

IDIOPATHIC INTRACRANIAL HYPERTENSION UNITED KINGDOM

England & Wales · Charity number 1143522

Details

Other names IIH UK

Status Registered

Legal form Other

Registered 2011-08-24

Register [View on the Charity Commission register](#)

Contact

Address 19 Woburn
Washington
NE38 7JX

Phone 01914169998

Email INFO@IIH.ORG.UK

Website www.iih.org.uk

Activities

Objects: 1) TO PRESERVE AND PROTECT THE PHYSICAL AND MENTAL HEALTH OF SUFFERERS OF IDIOPATHIC INTRACRANIAL HYPERTENSION (HEREINAFTER REFERRED TO AS "IIH") THROUGH THE PROVISION OF THE BEST POSSIBLE SUPPORT, EDUCATION AND PRACTICAL ADVICE.2) TO ADVANCE THE EDUCATION OF THE PUBLIC IN GENERAL, SUFFERERS AND THE MEDICAL COMMUNITY IN PARTICULAR ON THE SUBJECT OF IIH.3) TO PROMOTE AND SUPPORT RESEARCH FOR THE PUBLIC BENEFIT IN ALL ASPECTS OF THE CONDITION IIH AND TO PUBLISH THE USEFUL RESULTS.

Activities: IIH UK is dedicated to providing sources of information and support to those with Idiopathic Intracranial Hypertension (IIH) and all who support them. We provide small research grants, promote awareness, campaign for funding to facilitate research, and advocate the Charity's public, social and support activities.

Classification

- **How:** Provides Human Resources, Provides Services, Provides Advocacy/advice/information, Sponsors Or Undertakes Research
- **What:** General Charitable Purposes, Education/training, The Advancement Of Health Or Saving Of Lives, Disability
- **Who:** Children/young People, Elderly/old People, People With Disabilities, Other Charities Or Voluntary Bodies, The General Public/mankind

Geography

- Northern Ireland
- Scotland
- Throughout England And Wales

Finances

Period end	Income	Expenditure	Assets	Employees
2025-06-30	£19,470	£40,118	-	-
2024-06-30	£17,119	£47,033	-	-
2023-06-30	£34,341	£18,541	-	-
2022-06-30	£35,455	£23,296	-	-
2021-06-30	£26,814	£22,990	-	-

Trustees

Name	Role	Appointed
MICHELLE WILLIAMSON	Chair	2022-09-14
Amanda Lisa Denton		2022-09-14
Betsy Clarke		2022-09-14
Clare Parr		2022-09-14
Kerryann Chalmers-Worth		2023-04-19

Accounts



IDIOPATHIC INTRACRANIAL HYPERTENSION UK (IIH UK)

TRUSTEES' ANNUAL REPORT AND ACCOUNTS 2022-23

(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 2022 to 30 June 2023:

Michelle Williamson	Chair
Clare Parr	Information Rep
Betsy Clark	Treasurer
Amanda Denton	Research Rep
Kerryann Chalmers-Worth	Secretary (From March 23)

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 2022-23 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 v below.)

7. At the year-end, our team members are Shelly Williamson, Trustee. Clare Parr, Trustee. Betsy Clark, Trustee. Amanda Denton, Trustee. Kerry Ann Chalmers-Worth, Trustee. Krystal Kirkby, Research Rep. Nisha Sedani, Research Rep. Katie Williamson, Shop Rep. Mellissa Monsoon, Arts and Culture Rep. Lisa Whelan, Publicity Rep. Lizzie Davies, Newsletter Rep. Kirsty Robertson, Fundraising Rep.

Charity Objects

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

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

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

Summary of IIH UK's achievements during 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 fiscal year 227,719 pages were viewed, 10,171 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.

Website statistics.

Audience Overview



- 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 @IIH UK and via our patient leaflets and patient conference/webinar.

c. **HOPE project.**

Our HOPE project created a virtual support community for people with IIH and parents of children with IIH from around the UK.

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

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

Statistics for IIH Hope Courses during the fiscal year.

	Date of Course	Enrolled	Not active	Completed Course
Adult	08/09/2022	50	14	36
Adult	12/01/2023	26	5	21
Parents	12/01/2023	7	1	6
Adult	20/04/2023	65	17	48
Parent	20/04/2023	9	4	5

- d. **Twitter.** We have now been on twitter for 12 years @IIH UK. A lot of clinicians are on Twitter whom you can follow, ask questions etc. We have 2642 followers on twitter, up 94 on the previous year.
- e. **Instagram.** We created an Instagram account in March 2021. Although slow to take off we are slowly building our followers and now have 684.

