



IDIOPATHIC INTRACRANIAL HYPERTENSION UK (IIH UK)

TRUSTEES' ANNUAL REPORT AND ACCOUNTS 2019-20

(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 2019 to 30 June 2020:

Michelle Williamson	Chair
Lizzie Aylott	Treasurer
Norma Ann Dann	Secretary
Clare Parr	
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 July 2019. The charity is constituted by association.
3. All trustees have given their time voluntarily during 2019-2020 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.

Charity Objects

5. The charity's objects as amended in the constitution on 13 June 2020 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

6. 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. 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 objects 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.

At the yearend our team members are: Shelly Williamson, Trustee. Clare Parr, Trustee. Norma Dann, Trustee. Amanda Denton, Trustee. Krystal Kirkby, Research Rep. Nisha Raval, Research Rep. Steph Sinclair, Fundraising Rep. Laura Kerbey, Publicity Rep. Letty Jones, Newsletter Rep. Betsy Clark, Accounts Rep. Katie Williamson, Shop Rep. Hannah McNeill, Graphics Rep/Fb admin. Andrea May, Fb Mod. Claire Johnston, Fb Mod. Laura Mauchan, Fb Mod. Michelle Leatham, Fb Mod. Tiffany Heaven, Fb Mod.

7. We became General Data Protection Regulation (GDPR) compliant in March 2018.
8. 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 iii below.)

Summary of IIH UK's achievements during 2019-20

9. 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 79,998 unique visits were made and 121,886 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.
- b. **Management of Facebook Support Group.** IIH UK continues to run and administer the Fb group 'IIH Support UK'. With an ever-growing membership (1158 new members this year) this group now has 6568 members; often with people joining within days of diagnosis, it has enabled the Charity to respond and support people more quickly.

- c. **Regional Groups.** Membership of the online regional groups, which are facilitated by IIH UK, continue to increase with the South East still being the largest group in terms of numbers. The restructuring continues to work well in the 14 groups which cover all four nations and allows people to discuss local issues and meet-up socially.
- d. **Weight Loss Support Group.** There are now 2210 members in the Weight Loss Support Group, a growth of 380 over the year. IIH UK facilitates the group to provide healthy recipes and links to NHS healthy eating websites. There is definitive evidence that weight and IIH are related and with over 90% of patients diagnosed with IIH being overweight women, IIH UK is committed to supporting healthy weight loss.
- e. The **IIH Employment and Study support group** now has 635 members; this group supports people with IIH who are in work or further education.
- f. **IIH support for men** was created 'just for men', a safe place where they can discuss men's issues. Membership of this group stands at 54, a growth of 30 over the last year which is the largest yearly growth we have had since we launched the group in 2017.
- g. **Twitter.** We have now been on twitter for 9 years @IIH UK. The advantage over Facebook is that a lot of clinicians are also on Twitter whom you are able to follow, ask questions etc. We have 2052 followers on twitter, up 354 on the previous year.
- h. **COVID-19.** As the situation with Coronavirus (Covid-19) developed, 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.

Education

- i. **Leaflets.** Three years ago we commissioned the 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)

- j. Our **Patient Conference** was held in Exeter, Devon on the 13th July 2019.

Speakers were:

Dr Brendan Davies – Consultant Neurologist - University Hospitals of North Midlands. Clinical Director of the North Midlands Regional Headache Clinic.

Dr James Mitchell – Consultant Neurologist. Clinical Research Fellow, the University Hospitals Birmingham.

Dr Abd Tahrani - Institute of Metabolism and Systems Research, NIHR Clinician Scientist at the University of Birmingham. Honorary Consultant in Obesity, Diabetes and Endocrinology at University Hospitals Birmingham NHS Foundation Trust.

Professor Alexandra Sinclair – IIH UK Patron. Consultant Neurologist, University Hospitals Birmingham. NIHR Clinician Scientist, Institute of Metabolism and Systems Research, the University of Birmingham and the Centre for Endocrinology, Diabetes and Metabolism, Birmingham Health Partners.

Amanda Denton – IIH UK Research Rep.

- 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) There were 3 meetings arranged during the year. The September 19 meeting went ahead as planned but sadly the face to face meetings that were to be held in March 20 and May 20 were cancelled due to COVID - 19. Instead a virtual meeting was held to discuss the ongoing task of developing Paediatric IIH Guidelines.

A virtual Paediatric IIH education day is being arranged by the Cambridge team which is to be held in October 2020 which we have sponsored. Paediatric IIH has been ignored for too long and we are hopeful that these meetings and education days will give paediatric IIH the attention it deserves.

