



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

### **TRUSTEES' ANNUAL REPORT AND ACCOUNTS 2020-21**

(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 2020 to 30 June 2021:

Michelle Williamson	Chair
Clare Parr	Acting Treasurer
Norma Ann Dann	Secretary
Amanda Denton	

#### **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 2020-21 and have not received remuneration or any other benefits in undertaking their duties. 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.
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. Norma Dann, Trustee. Amanda Denton, Trustee. Krystal Kirkby, Research Rep. Nisha Sedani, Research Rep. Jemma Fisk, Fundraising Rep. Laura Kerbey, Publicity Rep. Letty Jones, Publicity/Newsletter Rep. Betsy Clark, Accounts Rep. Katie Williamson, Shop Rep. Mellissa Fisher, Arts and Culture 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 and the running of the very active IIH UK groups on Facebook until 14<sup>th</sup> April 2021. 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 2020-21**

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 69,669 unique visits were made and 164,393 pages were viewed. The website is maintained by FAT Promotions and is kept up to date by both FAT and some of our volunteers. The live @IIHUK Charity Twitter feed continues to be a popular feature, and feedback from users (both patients and clinicians) remains positive. We are in the final throes of developing a new website which will be launched soon.
- b. As a charity run by volunteers, we continually review how we can best support the IIH community with the limited resources and volunteers that we have. After much discussion among Trustees we decided to relinquish ownership of our Facebook groups which have now been ran independently since 14<sup>th</sup> April 2021.

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, in our members newsletters and via our patient leaflets and annual conference.

We are looking forward to hosting more webinars, we are also developing 2 new programmes of virtual support. (See item c below) and our new website is nearing completion. The new website will have a members only area where you can view current and past newsletters, download benefit information guides and find the latest conference news as it is announced.

Managing the groups under the charity governed by the charity commission was a lot of work for our volunteers but when groups are run independently there are not as many rules and regulations to follow making them easier to manage. Handing over the groups has freed up some volunteers' time which will enable them to focus on other areas as IIH UK evolves and expands in different ways. The Fb groups have been left in very capable hands with Hannah McNeill and other moderators. (Hannah is stepping down from her team role to enable her to take over the groups.)

**c. HOPE project.**

Our HOPE project will create a virtual support community for people with IIH around the UK. The planned project will allow many opportunities for stakeholder involvement in the development of a bespoke programme for IIH including focus groups, surveys and a steering group. In addition, participants may be offered the opportunity to become facilitators of the HOPE programme and become involved in delivering the HOPE programme to future cohorts. We will tell you about how you can do this as this programme of support develops.

Our Hope Project will provide 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 will be two programmes: a. For people with IIH. b. For parents of children with IIH.

The parent's course will be funded by IIH UK and we have applied for lottery funding to develop a course for adults with IIH.

You can read about the HOPE programme here:

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

- d. **Twitter.** We have now been on twitter for 10 years @IIH UK. A lot of clinicians are on Twitter whom you are able to follow, ask questions etc. We have 2351 followers on twitter, up 299 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.** As the situation with Coronavirus (Covid-19) 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.
- g. Last year we began working with Mellissa Fisher, who was then the artist in residence at University Hospitals Birmingham. Impressed with the work she was doing we invited Mellissa to join our team and she is now our Arts and Culture Rep with an aim to develop a positive culture in people with IIH through Art. Soon she will be launching workshops aimed at Visualising Physical Pain through art, you will find details of these workshops on our website and social media sites.