Education.

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

What is IIH
What is IIH without Papilloedema (IIHWOP)
Optic Nerve Sheath Fenestration
IIH and Weight
Headache Acetazolamide
Information for friends, family and carers ICP Monitoring
IIH and Education Benefits information Employment with IIH
Medication Overuse Headache in IIH Shunts and IIH
Stents and IIH Topiramate
Visual Problems in IIH
When I go to the Eye Clinic

Future Leaflets:

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

g. This year our **patient conference** was held on 14th September 2022 via online webinar.

Speakers

Dr Sally Abbott - Dietician

Sally Abbott is a Dietitian who has worked in obesity services for the past nine years and has treated patients with IIH. She is the Clinical Lead for Specialist Weight Management at University Hospitals Coventry and Warwickshire NHS Trust and an Assistant Professor in Dietetics at Coventry University. Sally is also the Bariatric Officer for the British Dietetic Association (BDA) Obesity Specialist Group committee and sits on the British Obesity and Metabolic Surgery Society council.

Amanda Denton – Research Representative and Trustee of IIH UK.

Update on IIH UK activities over 2022.

Fionnuala Donovan - Highly specialist neuro-physiotherapist, Guys and St Thomas NHS Foundation Trust.

How can Physiotherapy best support people living with IIH? an update on the IIH UK funded research grant.

Summary: This talk will describe the current research being conducting in the IIH Physiotherapy led clinic at GSTT. This will include: 1. What the current literature says regarding Physical activity and IIH; 2. A summary of the current service and outcomes in the IIH Physiotherapy clinic; 3. A summary of 1:1 interviews conducting with people with IIH who have accessed the IIH clinic at GSTT with particular focus on physical activity and support; 4. Outlines of the next stages of the study including: the development of a larger short answered questionnaire to identify what support people with IIH would like from a physio led IIH clinic (based on the information gained in the 1:1 interviews); distribution of this questionnaire and a summary of the results; implementation of identified service based on questionnaire results; service review of the new service.

Miss Olivia Grech - Institute of Metabolism and Systems Research PhD Student, University of Birmingham

Cognitive Function in people with IIH

Cognition issues have long been noted in Idiopathic Intracranial Hypertension (IIH), however, cognitive function is not widely recognised or addressed in IIH. Researchers performed cognitive tests in 66 IIH participants compared to 25 body mass index-matched control participants to identify impairments in reaction time, memory and executive function. Cognitive performance was

also compared at the start of the study, after a lumbar and following 12-months of a weight loss intervention. The researchers demonstrated that executive function and attention is impaired in IIH participants compared to controls at baseline (start of the study with active disease). However, after a lumbar puncture (which temporarily reduced the brain pressure) the measure of attention improved in IIH participants. The cognitive issues identified were reversible, as participants improved in their measures of executive function, sustained attention and memory over 12-months. These improvements were also linked to a reduction in brain pressure. Grech et al, propose that cognitive impairment should be accepted as a clinical feature of IIH and that cognitive deficits can improve over time and with reduction of intracranial pressure.

Laura Kerbey - HOPE programme facilitator- Live well with HOPE

Update on the IIH UK funded Hope Programme for Parents of Children with IIH.

Laura's background as a parent talks about how the impact having a child with IIH had on her and her mental health, family, work etc.

Why she wanted to be a facilitator for the HOPE Programme

What was covered in the programme and how this is so beneficial to parents

Benefits of the HOPE Cafes for parent carers

Dr Anna Lynall, Project Delivery Lead, HOPE for the Community – Live well with HOPE

Update on the IIH UK and National Lottery Funded HOPE programme for Adults with IIH

This session will give an overview of the Hope programme for adults living with IIH that has been co-created with Hope for the Community CIC. Over 200 people living with IIH have now been through the programme and the session will explore the difference that the programme has made to the knowledge, skills and confidence of participants to manage their lives with IIH.

Dr Mark Thaller, Clinical Lecturer and Neurology Registrar. University of Birmingham

Reproductive health in women with IIH.

