ANNUAL REPORT

Names of Charity Trustees during the report period

David Dennis        Chairman
Natalie Garrett     Secretary
Michelle Williamson Treasurer
Kerry Lamerton      Merchandise Officer (until September 2012)
Sarah Newton        Membership Officer (until November 2012)
Sandra Doughty      Fundraising Officer (from December 2012)

Structure, Governance and Management

1. IIH UK was established as a charity in 2011 and is governed by its founding constitution, as amended on 12 May 12. The charity is constituted by association. Trustees are normally appointed or re-elected at the Annual General Meeting, although trustees are empowered to appoint new trustees in-year by extraordinary trustee meeting.

2. All trustees have given their time voluntarily during 2012-13 and have not received remuneration or any other benefits in undertaking their duties.

3. IIH UK is a member of the NASA Human Health Programme, the Wales Neurological Alliance and Rare Disease UK.

Objectives and Activities

4. The charity’s objects, as set out in the constitution, are:

   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

5. In planning and undertaking the activities shown below during the report period, IIH UK trustees kept in mind the Charity Commission’s guidance on public benefit:

a. In November 2012, IIH UK ran a major radio awareness campaign about the condition IIH.

b. In January and February 2013, IIH UK hosted 2 medical conferences covering paediatric and adult IIH themes, events that were well attended by medical consultants, neurologists, ophthalmologists, neuro nurses and other interested clinicians.

c. IIH UK developed the concept of a non-invasive pressure monitoring device which was discussed with clinicians at the February 2013 medical conference.

d. In June 2013, IIH UK held a Patient Conference for IIH sufferers and their families/friends.

e. IIH UK developed and distributed over 5,000 IIH UK patient leaflets to neurology and ophthalmology departments throughout the UK, as well as manning an Information Stand in one hospital.

f. IIH UK successfully liaised with the Department of Work and Pensions (DWP) to get IIH added to their approved list of medical conditions.

g. IIH UK created 7 regional support groups.

5. A great contribution is made by IIH UK’s small number of volunteer members who help with the day to day running of the charity. These volunteers operate in the following areas: Membership, Fundraising, Publicity, Forum Moderation, Newsletter, Merchandise and Social network administration.

Summary of IIH UK’s main achievements during 2012-13

6. These are as follows:

a. Recognition of IIH by the Department of Work and Pensions. In making medical assessments for benefit payments, DWP assessors often assumed that the word hypertension (as referred to in the condition Idiopathic
Intracranial Hypertension) was high blood pressure and, as such, turned down claims on the basis that IIH was not recognised. However, the hypertension described in IIH is defined as high Cerebral Spinal Fluid pressure. Keen to address this issue, IIH UK brought this fact to the DWP’s attention and, after much discussion, IIH now features as code G99 on the DWP’s list of known medical conditions. Decision makers are now advised to consult the DWP’s Medical Services Provider when assessing someone with IIH.

b. Nationwide media promotion about IIH. In November 2012, the Chairman of IIH UK visited a radio studio in London where 30 national and regional radio stations took up the opportunity to interview him on a range of IIH related subjects including the symptoms, its rate of incidence (especially among children) and the condition’s impact on sufferer’s lives. At the same time, the opportunity was also taken to promote the role of the charity IIH UK and to describe the actions being taken to support sufferers and raise awareness of the little known condition within the general public and the medical community in particular. It is estimated that up to 12 million people could have listened to the broadcasts. There was also an opportunity for audience participation and many IIH sufferers spoke on air at their local radio stations about IIH and how it affects them.

