



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

### **TRUSTEES' ANNUAL REPORT AND ACCOUNTS 2016-17**

(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 2016 to 30 June 2017:

Michelle Williamson	Chair
Lizzie Aylott	Treasurer
Norma Ann Dann	Secretary
Clare Parr	
Keri Bunnell	

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

2. IIH UK was founded in 2008 and established as a registered charity in 2011, it is governed by its founding constitution, as subsequently amended on 12 May 2012 and 21 June 2014. The charity is constituted by association.
3. All trustees have given their time voluntarily during 2016-17 and have not received remuneration or any other benefits in undertaking their duties. Following endorsement by the 2014 Annual General Meeting (AGM), trustees are now 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 Rare Disease UK, the Neurological Alliance, the Nasa Human Health Programme, the Health and Social Care Alliance Scotland, Benefits and Work and an affiliate of the James Lind Alliance.

#### **Charity Objects**

5. The charity's objects as set out in the constitution on 21 June 2014 were as follows:
  - a. To preserve and protect the physical and mental health of sufferers of Idiopathic Intracranial Hypertension through the provision of the best possible support, education and practical advice.
  - b. To advance the education of the public in general, sufferers 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.

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

6. IIH UK would not be able to exist without the small number of dedicated volunteers who freely give their time; many of whom are IIH sufferers themselves. They assist with the day-to-day running of the charity in areas such as fundraising, membership, publicity, forum moderation, merchandise, newsletter production and the running of the very active IIH Support group on Facebook. In planning and undertaking the activities during the report period, IIH UK trustees were cognisant of the Charity Commission's guidance on public benefit. With the objects in mind, the Charity's key activities fall into 4 main areas: to provide an excellent support network for sufferers 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 the IIH.

## Summary of IIH UK's main achievements during 2016-17.

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

### Support

- a. **IIH UK website.** The Charity's website traffic at [www.iih.org.uk](http://www.iih.org.uk) continues to increase. During the first quarter of 2017 35,955 unique visits were made and over 41,000 pages viewed. The live Charity Twitter feed that was added to the front page of the website continues to be a popular feature and feedback from users (both patients and clinicians) remains positive. The website is maintained by FAT Promotions and is kept up to date by both FAT and some of our volunteers.
- b. **IIH Support Forum.** In April we replaced and launched our new support forum [www.iihsupport.org](http://www.iihsupport.org) as it was becoming increasingly difficult to maintain the old one due to its ancient coding. We listened to IIH Patients and ensured the new support forum was mobile friendly. In the first three months 128 people requested to join. We don't expect this new forum to be in as much demand due to the advancement of social media but felt it was important to keep it as some people do not use social media. Forum statistics will be made available in our next annual report.
- c. **Management of Facebook Support Group.** IIH UK continues to run and administer the Facebook group 'IIH Support UK'. With an ever growing membership, currently 3600 members, often with people joining within days of diagnosis, it has enabled the Charity to respond and support people more quickly and to provide links to the IIH UK medically verified website for more commonly asked questions.
- d. **Regional Groups.** Membership of the online regional groups, which are facilitated by IIH UK, has increased during the year, with the South East still being the largest group in terms of numbers. The restructuring continues to work well in the 14 groups which cover all four nations and allows people to discuss local issues and meet-up socially. The North West Group remains the most active in terms of meet-ups.

- e. **Weight Loss Support Group.** There are now over 1000 members in the Weight Loss Support Group. IIH UK facilitates the group to provide healthy recipes and links to NHS healthy eating websites. There is definitive evidence that weight and IIH are related and with over 90% of patients diagnosed with IIH being overweight women, IIH UK is committed to support healthy weight loss.
- f. **New groups for 2017.** We have created two new support groups on Fb this year. IIH Employment and Study support now has over 200 members; this group supports people with IIH who are in work or further education. IIH support for men was created 'just for men', a safe place where they can discuss men's issues. Membership of this group stands at 10. We do not expect this number to rise greatly due to the fact that IIH predominantly affects women.
- g. We made a donation of £500 to The Brain & Spine Foundation this year to help fund their telephone helplines which are staffed by neuroscience nurses. This is an area that we ourselves are unable to afford and we are extremely grateful to the Brain & Spine Foundation for allowing us to promote this very important service.