## **Education**

- h. **Leaflets.** Four 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, it's been a long process and they will be added to the Leaflet page of our website as they are completed. Leaflets completed so far are:

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  
 Pappiloedema

Pregnancy and Family Planning with IIH  
 IIH and Flying  
 Greater Occipital Nerve Block (GON)  
 BOTOX/ Calcitonin Gene-Related Peptide (CGRP)

- i. Our **Patient Conference** was held by Webinar on 26<sup>th</sup> June 2021. Recording of this webinar have been sent to all members and will be made public during September Awareness Month 2021.  
 Webinar Programme:

Welcome and Housekeeping	Amanda Denton IIH UK Trustee and Research Representative
Developing a positive culture in people with IIH through Art	Melissa Fisher Arts and Culture Representative IIH UK
Development of paediatric guidelines for children with IIH	Dr Pooja Harijan and Dr Deepa Krishnakumar Addenbrookes
HOPE programme for IIH For parents of children with IIH and people with IIH	Gabriela Matouskova Chief executive officer Hope for the community
<b>B R E A K</b>	
Group management for people with IIH	Dr Sui Wong Guys and St Thomas Hospital
What is medication overuse, and how do I avoid it?	Dr Ben Wakerley Gloucestershire
<b>L U N C H</b>	
New Trial Shunts vs Stent	Dr Ben Wakerley Gloucestershire
IIH:WT and IIH androgen study	Prof Alex Sinclair and Miss Susie Mollan Birmingham University
What is polycystic ovarian syndrome and does it impact my IIH?	Dr Mark Thaller Birmingham
<b>B R E A K</b>	
Obesity Stigma Results of the IIH UK survey	Amanda Denton IIH UK Research Rep and Trustee

Research Round up	Prof Alex Sinclair IIH UK Patron
-------------------	-------------------------------------

- j. On the 02/02/21 IIH UK undertook its first webinar for IIH UK Members with guest speakers Prof Alex Sinclair, Dr Mark Thaller, Dr Andreas Yiangou and Miss Susan Mollan. This webinar was centred around the impacts of COVID-19 on IIH patients and the introduction of a new headache treatment for IIH. It also provided IIH UK members with the opportunity to submit questions to the panellists in the form of a Q&A. You can watch it here:  
<https://www.youtube.com/watch?v=3XtuVKgo5Z0>
- k. We continue to sponsor the **Paediatric IIH Special Interest Group (SIG)**, led by Dr Krishnakumar - Addenbrookes, Cambridge. Our Chair Shelly Williamson and Publicity Rep Laura Kerbey are members of this SIG. (both have children with IIH) also, Nisha Ravel, our Research Rep joined the SIG in February. There was 1 virtual meeting during the year on 26/6/21 to discuss the ongoing development of paediatric guidelines.
- l. The 2nd Cambridge Paediatric PTCS/IIH study day was held virtually on Friday 2nd October 2020. Organised by Dr D Krishnakumar, sponsorship from IIH UK for administrative support meant excellent organisation and attendee experience. We missed the lovely atmosphere from the previous year in Cambridge with invaluable face to face contact. On the other hand, the virtual format meant that they could welcome a larger audience of over 50, including international colleagues. The positive feedback reflected a wealth of expert speakers from Cambridge, London and Birmingham and also active audience participation with many paediatricians, paediatric neurologists and ophthalmologists joining in the national conversation about paediatric IIH. We hope that they can build on this experience and that the meeting continues to stimulate interest and debate in paediatric PTCS/IIH in coming years.

Programme of Speakers. Evaluating Optic Disc Swelling – The Ophthalmologist’s Perspective  
Mr Adam Bates, Consultant Ophthalmologist, Maidstone and Tunbridge Wells.

The Role of CSF Diversion In PTCS-IIH. Mr Conor Mallucci, Consultant Paediatric Neurosurgeon, Liverpool.

CSF Infusion Studies In PTCS-IIH Mr Ibrahim Jalloh, Consultant Paediatric Neurosurgeon, Cambridge.

Radiological features of PTCS-IIH. Professor Swarupsinh Chavda / Dr Satheesh Ramalingam, Consultant Neuroradiologists, Birmingham.

PTCS/IIH - A Single Centre Experience Dr Prab Prabhakar, Consultant Paediatric Neurologist, GOSH.