c. Staging of IIH Medical Conferences. In early 2013, two medical conferences were hosted by IIH UK, the first focused on children with IIH, the second (entitled ‘The Sarah Hibberd Conference’) relating to the condition as it affects adults. Both medical conferences were well attended by clinicians from around the UK. Topics discussed across the 2 events included: best practice for Lumbar Puncture guidelines, non-invasive pressure monitoring, a UK service framework for standard care management in IIH and the UK integrated care pathway for Adults and Children and, finally, the development of an IIH Life Registry which will seek to capture data on IIH treatment across the UK with the aim of finding the optimal treatments for managing sight, headaches and the quality of life of IIH sufferers. For over 100 years, little has changed in the care and development of treatment for IIH and it is an enduring aim of the charity to bring interested clinicians together to advance the treatment and care of sufferers of IIH.

d. Staging of IIH Patient Conference. In June 2013, IIH UK held a Patient Conference in Bournemouth which was well attended by IIH sufferers, their families and friends. As part of the event, a representative from Codman held a highly praised workshop during which attendees had the chance (many for the first time) to see, touch and ask questions about Intracranial Pressure monitors, shunts, catheters and the tools used during shunt surgery. As in previous years, the Patient Conference was held alongside the IIH UK Annual General Meeting, an event which has fondly become known as our
‘Weekender’, with many delegates taking the opportunity to stay two nights at the conference venue. IIH is a rare, chronic and debilitating illness and it is very clear that sufferers and their families take great comfort in having a chance to get together with other sufferers and share experiences. Just knowing that they are not alone gives them a huge boost.

e. **Establishment of Regional Support Groups.** Over the 12 month period, IIH UK has created seven popular regional groups on Facebook. These groups have enabled many IIH sufferers to meet and make friends in their respective areas and informal monthly social meetings are now a common occurrence. The charity hopes to create even more groups in the future.

7. IIH UK is funded primarily through fundraising, with other income sources including donations and membership fees. Without the fantastic help of our supporters, the charity could not have achieved its key objectives and fundraising, in particular, has enabled IIH UK to provide a website and support forum, hold medical conferences, meet with clinicians and attend other organisations conferences, raise awareness of IIH, e.g. by provide IIH patient leaflets and posters for display in hospitals nationally and through media awareness campaign and support sufferers of IIH.
I H UK
Independent Examiners Report to the Trustees

I report on the accounts of the charity for the year ended 30 June 2013 which are set out on the attached accounts.

Respective responsibilities of trustees and examiner
The trustees are responsible for the preparation of the accounts. The trustees consider that an audit is not required for this year under section 144(2) of the Charities Act 2011 (the 2011 Act) and that an independent examination is needed. I am qualified to undertake the examination by being a qualified member of the Association of Chartered Certified Accountants.

Having satisfied myself that the charity is not subject to audit and is eligible for independent examination, it is my responsibility to:

- examine the accounts under section 145 of the 2011 Act;
- to follow the procedures laid down in the general directions given by the Charity Commission under section 145(5)(b) of the 2011 Act; and
- to state whether particular matters have come to my attention.

Basis of Independent Examiner’s Report
My examination was carried out in accordance with the general directions given by the Charity Commission. An examination includes a review of the accounting records kept by the charity and a comparison of the accounts presented with those records. It also includes consideration of any unusual items or disclosures in the accounts, and seeking explanations from you as trustees concerning any such matters. The procedures undertaken do not provide all the evidence that would be required in an audit and consequently no opinion is given as to whether the accounts present a true and fair view and the report is limited to those matters set out in the statement below.

Independent Examiner’s Statement
In connection with my examination, no matter has come to my attention:

(1) which gives me reasonable cause to believe that in any material respect the requirements:
- to keep accounting records in accordance with section 130 of the 2011 Act; and
- to prepare accounts which accord with the accounting records and to comply with the accounting requirements of the 2011 Act have not been met; or

(2) to which in my opinion, attention should be drawn in order to enable a proper understanding of the accounts to be reached.

Jamie Westwater FCCA
Chartered Certified Accountant
Westwaters
34 Frederick Street
Sunderland
SR1 1LP

4th April 2014
CARRIED FORWARD FROM 2011-12 £8,214.31

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CLOSING BALANCE AT 30 JUN 13 £6,166.41