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 The IIH:Life registry for the next 2 years at a cost of £5,000 per annum.
- m. **The IIH:Life** registry database comprises of two parts – one for clinician entries and the other for patient input. The medical professionals will be entering data which will include: visual test results, lumbar puncture opening pressures, medication (including

dose), height, weight etc. The patient will be asked about their pain levels and asked to complete an annual Quality of Life survey. It is hoped that the registry would be able to indicate the optimal treatment for:

1. Sight Preservation
2. Managing Headaches
3. Improving IIH Sufferers' Quality of Life.

- n. **IIH:DT** Trustees sat on the steering group for the IIH Drug Trial. Launched in 2015 this research trial titled: 'Assessing the Efficacy and Safety of an 11 β -Hydroxysteroid Dehydrogenase Type 1 Inhibitor (AZD4017) in the Idiopathic Intracranial Hypertension Drug Trial, IIH:DT Clinical Methods and Design for a Phase II Randomized Controlled Trial'. This trial recruited 31 patients and is the first phase 2 randomized controlled trial in idiopathic intracranial hypertension evaluating a novel therapeutic target. The results have now been published and concluded; "This is the first phase II study evaluating the novel pharmacological therapy AZD4017 in IIH. We demonstrate safety, tolerability and provide strong in vivo evidence for effective 11 β -HSD1 inhibition. There was a significant reduction in ICP in the AZD4017 and not the placebo group over the treatment duration (exploratory within-group analysis) and reduction in ICP significantly correlated with reduction in serum cortisol:cortisone ratio; however, the primary analysis evaluating the difference between groups at 12 weeks did not reach statistical significance. The data suggest that 11 β -HSD1 inhibition may have utility for reducing the effects and consequences of raised ICP in patients with IIH. Further evaluation of these therapeutic strategies in this disabling disease, for which few useful medical options exist, would be worthwhile." You can read the paper here:

<https://academic.oup.com/braincomms/article/2/1/fcz050/5699900>

o. **Sir Jules Thorn Charitable Trust**

We were very pleased to hear that during the course of the year our Patron, Professor Sinclair, was awarded a Research grant by the Jules Thorn Charitable Trust for £1.68 Million to develop her research.

Professor Alexandra Sinclair and her team will use the award to address a rising incidence of Idiopathic Intracranial Hypertension (IIH). "There are currently no specific treatments for raised brain pressure and headaches in IIH and the underlying causes of them are unknown. Professor Sinclair's previous work has identified that an existing drug, Exenatide, could prove beneficial to IIH sufferers. The project will include a UK-wide trial to evaluate the benefits of Exenatide in this context and complimentary research to evaluate how raised brain pressure directly causes headaches. In addition to the potential benefits for IIH, the results may be relevant to other conditions of raised brain pressure, including traumatic brain injury."

We supported Professor Sinclair in her bid for this grant as a collaborator. IIH UK will advise on all aspects of the trial from the perspective of patients, and have been involved in its design - having taken part in a patient and public involvement focus group meeting in March 2019. Our expertise in communicating with IIH patients and our wide reach will enable us to play an integral part in the trial; from the recruitment of participants, to obtaining endorsement from the wider IIH community for the development of the first ever IIH-specific treatment.

To facilitate patient completion of the trial, the group felt that an “IIH Hero’s” campaign could be an option for patients (after appropriate information in the Participation Information Sheet and consent) whereby patients enrolling and ultimately completing could be given special recognition by the charity for their role in moving the research forward. A member of the IIH UK team will join the trial steering committee.

In demonstration of our strong support, IIH UK is able to provide tailored care for IIH patients taking part in this trial through an independent IIH advisor (available over the phone) to support wellbeing, as well as financial assistance. In terms of the financial contribution, some patients may require additional assistance in order to participate in the trial. IIH UK will consider providing costs that fall outside of this grant application on a case by case basis (for example patients with full time caring responsibilities that may require childcare to participate fully).

p. **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.

q. **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.

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

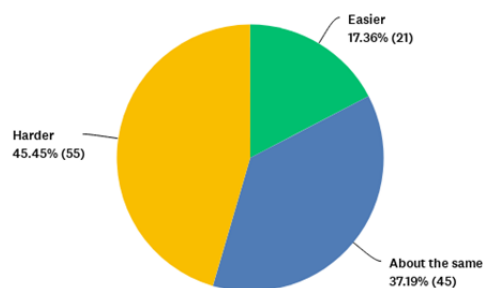
Research Reps Amanda Denton and Dr Krystal Hemmings (University of Derby) and a Physiotherapy researcher from Plymouth University Dr Hilary Gunn carried out and analysed this survey. An online survey was sent to people with IIH to complete. The survey contained measures of physical activity, quality 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 workshop 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.