### Education

- h. **New Leaflets.** This year we launched our new Paediatric Patient Leaflet, this leaflet is aimed at young children and their parents and we would like to thank Dr W Whitehouse (Paediatric Neurologist, Nottingham) for his help in creating this leaflet.
- i. **Educational Videos.** May 2017 saw our Trustees Shelly Williamson and Norma-Ann Dann travel to Birmingham to record a series of educational videos with Dr Sinclair and Miss Mollan. We hope to release these video's during September Awareness Month. **Titles:** 1. What is IIH? 2. What are the symptoms of IIH? 3. What is the underlying cause of IIH? 4. What is papilloedema? 5. What is IIH without Papilloedema? 6. How is IIH Treated? 7. Why is Lumbar Puncture needed? 8. How is IIH linked with weight? 9. How is IIH affected by hormones and pregnancy? 10. How are headaches treated in IIH? They also recorded a video for the JLA IIH PSP.
- j. Our **Patient Conference** was held in Harlow, North London on 9<sup>th</sup> July 2016, it was attended by 43 IIH patients, their carers, families and friends. IIH UK Chair opened the conference with an overview of the charity.

Other speakers were:

Sarah Venugopal – Introduction to Raremark  
 Dr Alexandra Sinclair – Headache in IIH  
 Miss Ruchika Batra - Optical Coherence Tomography (OCT)  
 Miss Susan Mollen - Trends in IIH over the last decade  
 Dr James Mitchell - Clinical Research Roundup  
 Dr William Whitehouse - IIH in children & young people in the UK

You can read the 2016 Patient Conference report on our website.

## Research

- k. **Support/Fund Research.** Trustees and our Research Rep continue to attend trial steering group committee meetings and teleconferences for the IIH Weight Trial (IIH:WT), IIH Registry (IIH:Life), IIH:Guidelines and the JLA IIH Priority setting partnership.

The 66th and final patient was recruited to the **IIH:WT** in May 2017, 5 months ahead of schedule and 2 above target. The primary outcome will be reached in May 2018 with long term follow up continuing until 2022. This is a 5 year study and we will continue to fund the travelling expenses of IIH patients as they return for ongoing appointments. The aim of the IIH:WT trial is to assess if weight loss through bariatric surgery and/or dietetic intervention is an effective sustainable treatment for IIH, with sustained reduction of ICP, visual symptoms and headaches.

**The IIH:DT** finished follow up in December 2016 and the Birmingham central team spent much of February and March with data querying and cleaning. The Birmingham team look forward to getting a paper submitted for publication by the end of the year. The IIH:DT aims to prove that blocking the 11 $\beta$ -HSD1 enzyme will reduce the pressure in the brain and will hopefully improve symptoms, such as headaches and visual problems, seen in IIH.

**The IIH:Life** registry database comprises of two parts – one for clinician entries and the other for patient input. The medical professionals will be entering data which will include: visual test results, lumbar puncture opening pressures, medication (including dose), height, weight etc. The patient will be asked about their pain levels and asked to complete an annual Quality of Life survey. It is hoped that the registry would be able to indicate the optimal treatment for:

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

This is an ongoing registry and we have committed to fund it at a cost of £5K per annum.

