

ICP Support

intrahepatic
stillbirth
gallstones
urso
liver
education
pruritus
symptoms
scratch
itchy
risk ICP
research
information
awareness
cholestasis
fundraising
families
bile acids
heredity
UDCA
genetics
pregnancy
support

**Trustees' Annual Report for the period
1 April 2014–31 March 2015**



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Reference and administration details

| | |
|---|--|
| Charity name | ICP Support |
| Registered charity number (if any) | 1146449 |
| Charity's principal address | Flat 3, Russell Court, Walsall Road, Sutton Coldfield, West Midlands B74 4NS |
| Names of the charity trustees who manage the charity | |
| Trustee name | Office (if any) |
| Jenny Chambers | Chair |
| Judith Hibbert – Resigned 15/09/14 | Vice-Chair |
| Sian Eaton | Treasurer |
| Peter Dixon | |
| Victoria Geenes | |
| Judith Gray | |
| Karen Grundy – Resigned 19/09/14 | |
| Magdalen Rees | |
| Alice Tuson | |

Structure, governance and management

Description of the charity's trusts

| | |
|---|--------------------------------------|
| Type of governing document – dated 20/10/11 | Articles & Memorandum of Association |
| How the charity is constituted | Company Limited by Guarantee |
| Trustee selection methods | Elected by members |

Objectives and activities

Intrahepatic cholestasis of pregnancy (ICP) is a liver condition of pregnancy that affects around 5,500 women a year in the UK. Its main symptom of itching can be debilitating for the mother-to-be and in severe cases it can also cause the death of the baby just before birth (stillbirth).



The aims of the charity are:

- ◆ to provide support and information to people affected by ICP
- ◆ raise awareness of the condition
- ◆ promote and fund research into it

The Charity's object as set out in the company's memorandum and articles of association is:

The relief of sickness and preservation of good health among women affected by the liver condition of pregnancy called intrahepatic cholestasis of pregnancy (ICP) also known as obstetric cholestasis (OC), in particular but not exclusively by:

- (a) *providing information and support to such women and their families*
- (b) *advancing education for the public benefit of the condition*
- (c) *promoting, supporting and raising funds for research into the condition, the useful results of which will be disseminated for the public benefit*

The work of the charity is to ensure that all pregnant women and all health professionals who provide care for them are aware of this potentially devastating condition. This is vital if unborn ICP babies are to be better protected.

We aim to achieve this by raising the profile of the condition in the public sector and working with health professionals to facilitate what is considered to be 'best practice'. We will continue to provide support to all people affected by the condition and to promote and fund research into understanding the condition.

We are guided by recommendations from the Charity Commission, and as such the trustees meet at least three times a year but also strive to hold telephone conferences to discuss our Policy & Strategy, Finance & Fundraising and Media & Communications. The governing principle of each meeting is to plan activities which will contribute towards the established aims and objectives.

The focus of our work and how we demonstrate public benefit

To provide information and support to people affected by the condition

Information

The general leaflet continues to act as a signpost for information about the condition (and contains pertinent facts about ICP). During 2014–2015

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it was distributed at conferences and at fundraising events around the UK (especially during our Awareness Week).

The first draft of our information booklet was written by April 2014 and we are currently receiving feedback from health professionals and people affected by ICP (such as women who have or have had the condition) on it. We are hoping that publication will take place later in the year.

Both the leaflet and information booklet are, and will be, based on known research to ensure that the public have clear and accurate information regarding the condition. ICP Support's involvement with one of the world's leading research groups, based in London, will help to ensure this.

Facebook group numbers increased by 120% – this means we supported an extra 700 families this year.

Information is also disseminated through social media such as Twitter, Facebook groups and a Facebook page. The open Facebook group currently has 1,800 members – an increase of almost 700 since our last report. The Facebook page is primarily used to update members about fundraising activities and any research or new research findings on the condition, and we currently have 1,600 followers, which is an increase of 120% from last year.

The amount of email we receive asking for information has not changed significantly, and we continue to receive an average of 5–6 emails per week. These emails come from women in other countries as well as the UK.

Support

The charity has a telephone support line that operates Monday–Friday, 9am to 9pm. We do not give medical advice; nor do we provide counselling. However, the volunteer who takes the calls has had the condition, is a trustee of the charity and has been answering the line for over three years. She is supported and supervised by another trustee of the charity who has had counselling training. This year there have been 51 new callers, with some of these callers making repeat phone calls. The callers are mainly women with the condition, although there have also been calls from fathers, grandmothers and a surrogate family, along with a few international calls. The calls are often quite lengthy; at least 25 minutes and sometimes an hour long. This illustrates that despite the success and impact of the social media groups, the need to be able to speak with someone in person is often vital.

