence to do the activities	1.0 (1.1)	1-5
33. I have enough resources to do the activities	0.9 (1.1)	1-5
34. I have enough information to do the activities	0.8 (1.1)	1-5
35. I have enough support to do the activities	0.7 (1.1)	1-5
36. I have enough encouragement to do the activities	0.6 (1.1)	1-5
37. I have enough knowledge to do the activities	0.5 (1.1)	1-5
38. I have enough skills to do the activities	0.4 (1.1)	1-5
39. I have enough confidence to do the activities	0.3 (1.1)	1-5
40. I have enough resources to do the activities	0.2 (1.1)	1-5
41. I have enough information to do the activities	0.1 (1.1)	1-5

Table 3 Physical Activity Associations

Variable	Mean (SD)	Range
Age	36.7 (10.2)	18-67
Female (%)	92.7	
Physical Activity (MET)	1.0 (0.4)	0.1-5.0
Quality of Life (SF-36)	48.5 (10.5)	25-75
Headache Impact (HIT-6)	58.5 (10.5)	30-80

p. Following the results from our Physical activity, quality of life and headache impact in pwIIH survey. We put out a Physical Activity in IIH funding call in November 2021 to further

research this neglected area. Dr Sui Wong and her team at Guy's and St. Thomas Hospital NHS Trust, London won this call and was granted £9996.00 plus a reserve of £2500 to pay the open access fees of the research paper once published.

(Note we have paid the open access fees for several previous research papers as we feel it is important that pwIIH have the opportunity to read research articles in journals that usually require a subscription.)

Summary of Dr Wong's research funding bid.

Idiopathic intracranial hypertension (IIH) is associated with excess body weight, and research has shown that weight loss may lead to remission of IIH. This has also been prioritised by people pwIIH as an important area of research.

Physical activity is a key aspect of successful and sustainable weight management, and can also improve other health conditions associated with IIH, including cardiovascular and metabolic health conditions.

At Guy's and St Thomas' NHS Foundation Trust (GSTT), they have a track record of working in partnership with pwIIH to develop services that empower them, including group consultations that facilitates peer-to-peer learning and lifestyle support to empower pwIIH to better manage their condition; and wellbeing workshops to support sustainable lifestyle measures including physical activity. Their multidisciplinary IIH team includes physiotherapists who support physical activity for pwIIH.

This research aims to develop recommendations and practical implementations on physical activity for pwIIH. The work will include research into current evidence and gathering new evidence through research in partnership with pwIIH, including focus groups, questionnaires and data gathered from pilot work on the effectiveness of group education sessions. Appropriate video guidance will also be developed in partnership with pwIIH. The work will be incorporated with current work on the HOPE programme for pwIIH. The gaps in knowledge in this area will also be identified.

Output from this research will be shared with the IIH UK trustees and members. This will also be disseminated to health professionals to advocate support and better care for pwIIH.

q. IIH EVOLVE Trial Update

#3 of our James Lind Alliance Priority Setting Partnership is 'Can new therapies for IIH be developed which are effective, safe and tolerable and potentially help with weight loss as well as reducing brain pressure.'

Currently there are no drugs designed to treat IIH, all current medications used to treat it are used off label. There is a need for new safe and effective treatments for IIH and Invex Therapeutics (Invex) is developing a once per week injectable formulation of Exenatide to treat IIH.

Invex Therapeutics is an Australian biopharmaceutical company co-founded by Professor Sinclair which is 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, a condition with

you all for your input into this survey which is an emotive subject for people with IIH. We are already liaising with medical teams to action your responses to improve the dialogue about weight in IIH. The responses already show clearly significant room for improvement in how the topic of weight is discussed and that a lack of evidence based support being offered. We are aware that researchers have already used our data in when applying for funding. This is an emotive but important subject and we will endeavour to keep up the conversation about Obesity stigma in IIH with professionals that treat people with IIH.

Read **Discussing weight with people with Idiopathic Intracranial Hypertension, Results of an online survey: Stigma, support and changing the dialogue** on our website here: [IIH UK Obesity Stigma survey results](#)