- s. The Birmingham Research team recruited the 16 patients necessary for the second phase of the research trial, **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 (Exanatide) 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 results from the Phase II trial will be released soon.
- t. **Life in Lockdown survey.**
In March 2020 the UK and world experienced an unprecedented event of a global pandemic Covid-19. In the UK lockdown started on March the 23rd and IIH UK was keen to capture the impact on the lives of people with IIH. A great response was received to the IIH UK short survey about lockdown. 121 people responded to the survey which ran from 24/05/2020 to 24/06/2020. 120/121 who responded added additional comments to explain their response. Most people felt that life was easier or about the same (54%) however 45% felt that life in lockdown was harder

Q1 Life in lockdown with IIH is....



You can read our 'Life in Lockdown' report on our website Here:

https://www.iih.org.uk/images/Life_in_lockdown_result_summary.pdf

- u. During the year we started working with Melissa Fisher who has become artist in residence at University Hospitals Birmingham. Melissa has IIH and was keen to promote awareness of IIH in her work. So far in the residency we have helped her collect data from the IIH community with a questionnaire about sensory experiences of symptoms. She hopes to visualise the data and create installations that will give an insight into what the condition feels like. Melissa has been creating

sculptures of parts of the body that are affected by IHH like the spine, brain and ears and is currently developing an interactive sound artwork based on pulsatile tinnitus. Overall, she wants to give the IHH community an additional voice into the art and science world, with aims to raise awareness and understanding of invisible symptoms, delivering powerful sensory exhibitions, engaging workshops, public talks, whilst collaborating with leading researchers in the UK.

Raising the Profile of IHH

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

Paediatric IHH Study Day. September 19, Addenbrookes, Cambridge.

Find a Cure Rare Disease Showcase. October 19. Manchester.

Headache Academy Event. October 19. RCO, London. (two day event)

Focus Group Meeting with Prof Sinclair and team. Nov 19. Birmingham.

Patient and public Involvement Meeting. Nov 19. Walton, Liverpool.

Neurological Alliance Members Meeting. Nov 19. London.

Rare Disease Day Reception. Feb 20, London.

Events Cancelled due to COVID-19

UK Neuro-Ophthalmology Society Event. Mar 20, St. Thomas', London.

CSF Disorders Day. May 20. Birmingham.

Virtual Meetings/Events.

National Neuro Advisory Group & Clinical Reference Group Meeting. Mar 20.

Focus Group Meeting with Prof Sinclair and Miss Mollan. May 20.

Paediatric IHH Meeting. May 20.

European Headache Federation Congress. June 20.

Attending other organisations' conferences/meetings provide an opportunity for Trustees to meet other attendees and develop friendships with other likeminded organisations enabling us to raise the profile of IHH.

- w. In February we submitted an abstract to the Congress of the European Headache Federation (EHF) titled 'Describing the impact of headache in the words of people with Idiopathic Intracranial Hypertension - A qualitative social media study' and it was accepted as an ePoster. We were due to travel to Berlin to present this poster, due to COVID-19 the event moved to online. The abstract submitted by IHH UK will be published in The Journal of Headache and Pain, a peer reviewed medical journal. This is a fantastic opportunity to spread awareness of the impact of headache in IHH among clinicians.

In July we developed a series of quotes from this research and shared them on our social media sites, this gained much interest from the medical community and the quotes were shared by many doctors.

Describing the impact of headache in the words of people with Idiopathic Intracranial Hypertension (IIH) - A qualitative social media study
Denton AJ, Williamson SJ, Grech OJ, Mollan, SP and Sinclair, AJ*

Background
Idiopathic intracranial hypertension (IIH) is a new disabling condition characterized by elevated intracranial pressure (ICP) and disordered cerebrospinal fluid dynamics (CSF). People with IIH experience chronic headaches alongside other symptoms such as visual loss (2). Quantitative reports of headache in IIH show that it negatively affects quality of life (3-5) and is daily in most (6-8) (4-6). In 2018 the James Lind Alliance Priority Setting Partnership (JLAPP) involving health professionals, patients and carers identified headache as one of the top 10 unmet needs in IIH (3). The qualitative lived experience of the impact of headache in people with IIH is under reported.

Question - What is the lived experience of headache in the words of people with IIH?