In addition to the phone line, we facilitate an email support line whereby we can reply to women directly and confidentially. We aim to be contactable via every different means available as we recognise that whilst social media may suit many people, others may prefer a different method. Contact for support via email continues to be steady: although not overly demanding, these often result in a supportive relationship that can last several months (often until the pregnancy is completed). During our financial year we had 86 emails from women wanting information or support.



The majority of support is given via social media. We have five Facebook groups that provide support. However, there were also 90 direct Facebook messages to the founder of the charity (Jenny Chambers) and some of the moderators. We currently have:

- ◆ An Open* group, 'ICP Support' (1800 members). It is open so that anyone can see the posts and glean information about the condition without ever having to join.
- ◆ A Secret* group, 'ICP Support Private' (50 members) for those people who need support or information, but do not want their posts to be seen by family or friends in the open group.
- ◆ A Closed* group, 'Precious Memories', for anyone who has been affected by the loss of a baby through ICP.
- ◆ A Closed* group, ICP Support South Africa.
- ◆ A Closed* group, ICP Support Australia and New Zealand, with 157 members

*as defined by Facebook

All of these groups are monitored by volunteers (called moderators). They offer support in the form of a listening ear as opposed to formal counselling, and information (based on research). Although no formal counselling is offered the Chair of the charity is a trained counsellor and is able to identify people who may need additional support and can signpost them to this support should they want it. She is also able to offer supervision to the other volunteers as required.

“I'm so glad I had this group for support”

To raise awareness of the condition (advancing education)

Leaflets

The general leaflet has helped to raise awareness about the condition, as it has been distributed at fundraising events and health professional conferences. It is sent out to anyone who wishes to use it to help us with our aims, and this year we needed a further reprint, showing an increase in the demand for it.

The new information booklet is still being written, but we hope it will in print for later in 2015. The authors of the booklet are trustees and volunteers, so the delay has been purely due to their own work commitments elsewhere.

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Media

We were delighted to exceed our target of one media article every two months to almost one a month (11 articles in total). The charity's international reach is continuing to expand, and it was encouraging to have the charity represented in the media in South Africa as well as Australia. There have also been a range of articles published in the UK, all containing factual information about the condition as well as signposting to our charity. Highlights of the year include two stories that appeared in UK magazines, *Real People* and *New!*, each of which has a circulation of over 150,000 copies. It was also very encouraging that there was further media coverage in Scotland, as until the previous year, the condition had never appeared (to our knowledge) in Scottish media.

Conferences and talks

May 2014 saw ICP Support's inaugural stand at the Primary Care Conference at the NEC in Birmingham. This conference attracts both midwives and



Alice Tuson (left) speaking to midwives at the Primary Care Conference

GPs, two groups of health professionals with whom (as part of our aims) we are looking to share our information. Jenny Chambers (Founder) and Alice Tuson (Media Coordinator) facilitated the stand for the two days of the conference. It was an exceptionally busy event, with midwives stopping to take leaflets and to find out further information. Many of the midwives reported that whilst they were aware of the condition, they did not know many details regarding management of ICP.

In November 2014, Jenny returned to Telford to take a stand at the Royal College of Midwives (RCM) annual conference. We were able to utilise the skills of two of our Facebook moderators, Clare Johnson and Tracey Smith, to help provide support to Jenny. We were able to share information on the research and management of ICP with trainee and qualified midwives and were delighted to discover that midwives who had visited us the previous year sought out our stand to share their renewed experiences of treating women with ICP. The stand was busy for the two days of the conference and we saw an opportunity to further

develop our presence at the RCM in future years, namely in the form of an iLearn package (see later for more information).

In February 2015 Jenny attended the Maternity, Midwifery and Baby Forum in London. This was a quieter event that highlighted the need for us to have at least two charity representatives at these events, as although quieter, it was still challenging for one person to be able to speak to delegates. We were still able to raise our profile, but going forward we realise that it is important to have sufficient cover for these events.