This talk is based on several strands of his research looking at the impact of an IIH diagnosis on fertility, pregnancy complications of diabetes and pre-eclampsia, type of birth (i.e. caesarean section), practical guidelines for managing IIH in pregnancy and long term outcomes depending on the timing of pregnancy in relation to an IIH diagnosis.

Dr Sui Wong – Consultant Neurologist, Guys and Thomas, IIH UK Patron

Update from IIH UK patron

- 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 were no face-to-face meetings during the year and all discussions were done via email.

Research

- i. 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.

- j. **IIH Life Registry.** The IIH Life registry was developed by Professor Alex Sinclair and captures routine clinical data from neurologists/ophthalmologists/ neuro-ophthalmologists and orthoptic led clinics that management IIH patients around the United Kingdom. The 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 able to start to build out.
- k. **IIH Intervention Trial.** Is still ongoing. #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 are best to treat IIH and were delighted to be invited to the steering group to discuss the development of this new Stent v Shunt trial. This research aims to establish the best surgical intervention (shunt v stent) in people with IIH to prevent blindness. Finding out the most effective method of surgery is vital to improve the management and quality of life of people with IIH.

If you are selected to take part in this trial it is important to know that you are not able to choose the type of intervention that you want. Both (shunt v stent) are as equally important and as the aims of this research is to establish the best surgical intervention in people with IIH to prevent blindness it requires equal numbers of participants.

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.'

- l. Dr Wong, Guys and St Thomas, London was awarded the IIH UK Research Grant this year, here is a summary of her research funding bid. We will share the research finding with you once her research is completed.

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 with IIH as a key 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 people with IIH to develop services that empower them, including group consultations that facilitates peer-to-peer learning and lifestyle support to empower people with IIH 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 people with IIH.

This research aims to develop recommendations and practical implementations on physical activity for people with IIH. The work will include research into current evidence and gathering new evidence through research in partnership with people with IIH 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 people with IIH. The work will be incorporated with current work on the HOPE programme for people with IIH. 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 people with IIH.

- m. We added 2 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.

[Increased systemic and adipose 11 \$\beta\$ -HSD1 activity in idiopathic intracranial hypertension](#)

[Idiopathic intracranial hypertension: evaluation of births and fertility through the hospital](#)

n. Other notable research published during the year

Increased systemic and adipose 11 β -HSD1 activity in idiopathic intracranial hypertension
<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC9346265/>

Association of Amount of Weight Lost After Bariatric Surgery With Intracranial Pressure in Women With Idiopathic Intracranial Hypertension
<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC9536743/>

Nuclear Magnetic Resonance Spectroscopy Metabolomics in Idiopathic Intracranial Hypertension to Identify Markers of Disease and Headache
<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC9620805/>

Evaluation of diurnal and postural intracranial pressure employing telemetric monitoring in idiopathic intracranial hypertension

<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC9628104/>

Dysregulation of Amino Acid, Lipid, and Acylpyruvate Metabolism in Idiopathic Intracranial Hypertension: A Non-targeted Case Control and Longitudinal Metabolomic Study

<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC10088035/>

Defining the Phenotype and Prognosis of People With Idiopathic Intracranial Hypertension After Cerebrospinal Fluid Diversion Surgery

<https://www.ajo.com/action/showPdf?pii=S0002-9394%2823%2900026-0>

Different Characteristics of Pre-Pubertal and Post-Pubertal Idiopathic Intracranial Hypertension: A Narrative Review

<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC9988343/>

Defining the Phenotype and Prognosis of People With Idiopathic Intracranial Hypertension After Cerebrospinal Fluid Diversion Surgery

<https://www.ajo.com/action/showPdf?pii=S0002-9394%2823%2900026-0>

Current and emerging diagnostic and management approaches for idiopathic intracranial hypertension

<https://www.tandfonline.com/doi/full/10.1080/14737175.2023.2206567>

Raising the Profile of IIH

- o. Our online shop has lots of items to help raise awareness of IIH.
https://www.iih.org.uk/section/7/1/online_shop
- p. Trustees/Team members attended the following conferences during the year.

CSF Disorders Day – Edgbaston – July 2022

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.