Epidemiology of PTCS-IIH Dr William Whitehouse, Consultant Paediatric Neurologist, Nottingham

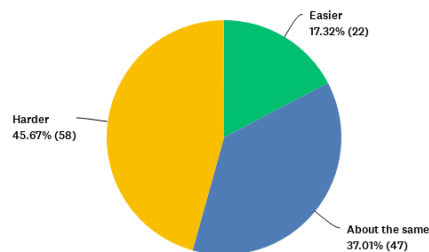
- m. During the course of the year, we developed information packs for clinicians. These are a work in progress and will be launched soon.

### **Research**

- m. **Life in Lockdown Survey:** Early July 2020 we released the information gathered from

a survey we put out titled Life in lockdown to see how Lockdown had affected the people we support. We asked just one question – Life in lockdown with IIH is .... You can see from the graph below that around 45% of people with IIH found it harder, around 37% found it about the same and around 17% found it easier.

Q1 Life in lockdown with IIH is....



The respondents told us why they chose the answer they did which we then shared on our social media sites in the form of quotes which we shared on our social media sites. Here is a small selection.



- n. 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 the IIH:Life registry at a cost of £5,000 per annum.
- o. **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 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.

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://jinnp.bmj.com/content/early/2020/12/23/jinnp-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.

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.

- p. #10 of our Top ten areas for IIH research is 'What is the best type of intervention to treat IIH' currently we do not know which of the current available treatments is the best to treat IIH so we 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.
- q. **Negative impact of COVID-19 lockdown on papilloedema and idiopathic intracranial hypertension** - <https://jinnp.bmj.com/content/92/7/795>  
We funded the open access costs to this paper as we thought it important that it be publicly available. At the time of publication we felt that if there was another National lockdown IIH clinics must not be cancelled!
- r. **Investigating painkiller use in individuals with IIH survey:**  
This survey was developed by our Research Rep Krystal Hemmings. We are busy writing up the results of this survey and will let you know as soon as they are published.
- s. **Barriers to weight loss and exercise survey:**  
This research was developed by our Research Reps Krystal Hemmings in conjunction with Derby University and Amanda Denton. They used the data from a smaller pilot survey to come up with a more focused survey that was relevant to IIH patients. Krystal and Amanda put together two surveys for people with IIH to firstly; identify perceived barriers to weight loss and exercise and then to rank these in order of importance. The survey highlighted that exercise exacerbates symptoms of IIH for many and that there was a mismatch between researcher's perceived benefits of weight loss and participants perceptions of the effect of weight loss on their symptoms.

Top 3 perceived barriers to weight loss – Fatigue, Pain and Mood

Top 3 perceived barriers to exercise – Fatigue, Headache and Dizziness

The results show that further research is needed to understand why some people with IIH experience exacerbations of their IIH symptoms with exercise. Explore what type of exercise is best for people with IIH and that there is a need to explore the barriers to weight loss and exercise with people with IIH at greater depth. An article outlining this research will be put onto the IIH UK Website soon.



t. **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 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 analysed. The results showed that people with IIH have low levels of physical activity and take little exercise. Physical activity is related to quality of life in people with IIH. Physical activity was not related to age, current or diagnosis BMI (Body Mass Index) or headache impact score in people with IIH.

‘Conclusion. 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 explored in people with IIH.’ We had hoped to develop this research further via a work shop that was to be held at our 2020 Patient Conference, unfortunately it was cancelled due to COVID-19 but we will continue to work on this research and share any future developments with you. This research was accepted as a e-poster at the International Headache Congress and European Headache Federation Congress. See item l below.

- u. **IIH:Pressure.** This trial aimed to use a new method of pressure monitoring to measure the brain pressure continuously without lumbar puncture and to test if a new drug (Exenatide) can change brain pressure. It was a randomised double-blind study so those who were accepted onto the trial were put into one of two groups which were decided at random. This trial was successful and a larger Phase III trial is being developed. The Phase III trial aims to reformulate exenatide into a drug that combats both pressure and pain, due to start late 2021 we will keep you informed and are excited to see the final results.