- s. We added 3 more Plain English Summaries to our website. Medical articles are notorious for being difficult to read which is why we request easy to read/understand versions.
- i. [IDIOPATHIC INTRACRANIAL HYPERTENSION AND COGNITIVE CHANGES](#) This summary is to explain new research in IIH. This research focus is on cognition which is the ability to perceive and react, process and understand, store and retrieve information, make decisions and produce appropriate responses.
- ii. [INTRACRANIAL PRESSURE DIRECTLY PREDICTS HEADACHE MORBIDITY IN IDIOPATHIC INTRACRANIAL HYPERTENSION](#) This research focus is on what was learnt regarding headaches in people with IIH from the IIHWT clinical trial.
- iii. [IIH COGNITION](#) This research focus is on cognition which is the ability to perceive and react, process and understand, store and retrieve information, make decisions and produce appropriate responses.
- iv. [POOR MENTAL FUNCTIONING \('BRAIN FOG'\) IN PEOPLE WITH IDIOPATHIC INTRACRANIAL HYPERTENSION](#) The main goal for this research study was to show the changes in mental function in people with Idiopathic Intracranial Hypertension.
- t. **Other notable research published during the year.**
- i. Obstructive sleep apnoea (OSA) found to be common in IIH-prevalence 47%, and is associated with changes in papilloedema independent of BMI. Whether OSA treatment has beneficial impact on papilloedema warrants further evaluation.
<https://link.springer.com/.../10.1007/s00415-021-10700-9.pdf>
- ii. The Patients perspective on the burden of IIH.
<https://thejournalofheadacheandpain.biomedcentral.com/articles/10.1186>
- iii. Cognitive performance in idiopathic intracranial hypertension and relevance of intracranial pressure.
<https://pubmed.ncbi.nlm.nih.gov/34704028/>
- iv. Intracranial pressure directly predicts headache morbidity in idiopathic intracranial hypertension.
<https://pubmed.ncbi.nlm.nih.gov/34620087/>

- v. Managing idiopathic intracranial hypertension in pregnancy: practical advice
<https://pn.bmj.com/content/22/4/295?fbclid>

Raising the Profile of IIH

- u. Our online shop has lots of items to help raise awareness of IIH.
https://www.iih.org.uk/section/7/1/online_shop
- v. We want everyone affected by neurological conditions to have access to high quality, joined up care and support to meet their needs wherever 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.
- w. Trustees/Team members attended the following conferences/meetings/lectures during the year.
- British Association for the Study of Headache (BASH).** July 21 - online
 - HIS & EHF joint congress.** September 21 - online
 - Genetic Alliance Members Meeting** October 21 - Online
 - Neurological Alliance Members Meeting** November 2021 - online
 - Rare Voice in Policy meeting** October 21 - online
 - Stent v Shunt Trial Steering Group Meeting** April 22 - online
 - HOPE Programme discussion** May 2022 - Zoom online livestream.
 - European Neuro-ophthalmology Society Conference.** June 2022. Birmingham.

Attending other organisations' conferences/meetings, albeit virtually this year, 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.

- x. **IHC and EHF joint congress**
In February 21 we submitted an abstract to the Congress of the International Headache Congress (IHC) and European Headache Federation (EHF) joint congress that took place 8-12th of September 2021 titled 'Associations between physical activity, quality of life and headache in people with Idiopathic Intracranial Hypertension' and it was accepted as an e-Poster. This is a fantastic opportunity to spread awareness of the difficulties that people with IIH have accessing exercise and was published online.
- 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 15th – 21st 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 huge success due to the shares and retweets the posts received. We kicked the month off with Rachel Turners (founding member) poem which alone was viewed by 54,183 people! A great start to IIH Awareness Month. Once again, we created profile photos for people with IIH to share on the fb and twitter profiles. This year 163 people contacted Shelly to ask her to create a new profile photo for them.

- 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'. All in all, 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 Day** on 5th December 2021. Twitter was the main platform for celebrating this day, raising the profile of IIH UK using the #InternationalVolunteersDay.
- iii. We also celebrated **Volunteers Week** which took place 1st – 7th June 2022.
- iv. **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 to become a member.
 3. **IIH UK online awareness merchandise sales**: www.iihukshop.moonfruit.com/
 4. **Easysearch**: www.iihuk.easysearch.org.uk/
 5. **Easyfundraising**: www.easyfundraising.org.uk/causes/iihuk/
 6. **The Weather Lottery**:
www.theweatherlottery.com/charitiesHomepage.php?client=IIHUK
 7. **The Charities Aid Foundation**:
www.cafonline.org/system/charity-search-results
 8. **Amazon Smile**: www.smile.amazon.co.uk
 9. **Facebook**: provides us with our main source of income from donations.
www.facebook.com/fund/IIHUKCharity/
 10. **PayPal Giving**: www.paypal.com/uk/fundraiser/charity/49628
 11. **eBay for Charities**: www.charity.ebay.co.uk/charity/IIH-UK/49628
 12. **Teespring**: www.teespring.com/en-GB/stores/iih-uk
 13. **DONATE**: <https://platform.nationalfundingscheme.org/idiopathic-intracranial-hypertension-united-kingdom-/HOPE>
 14. **Charity Choice**:
www.charitychoice.co.uk/idiopathic-intracranial-hypertension-united-kingdom-18148

