



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

### **TRUSTEES' ANNUAL REPORT AND ACCOUNTS 2015-16**

(Registered Charity Number – England & Wales 1143522, Scotland SC043294) ANNUAL REPORT

#### **Charity Trustees during the report period**

1. The following represented IIH UK as trustees during the report period 1 July 2015 to 30 June 2016:

Sandra Doughty	Chair (until Dec 15)
Alan Doughty	Secretary (until Dec 15)
Victoria Davies	Information Officer (until Dec 15)
Michelle Williamson	Treasurer/Chair (from Nov 15)
Keri Bunnell	Treasurer (from Dec 15)
Lizzie Aylott	Secretary (from Dec 15)
Norma Ann Dann	Secretary (from Dec 15)
Clare Parr	(from Dec 15)

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

2. IIH UK was established as a voluntary organisation in 2008 and registered with the HMRC for gift aid purposes. It became a registered charity in England and Wales in 2011 and is governed by its founding constitution, as subsequently amended on 12 May 2012 and 21 June 2014. The charity is constituted by association. It registered with the OSCR in 2012.
3. All trustees have given their time voluntarily during 2015-16 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 remains a member Rare Disease UK, the Nasa Human Health Programme, Genetic Alliance UK, the Brain & Spine Foundation and an affiliate of the James Lind Alliance and in May 16 we became members of the Health and Social Care Alliance Scotland (the ALLIANCE).

#### **Charity Objects**

5. The charity's objects as set out in the constitution on 1 July 2013 were as follows:
  - a. To promote and protect the physical and mental health of sufferers of Idiopathic Intracranial Hypertension (IIH) through the provision of support, education and practical advice.
  - b. To advance the education of the public in general and particularly amongst scientists on the subject of IIH and to promote research for the public benefit on all aspects of that

subject 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 have IIH 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 2015-16.**

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. The live Charity Twitter feed that was added to the front page of the website has proved 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.** Membership of our IIH Support International Forum [www.iihsupport.org](http://www.iihsupport.org) stands at 2400 members. During the report period, there have been 5076 posts on the Forum, 858 new topics have been created and an incredible 4.6 million pages viewed. The Forum has members from all over the world and is an essential source of information. It has an excellent search function and can be used as a useful database of IIH related questions and answers. Our forum has been subject to ongoing hacking attempts in recent months, this is due to ancient coding (the forum was built in 2004) Because of this we are looking at the costings to get a new forum built.
- c. **Management of Facebook Support Group.** IIH UK continues to run and administer the Facebook group 'IIH Support UK'. With an ever growing membership, 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 is working well in the 14 groups covering England, Northern Ireland, Scotland and Wales which allow people to discuss local issues and meet-up socially. The North West Group remains the most active.
- e. **Weight Loss Support Group.** There are now over 800 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.

### Education

- f. **New Leaflets.** Trustees with the help of paediatric neurologists have begun drafting a new Paediatric Patient leaflet which will be available early in 2017 and distributed to all Paediatric Neurology centre across the UK.

### Research

- g. **Support Research.** Trustees and our Research Rep continued to attend trial steering committee meetings and teleconferences for the IIH Weight Trial, IIH Drug Trial, IIH:Life and IIH:Guidelines.

The IIH Weight trial allows £400 to be paid for patient expenses. We continue to provide an additional £100 per patient on the trial to encourage patients from other regions of the UK to sign up including IIH patients living in Scotland. 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 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.

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 (including GP's), 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.

- h. **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). Unfortunately, due to lack of resource, the Charity was unable to move ahead. However by the introduction to the team of a new Research Representative this is now going ahead and it is likely the first meeting of the PSP will be early 2017.

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

- i. Trustees attended the following conferences during the year:
  - Neurological Alliance conference.** Nov 2015
  - Rare Disease UK Conference.** Jan 2016.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.
- j. The charity undertook lots of awareness raising of IIH again this year mainly during September IIH Awareness month, Brain Awareness Week and Rare Disease Day. We created profile pictures and posters for use on social media for those that requested one. Over 200 of our supporters helped us to spread awareness of IIH during these times. We also created posters to share on social media.

30<sup>th</sup> June 2016

*Michelle Williamson*

Michelle Williamson. Chair