v. **Obesity Stigma in IIH – IIH UK survey 2021 - Amanda Denton**

In 2021 IIH UK carried out a survey to explore obesity stigma and the management of weight in IIH. We were overwhelmed with responses from over 500 people within a week and closed the survey at 625 responses.(the maximum allowed on our survey monkey subscription) Thank you all for your input into this survey which is an emotive subject for people with IIH. The data was analysed and Amanda Denton, Trustee and Research Rep presented the research to IIH UK members on the 26th June at our annual members conference. 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 is being offered. A full report will be added to the new website in due course.

w. **Other notable research published during the year.**

- i. Exciting new research from the University of Birmingham evaluated the use of a migraine drug to treat headache in people with IIH who no longer have Papilloedema (Ocular Remission) but still have symptoms.

<https://headachejournal.onlinelibrary.wiley.com/doi/full/10.1111/head.14026>

- ii. **Systemic and adipocyte transcriptional and metabolic dysregulation in idiopathic intracranial hypertension.** <https://insight.jci.org/articles/view/145346>

‘Conclusion. These data from this research show that IIH is a metabolic disorder in

which adipose tissue dysfunction is a feature of the disease. Managing IIH as a metabolic disease could reduce disease morbidity and improve cardiovascular outcomes.

iii. **Effectiveness of Bariatric Surgery vs Community Weight Management Intervention for the Treatment of Idiopathic Intracranial Hypertension.** The first lot of results from this trial, (IIH:WT) which we funded the travelling expenses of participants, was published in April. You can read it here:

<https://jamanetwork.com/journals/jamaneurology/fullarticle/2778650>

iv. **Current Perspectives on Idiopathic Intracranial Hypertension without Papilloedema**

<https://www.mdpi.com/2075-1729/11/6/472/htm>

v. **Headache attributed to idiopathic intracranial hypertension and persistent post-idiopathic intracranial hypertension headache: A narrative review.**

<https://headachejournal.onlinelibrary.wiley.com/doi/10.1111/head.14125>

- x. As research papers are complicated to read we liaised with the researchers and have produced plain english summaries which will be available on our new website. We aim to do this for more research papers as they are published.

### **Raising the Profile of IIH**

y. **Art Competition.**

During December we held a virtual meeting with the entrants and judges of our Art Competition to announce the winners. The winner of the adult category was Alister McCracken and the winner of the Child category was Ellie Rogerson Rattigan. Ellie won an iPad as her prize and Alister was invited to attend an unveiling ceremony of his art work which will be displayed at Birmingham Queen Elizabeth Hospital. The date has been postponed due to COVID but as soon as all restrictions are lifted Alister and his mother will be invited to visit the IIH labs at Birmingham for the unveiling. You can view Alister and Ellie's artwork at the end of this report. Other entries can be viewed on our website soon.

- z. Trustees/Team members attended the following conferences/meetings/lectures during the year:

**Paediatric PTCS/IIH study day.** October 20. Online

**Genetic Alliance Members Meeting.** October 20. Online

**Focus Group Meeting with Birmingham Team.** October 20. Online

**Neurological Alliance Members Meeting.** Nov 20, Online

**APPG on rare, genetic and undiagnosed conditions.** Nov 20. Online

**First meeting with HOPE for the Community.** Nov 20. Online.

**Rare Disease Day Parliamentary Reception.** Feb 21. Online

**Shunt V Stent Trial Steering Group Meeting.** Apr 21. Online

**Children's Headache Network (CHaN) SIG Meeting.** June 21. Online.

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.

I. **IHC and EHF joint congress**

In February we submitted an abstract to the Congress of the International Headache Congress (IHC) and European Headache Federation (EHF) joint congress that takes place 8-12<sup>th</sup> of September 21 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.

II. **Brain Awareness Week (BAW)** is the global campaign to increase public awareness of the progress and benefits of brain research. This financial year it ran from 15<sup>th</sup> – 21<sup>st</sup> March. This year in support of Brain Awareness Week we shared quotes from our "Describing the impact of headache in the voices of people with IIH" research on our social media sites.