30th June 2022

Michelle Williamson

Michelle Williamson. Chair

Receipts and payments accounts**CC16a**For the period
fromPeriod start date
01/07/2021

To

Period end date
30/06/2022**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 £
A1 Receipts					
Donations & Fundraising	906	-	-	906	871
Just Giving	8,371	-	-	8,371	6,639
Facebook	7,949	-	-	7,949	10,252
Paypal Giving Fund	2,313	-	-	2,313	1,765
Other	11,383	-	-	11,383	1,698
Membership Fees	2,313	-	-	2,313	1,902
Conference Tickets		-	-	-	165
Merchandise	2,206	-	-	2,206	3,366
Bank Interest	6	-	-	6	2
Refunds	9	-	-	9	153
		-	-	-	-
		-	-	-	-
Sub total(Gross income for AR)	35,455	-	-	35,455	26,814
A2 Asset and investment sales, (see table).					
	-	-	-	-	-
	-	-	-	-	-
Sub total	-	-	-	-	-
Total receipts	35,455	-	-	35,455	26,814
A3 Payments					
Governance		-	-	-	£2,094
IT	£1,600	-	-	1,600	£9,343
Merchandise (Stock Purchase)	£726	-	-	726	£2,881
Paypal Fees	£187	-	-	187	£243
Postage & Packaging	£662	-	-	662	£952
Printing & Stationery	£446	-	-	446	£240
Transport		-	-	-	£0
Misc		-	-	-	£113
Refunds	£43	-	-	43	£6
Justgiving Membership	£216	-	-	216	£216
Other Membership	£60	-	-	60	£255
AGM/Patient Conf		-	-	-	£0
Symposium/Conference		-	-	-	£63
Partnership Donations	£12,946	-	-	12,946	£500
Education		-	-	-	£773
Research & Alliance		-	-	-	£0
Surveys	£372	-	-	372	£312
Representatives & Trustee Expenses	£518	-	-	518	£0
Publicity and Profile		-	-	-	£0
Focus Meetings		-	-	-	-
Life Registry		-	-	-	5,000
Hope Program Child	1,500			1,500	
Hope Prgram - Adult Donation	4,020			4,020	
Events		-	-	-	-
Sub total	23,296	-	-	23,296	22,990

<hr/>					
A4 Asset and investment purchases, (see table)					
	-	-	-	-	
	-	-	-	-	
Sub total	-	-	-	-	-
Total payments	23,296	-	-	23,296	22,990
Net of receipts/(payments)	12,159	-	-	12,159	3,825
A5 Transfers between funds	-	-	-	-	-
A6 Cash funds last year end	39,715	-	-	39,715	35,890
Cash funds this year end	51,874	-	-	51,874	39,715

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 £
B1 Cash funds	Bank Accounts	49,614	-	-
	Paypal	2,190	-	-
	Petty Cash	71	-	-
	Total cash funds	51,874	-	-
	(agree balances with receipts and payments account(s))	OK	OK	OK

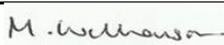
Categories	Details	Unrestricted funds to nearest £	Restricted funds to nearest £	Endowment funds to nearest £
B2 Other monetary assets	Stock	-	-	-
		-	-	-
		-	-	-
		-	-	-
		-	-	-
		-	-	-
		-	-	-

Categories	Details	Fund to which asset belongs	Cost (optional)	Current value (optional)
B3 Investment assets			-	-
			-	-
			-	-
			-	-
			-	-

Categories	Details	Fund to which asset belongs	Cost (optional)	Current value (optional)
B4 Assets retained for the charity's own use			-	-
			-	-
			-	-
			-	-
			-	-
			-	-
			-	-
			-	-
			-	-

Categories	Details	Fund to which liability relates	Amount due (optional)	When due (optional)
B5 Liabilities			-	
			-	
			-	
			-	
			-	

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

Signature	Print Name	Date of approval
	Mrs Michelle Williamson	16/01/2023
3		07/02/2023



Section A

Independent Examiner's Report

Report to the trustees/ members of

Idiopathic Intracranial Hypertension UK

On accounts for the year ended

30th June 2022

Charity no (if any)

1143522

Set out on pages

PAGE 1 OF 2

I report to the trustees on my examination of the accounts of the above charity ("the Trust") for the year ended

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 R O.

Date: 31st Dec 2022

Name: MRS BRENDA BINNIE

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

ACMA

Address:

9 Manor Close
PROSPECT, WORCS WR18 7HQ

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.