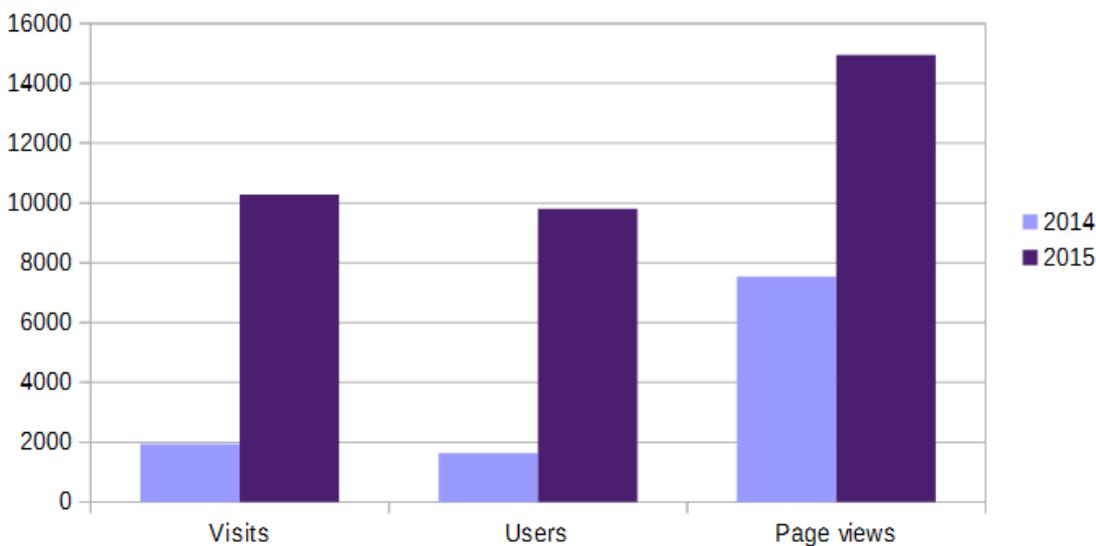


All the trustees are in no doubt about the benefits of attending these conferences, however given the costs associated with attendance, our presence at these meetings will be reviewed on a year by year basis. The 48 hours spent at each conference gives us a great opportunity to speak to and share knowledge with in excess of 400 health professionals, numbers that would be difficult to capture on a face-to-face basis via other means.

Awareness Week

This year it was decided that Awareness Week would not be as heavily promoted as the previous year due to a lack of volunteers to help run the event. However, we still had several supporters who held events for us and a total of £3,000 was raised. We also took the opportunity to launch a Thunderclap campaign asking people to spread awareness of ICP, and this was a great success. We were supported by over 840 people and achieved a social reach of 317,534 – a terrific way to raise awareness of the condition. As a result our website registered a large increase in visits compared with the 2014 Awareness Week. The following chart compares Awareness Week in 2014 and 2015.

Awareness week comparison



More details about website usage are given later in this report.

Promoting, supporting and raising funds for research

Promoting and supporting research

Through ethical approval given to Professor Catherine Williamson's studies based at King's College London and Imperial College, London, ICP Support is able to encourage and identify women interested in taking part in that



research. We are continuing to use the website and our Facebook page to tell women about the research taking place, to invite them to participate in studies and to disseminate progress and findings.



This year we asked their opinion about a new study that would involve the collection of white adipose tissue (i. e. fat cells). Following the involvement of women in the design of a study (called BEATS) using fetal ECGs (see later for more details), the Patient Information Sheet currently in use has the charity logo on it to show that it has been reviewed by ICP Support.

Collaboration

We are actively involved with organisations, such as the NIHR (National Institute for Health Research) speciality group, that help to support the delivery of all the current research projects that include reproductive health. This includes the studies by Professor Catherine Williamson into ICP. As part of the government's commitment to also include the views of the public and services users, called PPI (Public and Patient Involvement), we are still very committed to supporting representation from the charity to the group.

We were also asked to attend meetings held by MBRRACE-UK (Mothers and Babies – Reducing Risk through Audits and Confidential Enquiries across the UK), which is part of the NPEU (National Perinatal Epidemiology Unit), whose focus will include perinatal mortality. There will be opportunities for the charity to offer ideas for suitable audit topics into ICP.

We are now an affiliate member of the James Lind Alliance and organisation that brings patients, carers and clinicians together to identify and prioritise for research the treatment uncertainties which they agree are the most important. As a result of this affiliation, in February 2015, we were involved in helping to prioritise the top 10 research questions for stillbirth (in fact it became 11 research questions). We felt honoured to be asked to engage in this sensitive but important process.

This year our Chair, Jenny Chambers, also signed up to be a lay reviewer for the NIHR Health Technology Assessment (HTA) Programme – Clinical Evaluation and Trials. Jenny's interest in obstetrics together with her own personal experiences will be used to review applications for funding for research.

We also believe in the importance of collaboration with other charities working in the reproductive and childbirth sector. Organisations such as APEC, Sands, Count the Kicks and Mama Academy are all working towards the same aim – the reduction of stillbirths. We were delighted that Jenny Chambers was asked to be an information ambassador for Mama Academy and look forward to supporting them as they help to educate midwives and the public about ICP.