III. New items added to our online store at <http://www.iihukshop@moonfruit.com> this year are:

- a. Shunt Cards which hold all of your shunt details.
- b. During the year we teamed up with Nick Hardman at 3dtoyshop who has made his Teddy shunt valve in IIH colours exclusively for IIH UK. Available in Blue/Green and Blue/White. They are designed to be sewn onto your child's (or your own) soft toy and can be sewn on in all shunt positions including VP & LP. For every toy shunt valve purchased we will provide one free of charge to the NHS for neuro teams to use as a tool to help explain shunt surgery to children.

IV. **September Awareness Month.** Provides an opportunity for IIH Patients 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 28,196 people! A great start to IIH Awareness Month. All in all, the posts to our Fb Charity Page throughout September reached 209,649 people. An amazing achievement!

V. **Rare Disease Day** takes place on the last day of February each year.

This year our publicity Rep Letty created a RDD profile frame for everyone to add to their profile photo on Facebook, we ran a weeklong sale on selected items in our shop and all purchases were entered into a raffle to win one of our Giant plush brains. The theme for this year was 'We are Rare, we are many, we are strong and we are proud'. All in all, it was a perfect day spent spreading awareness and raising the profile of Idiopathic Intracranial Hypertension.

VI. As a Charity run solely by Volunteers, we just had to celebrate **International Volunteers Day** on 5<sup>th</sup> December 2020. Twitter was the main platform for celebrating this day, raising the profile of IIH UK using the #InternationalVolunteersDay.

VII. We also celebrated **Volunteers Week** which took place 1<sup>st</sup> – 7<sup>th</sup> June 2020.

VIII. **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. **Easysearch:** [www.iihuk.easysearch.org.uk/](http://www.iihuk.easysearch.org.uk/)
5. **Easyfundraising:** [www.easyfundraising.org.uk/causes/iihuk/](http://www.easyfundraising.org.uk/causes/iihuk/)
6. **The Weather Lottery:**  
[www.theweatherlottery.com/charitiesHomepage.php?client=IIHUK](http://www.theweatherlottery.com/charitiesHomepage.php?client=IIHUK)
7. **The Charities Aid Foundation:**  
[www.cafonline.org/system/charity-search-results](http://www.cafonline.org/system/charity-search-results)
8. **Amazon Smile:** [www.smile.amazon.co.uk](http://www.smile.amazon.co.uk)
9. **Facebook:** provides us with our main source of income from donations.  
[www.facebook.com/fund/IIHUKCharity/](http://www.facebook.com/fund/IIHUKCharity/)
10. **PayPal Giving:** [www.paypal.com/uk/fundraiser/charity/49628](http://www.paypal.com/uk/fundraiser/charity/49628)
11. **eBay for Charities:** [www.charity.ebay.co.uk/charity/IIH-UK/49628](http://www.charity.ebay.co.uk/charity/IIH-UK/49628)
12. **Teespring:** [www.teespring.com/en-GB/stores/iih-uk](http://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](http://www.charitychoice.co.uk/idiopathic-intracranial-hypertension-united-kingdom-18148)