IDIOPATHIC INTRACRANIAL HYPERTENSION PRIORITY SETTING PARTNERSHIP
Top 10 Priorities for IIH Research

- 1 CAUSES OF IIH**
In the individual with IIH, what causes the disease, the symptoms and the progression of the disease?
- 2 MECHANISMS OF HEADACHE**
What are the biological mechanisms of headache in IIH and why in some do headache continue even after papilloedema has resolved?
- 3 NEW TREATMENTS**
Can new therapies for IIH be developed which are effective, safe, and tolerate and potentially help with weight loss as well as reducing brain pressure?
- 4 PREDICTING VISUAL LOSS**
What is the biological explanation for the differences between rapid visual loss compared with gradual visual loss in IIH and how can this be prevented?
- 5 MONITORING VISUAL FUNCTION**
What are the best ways to monitor visual function?
- 6 IIH BIOMARKERS**
Can IIH biomarkers (tests in body fluids for example urine, saliva, blood, or brain scans) help diagnosis, predict the risk of future therapy decisions or not?
- 7 COMORBIDITIES**
What are the common causes for IIH and why is it primarily associated with female sex?
- 8 HEADACHE TREATMENT**
Which medications are effective and safe to treat IIH headache?
- 9 WEIGHT LOSS**
With regard to weight loss in IIH, how much is reasonable to aim for and how quickly should it be achieved? What is the best, safest and most acceptable method to achieve this in the short and long term? Additionally, does the initial body mass index (BMI) of the patient have an effect?
- 10 BEST TYPE OF INTERVENTION**
Which is the best type of intervention to treat IIH and when should surgery be performed?

Figure 1
James Lind Alliance Research Priority Setting Partnership in IIH (3)

Method
This study was an anonymous online survey using Survey Monkey™. The survey was emailed to members of the national charity for people with IIH (IIH UK) and shared on their national and regional social media sites (Facebook and Twitter - @IIHUK).

The survey asked: In one sentence explain how IIH headache has impacted/changed your life. How does it make you feel?

Results
152 people responded to the survey in one week in November 2019. IIH UK had 445 members and over 2,000 unique visitors to its Facebook pages. Common words from the responses were used to create a graphic (Figure 2) using WordArt™. Additionally thematic analysis of participant comments identified themes in the data to underpin the graphic.

Themes:
1. Changes in participation
2. Changes in mood and well-being
3. Water symptoms
4. The overwhelming, debilitating nature of IIH headache.

Theme 1 Changes in Participation
"It has completely changed my life over the past few years, it affects my work, my social life, everything"
"Lots of a wife / mother / daughter because I'm always in pain and shying away from things"
"Some days I can't even get out of my bed, it breaks my heart because I have young children"

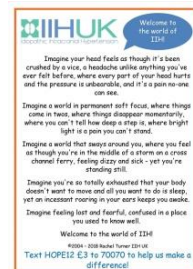
Theme 2 Changes in mood and Well Being
"It makes me feel worthless and like a failure and suicidal, I'm a shadow of the person I once was."
"Lots/not understood even by professionals"
"Helpless, useless, less of a human"
"I have lost my career because of it and struggle to keep up my hobby, it makes me feel dreadful and very down when at its worst"

Theme 3 Water Symptoms
"Tired. All the time. It affects what activities I can do with my children. I'm losing my memory, often when I am speaking, I get lost in my own words, I forget the simplest of words which leaves people staring at me and makes me anxious and upset"
"I feel worn out all the time"

Theme 4 The overwhelming debilitating nature of IIH Headache
"IIH headache is miserable and lonely. Nobody understands how debilitating it is"
"IIH headaches change my life, I don't really remember life before IIH but I remember having more life, IIH has robbed me of my life"
"I went from working a full time job and successfully keeping a household with my husband and children, to barely being able to get out of bed every day"

Conclusions
This survey shows the breadth and depth of the impact of headache in IIH. Current measures do not capture all elements of resultant disability. The methodology selected in this study was a pragmatic approach to capture the breadth of voices of people with IIH. Future research should explore the lived experience of IIH in greater depth to ensure that disability is not underrepresented in this complex condition.