- q. **Brain Awareness Week** (BAW) is the global campaign to increase public awareness of the progress and benefits of brain research. This reporting year we celebrated it from 13th –19th March.
- r. **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

IIH UK ANNUAL REPORT AND ACCOUNTS 2021-22 Website www.iih.org.uk; Twitter @IIHUK

E-mail info@iih.org.uk Facebook www.facebook.com/IIHUKCharity

September was once again a tremendous 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 15,776 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 35 people contacted Shelly to ask her to create a new profile photo for them. We also shared peoples stories of their experience of living with IIH and held a raffle which raised £243.00

- s. **Rare Disease Day** takes place on the last day of February each year. This year our Trustee Shelly created 60 profile pictures for people to add to their profile photo on Facebook. The theme for this year was 'Rare is strong, rare is many, rare is proud'. Overall, it was a perfect day spent spreading awareness and raising the profile of Idiopathic Intracranial Hypertension.
- t. As a Charity run solely by Volunteers, we just had to celebrate **International Volunteers Day** on 5th December 2022. Twitter was the main platform for celebrating this day, raising the profile of IIH UK using the #InternationalVolunteersDay.
- u. Our Arts & Culture Representative Mellissa Fisher - Artist built projects around themes of invisible symptoms of IIH, aiming to help others, raise awareness and inspire creativity in the community. She held an exhibition in Margate, Kent, where she shared the community views on body positivity and stories of people of people with IIH diagnosis journeys.
- v. We also celebrated **Volunteers Week** which took place 1st – 7th June 2023.
- w. We backed the #BackThe1in6 campaign run by the Neurological to improve neuro services across the UK.

Fundraising

- x. We use the following platforms to raise funds.
 - a. **Just Giving:** provides us with our main source of income from fundraising.
 - b. **Membership fees:** email membership@iih.org.uk to become a member.
 - c. **IIH UK online awareness merchandise sales:**
https://www.iih.org.uk/section/7/1/online_shop/
 - d. **Easysearch:** www.iihuk.easysearch.org.uk/
 - e. **Easyfundraising:** www.easyfundraising.org.uk/causes/iihuk/
 - f. **The Weather Lottery:**
www.theweatherlottery.com/charitiesHomepage.php?client=IIHUK
 - g. **The Charities Aid Foundation:** www.cafonline.org/system/charity-search-results
 - h. **Facebook:** provides us with our main source of income from donations.
www.facebook.com/fund/IIHUKCharity/

- i. **PayPal Giving:** www.paypal.com/uk/fundraiser/charity/49628
- j. **eBay for Charities:** www.charity.ebay.co.uk/charity/IIH-UK/49628
- k. **Teespring:** www.teespring.com/en-GB/stores/iih-uk
- l. **DONATE:** <https://platform.nationalfundingscheme.org/idiopathic-intracranial-hypertension-united-kingdom-/HOPE>
- m. **Charity Choice:** www.charitychoice.co.uk/idiopathic-intracranial-hypertension-united-kingdom-18148

y. **Grants Received.**

Arnold Clark - £2000
SSP Foundation - £500
Bistech Group PLC - £1000

Michelle Williamson. Chair



Idiopathic Intracranial Hypertension UK		No. 1143522		CC16a
Receipts and payments accounts				
For the period from	Period start date 01/07/2022	To	Period end date 30/06/2023	

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 & Fundraising	2,216	-	-	2,216	906
Just Giving	4,965	-	-	4,965	8,371
Facebook	4,397	-	-	4,397	7,949
Paypal Giving Fund	6,780	-	-	6,780	2,313
Other	10,476	-	-	10,476	11,383
Membership Fees	2,142	-	-	2,142	2,313
Conference Tickets		-	-	-	
Merchandise	3,242	-	-	3,242	2,206
Bank Interest	124	-	-	124	6
Refunds	-	-	-	-	9
		-	-	-	
Sub total(Gross income for AR)	34,341	-	-	34,341	35,455
A2 Asset and investment sales, (see table).					
	-	-	-	-	
	-	-	-	-	-
Sub total	-	-	-	-	-
Total receipts	34,341	-	-	34,341	35,455
A3 Payments					
Governance	£0	-	-	-	
IT	£1,926	-	-	1,926	£1,600
Merchandise (Stock Purchase)	£431	-	-	431	£726
Paypal Fees	£131	-	-	131	£187
Postage & Packaging	£462	-	-	462	£662
Printing & Stationery	£606	-	-	606	£446
Transport	£0	-	-	-	
Misc	£0	-	-	-	
Refunds	£0	-	-	-	£43
Justgiving Membership	£216	-	-	216	£216
Other Membership	£121	-	-	121	£60
AGM/Patient Conf	£0	-	-	-	
Symposium/Conference	£0	-	-	-	
Partnership Donations	£2,000	-	-	2,000	£12,946
Education	£0	-	-	-	
Research & Alliance	£4,344	-	-	4,344	
Surveys	£0	-	-	-	£372
Representatives & Trustee Expenses	£1,255	-	-	1,255	£518
Publicity and Profile	£0	-	-	-	
Focus Meetingsg	-	-	-	-	
Life Registry	-	-	-	-	
Hope Program Child	1,350	-	-	1,350	1,500
Hope Prgram - Adult Donation	5,700	-	-	5,700	4,020
Events		-	-	-	
Sub total	18,541	-	-	18,541	23,296
A4 Asset and investment purchases. (see table)					
	-	-	-	-	
	-	-	-	-	-
Sub total	-	-	-	-	-
Total payments	18,541	-	-	18,541	23,296