30<sup>th</sup> June 2021

*Michelle Williamson*

Michelle Williamson. Chair

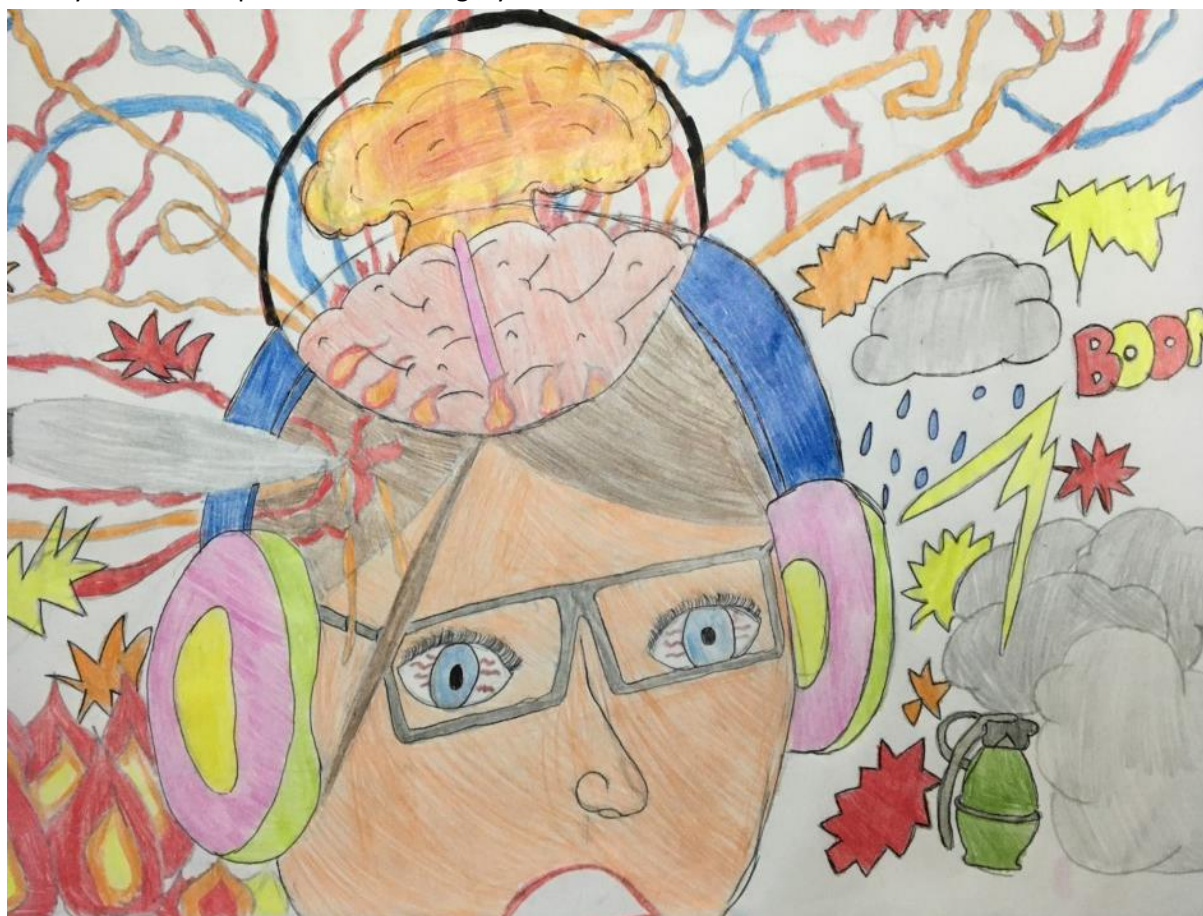
y. IIH Art Competition Adult category winner



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. Alister McCracken



y. IIH Art Competition Child category winner



Ellie Rogerson Rattigan Age 13. This drawing is my interpretation of idiopathic intracranial hypertension (IIH). My IIH journey began in April 2019 when I was 12 years old. IIH gives me bad headaches, and if I'm having a bad day it feels like a bomb going off inside my head! I had a lumbar puncture done in Addenbrookes Hospital during February. In my drawing everything has a meaning to it. I find if the weather is rainy/muggy my headaches become worse, this is why I have added clouds in my Art work. I put headphones on the girl in the drawing because listening to music relaxes me, and it calms me down. All the squiggly lines represent all the pain in my head. The explosion represents how sore my head can feel if I'm having a bad day. Finally, the flames and the knife also represent the pain in my head. I am now on medication to try and relieve pressure/swelling from my head, I hope that this will be successful. Ellie Rogerson Rattigan Age 13



**Section A**

**Independent Examiner's Report**

**Report to the trustees/  
members of**

Idiopathic Intracranial Hypertension UK

**On accounts for the year  
ended**

30th June 2021

**Charity no  
(if any)**

1143522

**Set out on pages**

Page 1 of 2

**Responsibilities and  
basis of report**

I report to the trustees on my examination of the accounts of the above charity ("the Trust") for the year ended **30/ 06 / 2021**. With a Total Cash Funs balance of £39,715

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").