- x. **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 16th – 22nd March. This year in support of Brain Awareness Week we focussed on a different topic each day; Research, Education, Support, Helpful tips, Your opinion and Positivity.
- y. **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 26,281 people! A great start to IIH Awareness Month. All in all the posts to our Fb Charity Page throughout September reached 186,649 people. An amazing achievement!
- z. **Rare Disease Day** takes place on the last day of February each year. This year we produced profile pictures for everyone to use on social media and spent the day tweeting and posting on our fb page, all in all it was a perfect day spent spreading awareness and raising the profile of Idiopathic Intracranial Hypertension.
 - i. As a Charity run solely by Volunteers we just had to celebrate **International Volunteers Day** on 5th December 2019. Twitter was the main platform for celebrating this day, raising the profile of IIH UK using the #InternationalVolunteersDay.
 - ii. We also celebrated **Volunteers Week** which took place 1st – 7th June 2020.



iii. **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. **Charity Choice:**
www.charitychoice.co.uk/idiopathic-intracranial-hypertension-united-kingdom-18148

30th June 2020

Michelle Williamson

Michelle Williamson. Chair

Receipts and payments accounts

For the period from	Period start date 01/07/2019	To	Period end date 30/06/2020
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Section A Receipts and payments

	Unrestricted funds to the nearest £	Restricted funds to the nearest £	Endowment funds to the nearest £	Total funds to the nearest £	Last year to the nearest £
A1 Receipts					
Donations	1,975	-	-	1,975	3,473
Fundraising	18,003	-	-	18,003	17,871
Membership Fees	1,892	-	-	1,892	2,055
Conference Tickets	275	-	-	275	315
Merchandise	2,477	-	-	2,477	2,012
Bank Interest	30	-	-	30	24
Refunds	166	-	-	166	-
Sub total (Gross income for AR)	24,818	-	-	24,818	25,750
A2 Asset and investment sales, (see table).					
	-	-	-	-	-
Sub total	-	-	-	-	-
Total receipts	24,818	-	-	24,818	25,750
A3 Payments					
IT	1,496	-	-	1,496	1,799
Merchandise stock	1,157	-	-	1,157	343
Paypal Fees	217	-	-	217	129
Postage and Packing	826	-	-	826	635
Printing and Stationery	235	-	-	235	83
Membership subscriptions	235	-	-	235	835
Justgiving	274	-	-	274	154
AGM	3,128	-	-	3,128	3,517
CSF Symposium	2,000	-	-	2,000	417
Surveys	312	-	-	312	712
Education	3,092	-	-	3,092	384
Research Grants	-	-	-	-	6,000
Focus meetings	1,217	-	-	1,217	514
Life Registry	5,000	-	-	5,000	5,000
JLA	-	-	-	-	26
Publicity and Profile	500	-	-	500	1,913
Events	116	-	-	116	-
Transport	871	-	-	871	-
Misc	165	-	-	165	-
Sub total	20,840	-	-	20,840	22,461
A4 Asset and investment purchases, (see table)					
	-	-	-	-	-
Sub total	-	-	-	-	-
Total payments	20,840	-	-	20,840	22,461
Net of receipts/(payments)	3,978	-	-	3,978	3,289
A5 Transfers between funds	-	-	-	-	-
A6 Cash funds last year end	31,912	-	-	31,912	28,623
Cash funds this year end	35,890	-	-	35,890	31,912

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	35,040		-
	Paypal	780	-	-
	Petty Cash	70	-	-
	Total cash funds	35,890		-

(agree balances with receipts and payments account(s))

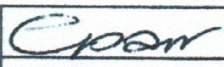
Categories	Details	Unrestricted funds to nearest £	Restricted funds to nearest £	Endowment funds to nearest £
B2 Other monetary assets	Stock	1,000	-	-
		-	-	-
		-	-	-
		-	-	-
		-	-	-
		-	-	-

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
	CLARE PARR	18/2/21
M. Williams	NICHELLE WILLIAMSON	19/2/21



Section A

Independent Examiner's Report

**Report to the trustees/
members of**

Charity Name
Idiopathic Intracranial Hypertension UK

**On accounts for the year
ended**

30 June 2020

**Charity no
(if any)**

1143522

Set out on pages

1 and 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 / 2020**. With a Total Cash Funds balance of £35,890.

As the charity's trustees, 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 all 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 in connection with the examination (other than that disclosed below *) which gives me cause to believe that in, any material respect:

- the accounting records were not kept in accordance with section 130 of the Charities Act; or
- the accounts did not accord with the accounting records; or
- the accounts did not comply with the applicable requirements concerning the form and content of accounts set out in the Charities (Accounts and Reports) Regulations 2008 other than any requirement that the accounts give a 'true and fair' view which is not a matter considered as part of an independent examination.

I have no concerns and have come across no other matters in connection with the examination to which attention should be drawn in this report 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:

Date:

20th February 2021

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 material 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.