<i>Net of receipts/(payments)</i>	15,801	-	-	15,801	12,159
A5 Transfers between funds	-	-	-	-	-
A6 Cash funds last year end	51,874	-	-	51,874	39,715
<i>Cash funds this year end</i>	67,675	-	-	67,675	51,874

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	66,496	-	-
	Paypal	1,108	-	-
	Petty Cash	71	-	-
	Total cash funds	67,675	-	-
	(agree balances with receipts and payments account(s))	OK	OK	OK
B2 Other monetary assets	Details	Unrestricted funds to nearest £	Restricted funds to nearest £	Endowment funds to nearest £
	Stock	-	-	-
		-	-	-
		-	-	-
		-	-	-
		-	-	-
		-	-	-
B3 Investment assets	Details	Fund to which asset belongs	Cost (optional)	Current value (optional)
			-	-
			-	-
			-	-
			-	-
			-	-
B4 Assets retained for the charity's own use	Details	Fund to which asset belongs	Cost (optional)	Current value (optional)
			-	-
			-	-
			-	-
			-	-
			-	-
			-	-
			-	-
			-	-
			-	-
B5 Liabilities	Details	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	
	M. Williamson	Michelle Williamson	24-Dec-23	



Section A

Independent Examiner's Report

Report to the trustees/
members of

Charity Name
idiopathic intracranial hypertension

On accounts for the year
ended

30th June 2023

Charity no
(if any)

1143522

Set out on pages

1 and 2

(remember to include the page numbers of additional sheets)

I report to the trustees on my examination of the accounts of the above charity ("the Trust") for the year ended **30 / 06 / 2023**.

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:

Date:

15/12/23

Name:

Brenda Binnie

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

ACMA

Address:

9 Manor Cose

Droitwich

WR9 8HG

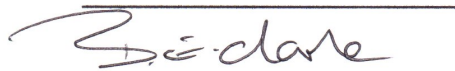
Section B**Disclosure**

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

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

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

Signature

A handwritten signature in cursive script, appearing to read "Betsy Clarke", written over a horizontal line.

Print Name

BETSY CLARKE

Date of approval |

3/7/23

Accounts



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 2 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:
- To provide the best possible support and advice network for people with Idiopathic Intracranial Hypertension (hereafter referred to as IIH) and their families.
 - To advance the education of the public in general, people with IIH and the medical community in particular on the subject of IIH.
 - To promote and support research for the public benefit on all aspects of the condition IIH and to publish the useful results.
 - 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

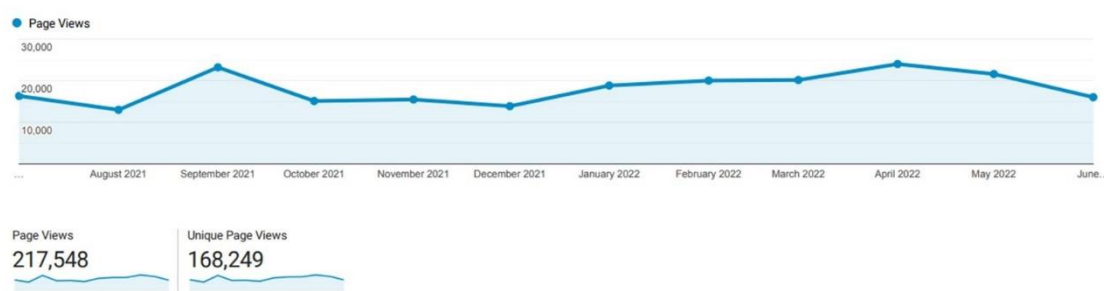
9. IIH UK would not be able to exist without the small number of dedicated volunteers who freely give their time; many of whom have IIH themselves. They assist with the day-to-day running of the charity in areas such as fundraising, membership, publicity, merchandise, newsletter production. In planning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