**Independent  
examiner's statement**

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.

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 Feb 2022*

**Name:**

Brenda Binnie

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

ACMA

**Address:**

9 Manor Close Droitwich, Worcestershire WR9 8HG

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.



## Receipts and payments accounts

CC16a

For the period  
from

01/07/2020

To

30/06/2021

### 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	871	-	-	871	19,978
Just Giving	6,639	-	-	6,639	-
Facebook	10,252	-	-	10,252	-
Paypal Giving Fund	1,765	-	-	1,765	-
Other	1,698	-	-	1,698	-
Membership Fees	1,902	-	-	1,902	1,892
Conference Tickets	165	-	-	165	275
Merchandise	3,366	-	-	3,366	2,477
Bank Interest	2	-	-	2	30
Refunds	153	-	-	153	166
		-	-	-	-
		-	-	-	-
<b>Sub total (Gross income for AR)</b>	<b>26,814</b>	<b>-</b>	<b>-</b>	<b>26,814</b>	<b>24,818</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>26,814</b>	<b>-</b>	<b>-</b>	<b>26,814</b>	<b>24,818</b>
<b>A3 Payments</b>					
Governance	£2,094	-	-	2,094	-
IT	£9,343	-	-	9,343	1,496
Merchandise (Stock Purchase)	£2,881	-	-	2,881	1,157
Paypal Fees	£243	-	-	243	217
Postage & Packaging	£952	-	-	952	826
Printing & Stationery	£240	-	-	240	235
Transport	£0	-	-	-	871
Misc	£113	-	-	113	165
Refunds	£6	-	-	6	-
Justgiving Membership	£216	-	-	216	274
Other Membership	£255	-	-	255	235
AGMPatient Conf	£0	-	-	-	3,128
Symposium/Conference	£63	-	-	63	2,000
Partnership Donations	£500	-	-	500	-
Education	£773	-	-	773	3,092
Research & Alliance	£0	-	-	-	-
Surveys	£312	-	-	312	312
Representatives & Trustee Expenses	£0	-	-	-	-
Publicity and Profile	£0	-	-	-	500
Focus Meetings	-	-	-	-	1,217
Life Registry	5,000	-	-	5,000	5,000
Events	-	-	-	-	116
<b>Sub total</b>	<b>22,990</b>	<b>-</b>	<b>-</b>	<b>22,990</b>	<b>20,840</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>	<b>22,990</b>	<b>-</b>	<b>-</b>	<b>22,990</b>	<b>20,840</b>
<b>Net of receipts/(payments)</b>	<b>3,825</b>	<b>-</b>	<b>-</b>	<b>3,825</b>	<b>3,978</b>
<b>A5 Transfers between funds</b>	<b>-</b>	<b>-</b>	<b>-</b>	<b>-</b>	<b>-</b>
<b>A6 Cash funds last year end</b>	<b>35,890</b>	<b>-</b>	<b>-</b>	<b>35,890</b>	<b>31,912</b>
<b>Cash funds this year end</b>	<b>39,715</b>	<b>-</b>	<b>-</b>	<b>39,715</b>	<b>35,890</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>	Bank Accounts	38,046	-	-
	Paypal	1,599	-	-
	Petty Cash	71	-	-
	<b>Total cash funds</b>	<b>39,715</b>	<b>-</b>	<b>-</b>
	(agree balances with receipts and payments account(s))			
		Unrestricted funds to nearest £	Restricted funds to nearest £	Endowment funds to nearest £
<b>B2 Other monetary assets</b>	Stock	-	-	-
		-	-	-
		-	-	-
		-	-	-
		-	-	-
		-	-	-
		-	-	-
<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	





**Section A**

**Independent Examiner's Report**

**Report to the trustees/  
members of**

Idiopathic Intracranial Hypertension UK

**On accounts for the year  
ended**

30th June 2021

**Charity no  
(if any)**

1143522

**Set out on pages**

Page 1 of 2

**Responsibilities and  
basis of report**

I report to the trustees on my examination of the accounts of the above charity ("the Trust") for the year ended **30/ 06 / 2021**. With a Total Cash Funs balance of £39,715

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").

