



IDIOPATHIC INTRACRANIAL HYPERTENSION UK (IIH UK)

TRUSTEES' ANNUAL REPORT AND ACCOUNTS 2014-15

(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 2014 to 30 June 2015:

Sandra Doughty	Chair
Michelle Williamson	Secretary
Alan Doughty	Treasurer
Victoria Davies	Information Officer
Jane Woodcock	Merchandise Officer

Structure, Governance and Management

2. IIH UK was established as a charity 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.
3. All trustees have given their time voluntarily during 2014-15 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. During the year, IIH UK became a member of Genetic Alliance UK and the Brain & Spine Foundation and became an affiliate of the James Lind Alliance. The charity remains a member of Rare Disease UK and the NASA Human Health Programme.

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 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 2014-15.

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

Support

- a. **Staging of Patient Conference.** The 2015 IIH UK Patient Conference was held in the west Midlands, near Birmingham, on 21 June 2015 and proved to be our most successful yet. As with other years, it was held in tandem with the AGM over a weekend, which gave people the opportunity to get together socially in a relaxed environment. It was attended by many IIH sufferers along with their families and friends who listened to four presentations throughout the morning.

IIH UK Chair Sandra Doughty outlined the work that IIH UK was undertaking and applauded and encouraged Birmingham's research work. Sandra reiterated how important research was to improve quality of life in some IIH patients and the need for patients to volunteer for the trials.

Dr Sinclair's presentation was very well received by the audience. Dr Sinclair spoke about IIH, its symptoms, how clinicians diagnose the condition and current treatments. She mentioned optic discs and why experts needed to look at images of papilloedema, as other conditions such as Optic Drusen can initially present as papilloedema to less experienced clinicians.

Dr Sinclair spoke about her experience in treating IIH and presented evidence from a weight loss study that she ran. The evidence had shown that weight loss had been effective in reducing ICP and improving headache in all the patients that took part in the study. However, she did acknowledge that weight loss is extremely difficult to achieve and maintain for many patients and that clinicians needed to develop strategies to help them.

Speaking about current medication, she acknowledged that headache is often not adequately addressed in IIH patients and there is currently not enough medical

knowledge on how best to treat it. She stated that headaches are complicated and can often be contributed to more than one thing such as high pressure, low pressure, migraine and medication over-use. New IIH treatments are urgently needed including a drug which needs to be very effective for vision and headache and that could treat the underlying disease 'cure'. The drug would also need to have minimal side effects, unlike Acetazolamide, the primary medication currently used, which cannot be tolerated by some patients. Dr Sinclair then answered many questions posed by the delegates.

Dr Keira Markey from the Birmingham clinical trial research team spoke to the delegates about IIH research and stated conditions like IIH have no known cause and little research to find this out currently diagnostic tests are currently invasive (LP) we would like to find non-invasive ways. Dr Markey also spoke about the IIH Drug and IIH Weight trials and took questions from delegates in the room.

Dr Thomas Walters and IIH UK designed a survey of 'Diagnostic Lumbar Puncture for IIH Patients'. Dr Walters from the University of Birmingham analysed and interpreted the data that was supplied by IIH patients and presented the results at the patient conference. He stated that we had received 502 responses to the survey and 463 replies were analysed for the survey. Dr Walters explained that LPs were typically an inevitable investigation in diagnosing IIH and IIH UK wanted to ascertain the opinions of patients undergoing this procedure to see how it could be improved.

Dr Thomas Walters concluded from the survey data that LPs are painful experience for patients and pain killers did not affect pain scores. In addition, a higher grade of doctor was linked with having significantly less post LP headache severity. The survey identified that there was clear evidence that LP's are a traumatic part of the IIH patients' clinical journey and steps need to be taken to improve this experience. He also concluded that there is a need for future research to evaluate the best techniques to use with needle type and using image guidance. Dr Walters also advised delegates that there is also a need to evaluate if better Dr training improves the experience and after effects and to look if producing an LP leaflet containing patient information would be helpful. Further information can be found on the IIH UK website Survey page – www.iih.org.uk/surveys

- b. **IIH UK website.** The Charity's website traffic at www.iih.org.uk continues to increase. During the first quarter of 2015, over 16,000 unique visits were made and over 175,000 pages viewed. A live Charity Twitter feed was added to the front page of the website and feedback from users (both patients and clinicians) remains positive. The website is updated by volunteers and IIH UK intends to update more as volunteers become available.