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

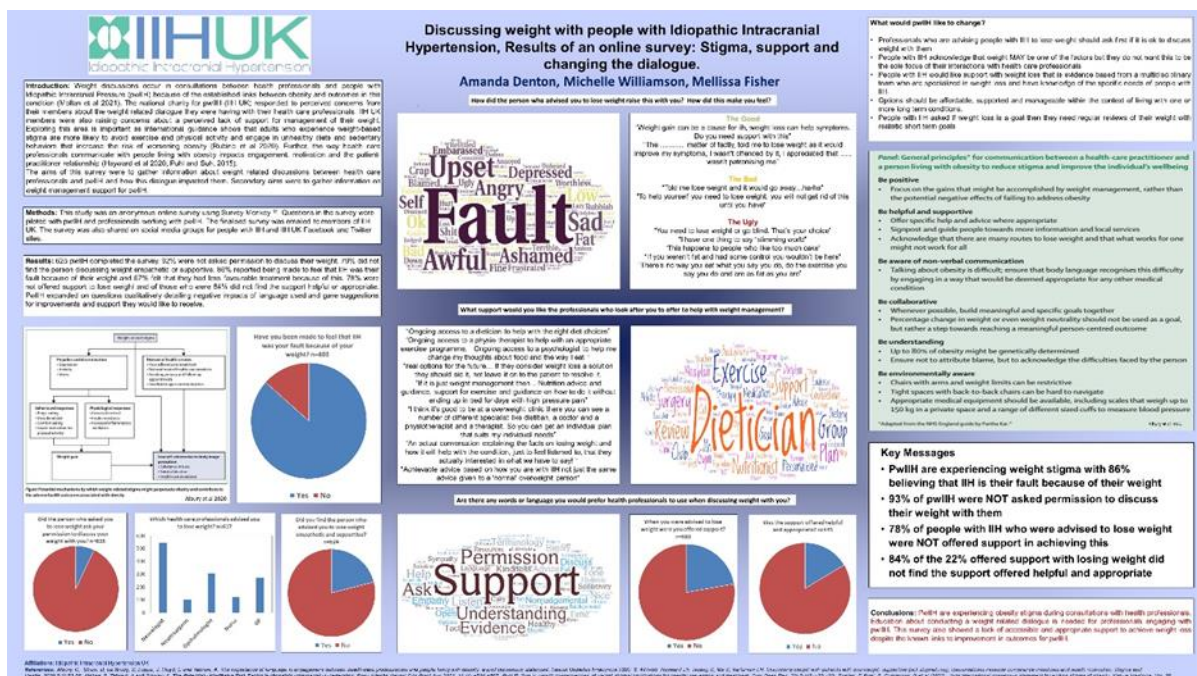
#3 of our James Lind Alliance Priority Setting Partnership is 'Can new therapies for IIH be developed which are effective, safe and tolerable and potentially help with weight loss as well as reducing brain pressure.'

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

Presendin is a sustained release (SR) formulation of Exenatide which will be delivered via a once per week, sub-cutaneous injection, and moving into Phase III development. This injection would be done at home by the patient (or care giver) once training has taken place. Exenatide is a small peptide and a synthetic version of the GLP-1 agonist exendin-4, which is currently approved for the treatment of type 2 diabetes (but does not cause dangerous lowering of blood sugar levels). Exenatide has been licensed for use in type 2 diabetes since 2005 so there is a wealth of knowledge about the drug safety. Common side effects of Exenatide include nausea, loss of appetite and dizziness, which are typically short lived. Exenatide can also cause weight loss.

IIH UK has been involved in both Patient and Public Involvements meetings and have supported researchers to link with international IIH non-profit organisations.