- l. Our Patron Dr A Sinclair has been commissioned by the Association of British Neurologists (ABN) to write **IIH Guidelines**. The guidelines are designed to be a practical document that all clinicians can use, therefore they are to be written in a concise and succinct manner, it is hoped that these will be finalised and adopted by the ABN in 2017/18. IIH Patients have been waiting a long time for such guidelines to become available, currently there are no national guidelines for IIH which we find to be detrimental to the health of IIH Patients. It is hoped that once more data becomes available via research the IIH Guidelines can be taken forward and become NICE guidelines.
- m. **IIH:Families** is a study by Dr Sinclair and her Birmingham team looking at why IIH can sometimes run in families. We do not yet know if IIH is genetic and we look forward to seeing how this study progresses. IIH UK helped with the recruitment of families for this study and initial recruitment found 27 families where more than one person has IIH.

- n. **IIH PSP.** A considerable amount of work was undertaken behind the scenes last year to attempt to get an IIH Priority Setting Partnership (PSP) underway with the James Lind Alliance (JLA). The IIH PSP was finally established in February 2017, in collaboration with the James Lind Alliance ([www.jla.nihr.ac.uk](http://www.jla.nihr.ac.uk)), to bring patients and clinicians together to identify the shared research priorities for IIH in adults (16+). We put out the initial survey in June 2017 which ran for 1 month. We had a total of 349 respondents which raised 1799 uncertainties (unanswered questions) about Idiopathic Intracranial Hypertension. The next few months will be spent collating the data and we expect the second survey to be launched in early 2018. The final workshop will be held in London during April 2018. We wanted your questions about IIH to guide future research and to help us to improve the care for patients suffering from IIH. This PSP gives a chance for IIH Patients, their carers, friends and clinicians to have a voice in shaping the next generation of research advances.
- o. **Investigating painkiller use in individuals with IIH Survey:**  
This survey was developed by our Research Rep Krystal Hemmings and we hope to have the results written up and published to our website soon.
- p. **Barriers to Weight Loss and exercise Survey:**  
We will soon be entering phase two of our 'Barriers to Weight loss and exercise survey' which was put out earlier this year. This survey was developed by our Research Rep Krystal Hemmings in conjunction with Derby University with the help of Amanda Denton, IIH Patient and lecturer in neuro-habilitation at Plymouth University. They have used the data from this pilot survey to come up with a more focused survey that will be relevant to IIH patients. They are putting this together over the next few weeks, will then put it through ethics within the University of Derby and it will hopefully be ready to launch towards the end of this year.
- q. Two years ago we put out a survey all about **IIH Patient Lumbar Puncture experience.** This threw out some very interesting results which helped us develop a paper we are writing in collaboration with the Birmingham Research team which we aim to have published. This is a work in progress but we are hopeful that the first publication outlining the collaboration between the charity and research clinicians titled 'Illuminating the Patient Experience of LP' will be published in a medical journal at the end of 2017/early 2018.

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

- r. Trustees attended the following conferences during the year:  
**Neurological Alliance conference.** Nov 2016  
**Rare Disease UK Conference.** Jan 2017.  
Attending other organisations conferences provide an opportunity for Trustees to meet other attendees and develop friendships with other likeminded organisations enabling us to raise the profile of IIH.
- s. Each year we sponsor and attend the CSF Disorders Day, a symposium organised by Dr Sinclair and Miss Mollen. This event is held in Birmingham each September. You can read the report from the 2016 event on our website.

- t. In June we were invited to attend a Patient Voice in Ophthalmic research event, Key sessions included; a, The Value of the Patient Voice and the Role of Patient Societies. b, The Patient Voice in Priority Setting and the Research Agenda. c, How Patients can Communicate their Experience of Disease and Treatment through Qualitative Research. d, How Patients can Define the Outcomes that Matter through Patient Reported Outcome Measures (PROMs) and Core Outcome Sets (COS) and lastly e, How the Patient Voice can communicate Research that Matters to the People that Matter. This event provided an excellent opportunity for us to raise the profile of IIH and our Research Rep Krystal Hemmings spoke about IIH and our involvement in setting up the IIH Priority Setting Partnership in association with the James Lind Alliance.

30<sup>th</sup> June 2017

*Michelle Williamson*

Michelle Williamson. Chair