- c. **IIH Support Forum.** Membership of our IIH Support International Forum www.iihsupport.org has continued to grow and now stands at over 2,500. During the report period, there have been 5684 posts on the Forum, 743 new topics have been created and an incredible 6.5 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.
- d. **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. It has also enabled IIH UK Chair Sandra Doughty to raise issues and questions to the Birmingham clinicians and has been a very useful platform for obtaining data for surveys launched by the Charity.
- e. **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. There was a small restructuring of regional groups due to demographics and the Midlands and Wales were split to enable people to connect to those more locally. There are now 14 groups covering England, Northern Ireland, Scotland and Wales which allow people to discuss local issues and meet-up socially.
- f. **Weight Loss Support Group.** There are now over 450 members in the Weight Loss Support Group. IIH UK facilitates the group to provide healthy recipes and links to NHS healthy eating links. There is now 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 health weight loss.
- g. **Surveys.** IIH UK used Survey Monkey to undertake a survey of IIH Diagnosing Lumbar Punctures. The questions were carefully chosen with guidance from doctors from the University Hospital Birmingham and pushed out for responses through the IIH UK Facebook group, Charity group, IIH UK website and Support groups. The overall take-up was good, with useful data analysed by doctors. A presentation of results was made at the IIH UK Patient Conference and the information that the survey provided will be used further to look for ways to improve patient treatment.

Education

- h. **New Leaflets.** The trustees have produced three new medically verified leaflets (Stents, Info for GPs and Depression) and published them to the IIH UK website. In addition, we have continued to distribute the charity's Patient Leaflets to UK hospitals. We are still committed to increasing our distribution in the coming year; with a focus on ensuring that as many newly diagnosed patients as possible have access to up-to-date IIH information and details of available support if they need it.
- i. **New Webpages.** Trustees created and produced two new medically verified webpages on the IIH UK website: IIH and Eyesight and IIH and Children. IIH UK has received positive feedback from parents whose children were diagnosed with IIH, stating that the information the page provided was very useful.

- j. **NHS Choices Website.** IIH UK contacted the NHS Choices website and enabled a direct link to IIH UK's website and List of Medical Conditions Associated with IIH leaflet to be made from their website.

Research

- k. **Support Research.** Trustees attended trial steering committee meetings and teleconferences for the IIH Weight Trial and IIH Drug Trial. IIH UK helped raise the profile of the IIH research trials in Birmingham and after the IIH Weight trial received Ethics approval for the Charity to advertise, IIH UK launched a series of adverts through various platforms to try to encourage patient enrolment. The IIH Weight trial allows £400 to be paid for patient expenses. IIH UK agreed 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.

Raising the Profile of IIH

- l. **British Association of Neuro Nurses 2014 Conference.** Trustee Victoria Davies delivered a presentation about IIH symptoms and the impact IIH can have on some sufferers' lives. In addition, she spoke about IIH UK's work and the IIH research being conducted in Birmingham. Victoria spoke to a number of the delegates during the breaks and received good feedback from those present.
- m. **2014 West Midland CSF Disorders Symposium.** IIH UK sponsored the symposium attended by international clinicians. Dr Alex Sinclair stated that the meeting would be run on a bi-annual basis and hoped that that it would forge discussion and collaboration for future research on IIH. IIH UK Chair spoke to Consultant Neurologist Headache specialists from the National of Neurology London and Sheffield and stated that pain management for IIH was not being fully addressed for many patients. She offered IIH UK's help to push out surveys to followers of the Charity and support group members to collate any data that specialists required to use as pre-trial data or collate information. The delegates were also introduced to the work of IIH UK.
- n. **IIH PSP.** A considerable amount of work was undertaken behind the scenes to attempt to get a Priority Setting Partnership (PSP) underway with the James Lind Alliance (JLA). Unfortunately, due to lack of resource, the Charity was unable to move ahead. This is however still a future aspiration that IIH UK and Dr Sinclair would like to see proceeding.

29th March 2016

Michelle Williamson

Michelle Williamson. Trustee