**Independent  
examiner's statement**

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.

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 Feb 2022*

**Name:**

Brenda Binnie

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

ACMA

**Address:**

9 Manor Close Droitwich, Worcestershire WR9 8HG

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.

## Receipts and payments accounts

CC16a

For the period  
from

01/07/2020

To

30/06/2021

### 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	871	-	-	871	19,978
Just Giving	6,639	-	-	6,639	-
Facebook	10,252	-	-	10,252	-
Paypal Giving Fund	1,765	-	-	1,765	-
Other	1,698	-	-	1,698	-
Membership Fees	1,902	-	-	1,902	1,892
Conference Tickets	165	-	-	165	275
Merchandise	3,366	-	-	3,366	2,477
Bank Interest	2	-	-	2	30
Refunds	153	-	-	153	166
		-	-	-	-
		-	-	-	-
<b>Sub total (Gross income for AR)</b>	<b>26,814</b>	<b>-</b>	<b>-</b>	<b>26,814</b>	<b>24,818</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>26,814</b>	<b>-</b>	<b>-</b>	<b>26,814</b>	<b>24,818</b>
<b>A3 Payments</b>					
Governance	£2,094	-	-	2,094	-
IT	£9,343	-	-	9,343	1,496
Merchandise (Stock Purchase)	£2,881	-	-	2,881	1,157
Paypal Fees	£243	-	-	243	217
Postage & Packaging	£952	-	-	952	826
Printing & Stationery	£240	-	-	240	235
Transport	£0	-	-	-	871
Misc	£113	-	-	113	165
Refunds	£6	-	-	6	-
Justgiving Membership	£216	-	-	216	274
Other Membership	£255	-	-	255	235
AGMPatient Conf	£0	-	-	-	3,128
Symposium/Conference	£63	-	-	63	2,000
Partnership Donations	£500	-	-	500	-
Education	£773	-	-	773	3,092
Research & Alliance	£0	-	-	-	-
Surveys	£312	-	-	312	312
Representatives & Trustee Expenses	£0	-	-	-	-
Publicity and Profile	£0	-	-	-	500
Focus Meetings	-	-	-	-	1,217
Life Registry	5,000	-	-	5,000	5,000
Events	-	-	-	-	116
<b>Sub total</b>	<b>22,990</b>	<b>-</b>	<b>-</b>	<b>22,990</b>	<b>20,840</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>	<b>22,990</b>	<b>-</b>	<b>-</b>	<b>22,990</b>	<b>20,840</b>
<b>Net of receipts/(payments)</b>	<b>3,825</b>	<b>-</b>	<b>-</b>	<b>3,825</b>	<b>3,978</b>
<b>A5 Transfers between funds</b>	<b>-</b>	<b>-</b>	<b>-</b>	<b>-</b>	<b>-</b>
<b>A6 Cash funds last year end</b>	<b>35,890</b>	<b>-</b>	<b>-</b>	<b>35,890</b>	<b>31,912</b>
<b>Cash funds this year end</b>	<b>39,715</b>	<b>-</b>	<b>-</b>	<b>39,715</b>	<b>35,890</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>	Bank Accounts	38,046	-	-
	Paypal	1,599	-	-
	Petty Cash	71	-	-
	<b>Total cash funds</b>	<b>39,715</b>	<b>-</b>	<b>-</b>
	(agree balances with receipts and payments account(s))			
		Unrestricted funds to nearest £	Restricted funds to nearest £	Endowment funds to nearest £
<b>B2 Other monetary assets</b>	Stock	-	-	-
		-	-	-
		-	-	-
		-	-	-
		-	-	-
		-	-	-
		-	-	-
<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	