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 whoever they are, whenever they need it and wherever they live. Getting the right care, treatment and support at the right time can make a lifechanging difference when you have IIH. But there are huge variations across the UK – not everyone with a neurological condition in the UK has access to the same high quality, joined up care and support so we partnered with the Neurological Alliance to help spread word of their My Neuro survey, by sharing their experiences the people we support will help to gather the evidence to make the case for change.
- 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 from	Period start date 7/1/2021	To	Period end date 6/30/2022
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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 & 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 Program - Adult Donation	4,020			4,020	
Events		-	-	-	-
Sub total	23,296	-	-	23,296	22,990

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
B2 Other monetary assets	Details	Unrestricted funds to nearest £	Restricted funds to nearest £	Endowment funds to nearest £
	Stock	-	-	-
		-	-	-
		-	-	-
		-	-	-
		-	-	-
		-	-	-
B3 Investment assets	Details	Fund to which asset belongs	Cost (optional)	Current value (optional)
			-	-
			-	-
			-	-
			-	-
B4 Assets retained for the charity's own use	Details	Fund to which asset belongs	Cost (optional)	Current value (optional)
			-	-
			-	-
			-	-
			-	-
			-	-
			-	-
			-	-
			-	-
B5 Liabilities	Details	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	
	M. Williamson	Mrs Michelle Williamson	1/16/2023	



CHARITY COMMISSION FOR ENGLAND AND WALES

Independent examiner's report on the accounts

Section A

Independent Examiner's Report

Report to the trustees/
members of

Charity Name
Idiopathic Intracranial Hypertension UK

On accounts for the year
ended

30th June 2022

Charity no
(if any)

1143522

Set out on pages

PAGE 1 OF 2

Remember to include the page numbers of additional sheets.

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

Responsibilities and
basis of report

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

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

Independent
examiner's statement

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

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

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

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

Signed: Brenda Binnie

Date: 31st Dec 2022

Name: Mrs Brenda Binnie

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

ACMA

Address:

9 Manor Close

Deerhurst, Wores Worsley

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.

Accounts



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 13th 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 14th 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 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 14th April 2021.

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, 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 26th 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 R E A K	
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
L U N C H	
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 R E A K	
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
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- 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

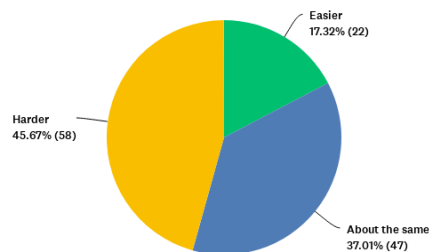
- m. During the course of the year, we developed information packs for clinicians. These are a work in progress and will be launched soon.

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 8-12th 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 15th – 21st 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 5th 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 1st – 7th 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 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 2021



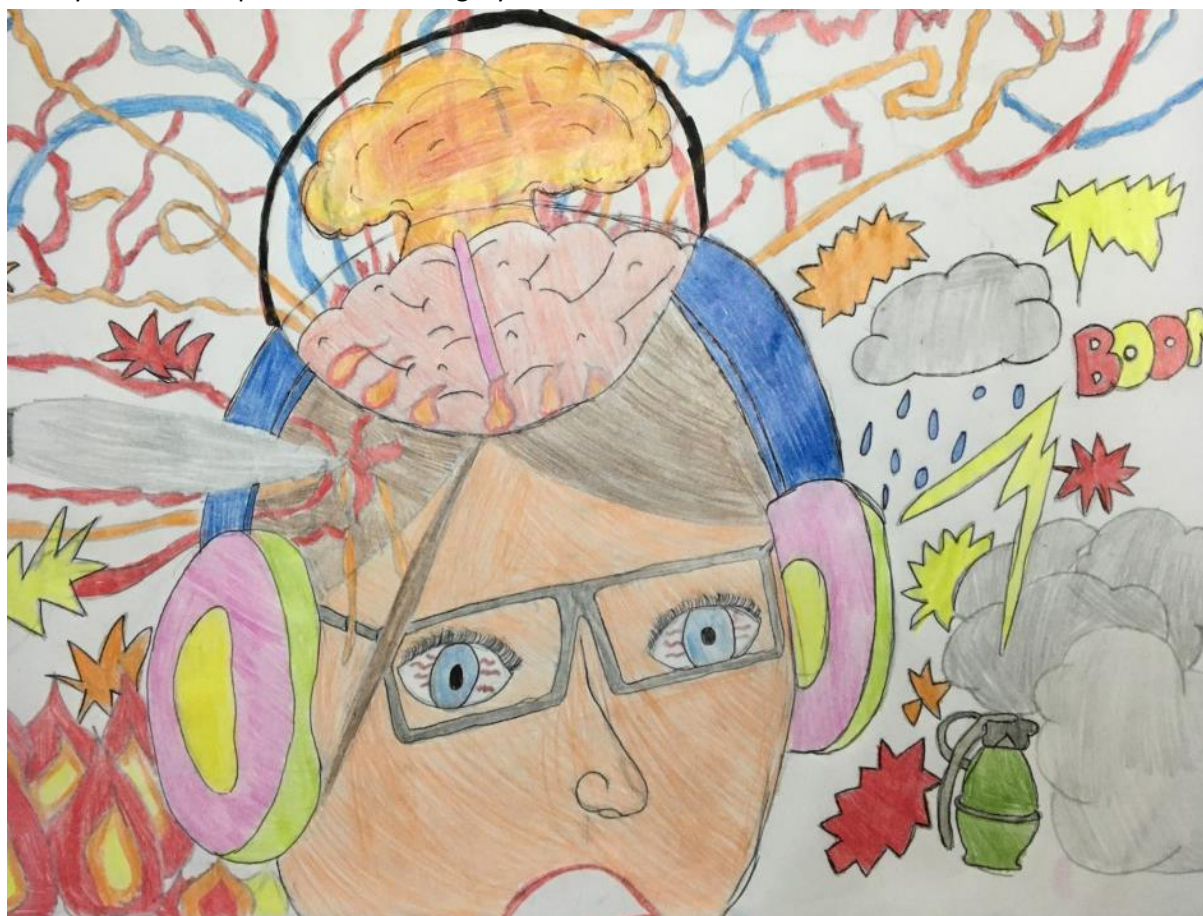
Michelle Williamson. Chair

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 Funds 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 £
A1 Receipts					
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
		-	-	-	-
		-	-	-	-
Sub total (Gross income for AR)	26,814	-	-	26,814	24,818
A2 Asset and investment sales, (see table).					
	-	-	-	-	-
	-	-	-	-	-
Sub total	-	-	-	-	-
Total receipts	26,814	-	-	26,814	24,818
A3 Payments					
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
Sub total	22,990	-	-	22,990	20,840
A4 Asset and investment purchases, (see table)					
	-	-	-	-	-
	-	-	-	-	-
Sub total	-	-	-	-	-
Total payments	22,990	-	-	22,990	20,840
Net of receipts/(payments)	3,825	-	-	3,825	3,978
A5 Transfers between funds	-	-	-	-	-
A6 Cash funds last year end	35,890	-	-	35,890	31,912
Cash funds this year end	39,715	-	-	39,715	35,890

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	38,046	-	-
	Paypal	1,599	-	-
	Petty Cash	71	-	-
	Total cash funds	39,715	-	-
	(agree balances with receipts and payments account(s))			
		Unrestricted funds to nearest £	Restricted funds to nearest £	Endowment funds to nearest £
B2 Other monetary assets	Stock	-	-	-
		-	-	-
		-	-	-
		-	-	-
		-	-	-
		-	-	-
		-	-	-
B3 Investment assets		Fund to which asset belongs	Cost (optional)	Current value (optional)
			-	-
			-	-
			-	-
			-	-
			-	-
B4 Assets retained for the charity's own use		Fund to which asset belongs	Cost (optional)	Current value (optional)
			-	-
			-	-
			-	-
			-	-
			-	-
			-	-
			-	-
			-	-
B5 Liabilities		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
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18 Feb 2022

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		Unrestricted funds to nearest £	Restricted funds to nearest £	Endowment funds to nearest £
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		-	-	-
		-	-	-
		-	-	-
		-	-	-
		-	-	-
		-	-	-
B3 Investment assets		Fund to which asset belongs	Cost (optional)	Current value (optional)
			-	-
			-	-
			-	-
			-	-
			-	-
			-	-
B4 Assets retained for the charity's own use		Fund to which asset belongs	Cost (optional)	Current value (optional)
			-	-
			-	-
			-	-
			-	-
			-	-
			-	-
			-	-
			-	-
B5 Liabilities		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	