We were also very pleased to have initial discussions with the RCM (Royal College of Midwives) about developing an iLearn package on ICP for them. The RCM's iLearn is an integral part of continuous professional development for those midwives registered with them and wishing to improve their knowledge of certain conditions. We have started work on writing the content for the ICP training module and, with the help of the RCM's iLearn team, aim to launch it at the RCM conference in November 2015.

Raising funds for research

Our commitment to research remains an important part of our charitable aims. We were able to donate £6000 to research (via Genesis Research Trust) and this money will be ring fenced for research into ICP. As well as helping to support some important genetic work being conducted by Professor Catherine Williamson, it also helped to purchase a fetal ECG monitor. This monitor is one of four monitors being used in a current study to evaluate whether they can detect any potential heart arrhythmias (irregular heart rates) in the babies of women with ICP (the BEATS study mentioned earlier). It is thought that bile acids may cause these arrhythmias and be the reason why stillbirth is associated with ICP. Current cardiotocograph (CTG) machines used within maternity hospitals cannot detect these irregularities and are therefore of no real benefit to women with ICP. However, we know that hundreds of women are given CTGs, mainly for reassurance purposes. It is both gratifying and exciting to be able to help with these important studies to either confirm or refute the possibility that there may be a better way to monitor unborn ICP babies and therefore better protect them.

Additional details of objectives and activities

Volunteers

All the charity's trustees are volunteers and there are a further 11 volunteers, three of whom were added after 31 March 2014. They act as:

- ◆ moderators of the support Facebook groups (managed by the Chair who is a qualified counsellor)
- ◆ support for the media coordinator in her work
- ◆ support for the fundraising manager
- ◆ IT support
- ◆ helping to manage the charity's shop

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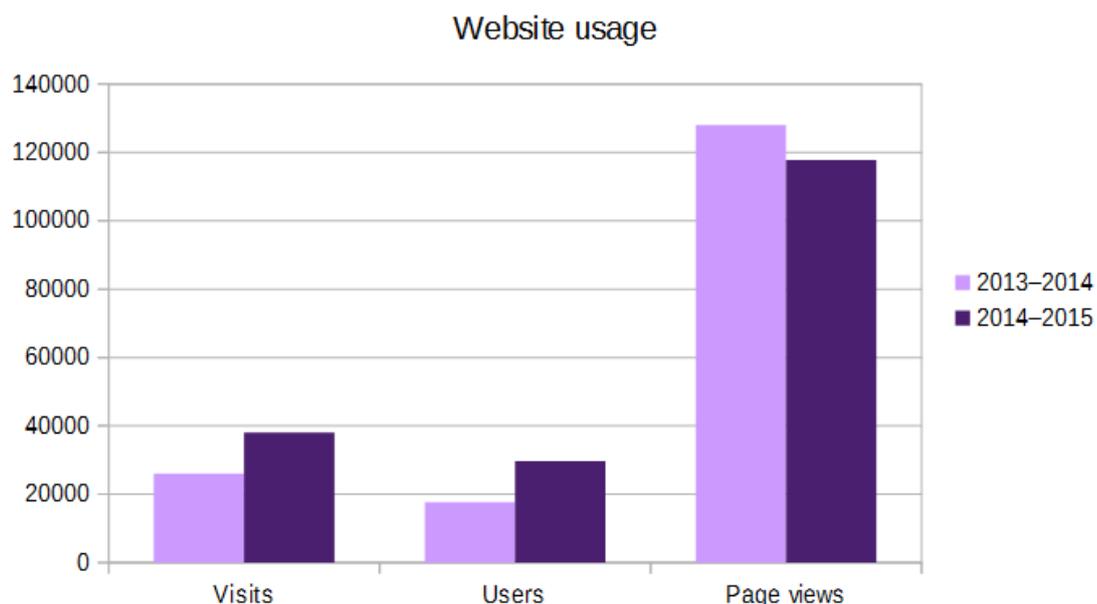
Website

The website plays a large role in helping us to achieve our targets. Although the charity funds the administration of the website this does not cover the full costs that would be charged by other companies for the services we receive. Our webmaster therefore also acts in a voluntary capacity to provide these services.

Last year's report showed data only from the final quarter of the reporting period for each year, as we did not have full-year data available. Now that we have two full years of data we can compare the complete years 1 April 2013–31 March 2014 and 1 April 2014–31 March 2015.

Other differences to note before presenting the data are that two sections of the website saw multiple pages combined into single pages; 2015's Awareness Week involved a Thunderclap promotion; and no adjustments have been made to remove the Awareness Week boosts in usage.

Website usage



Both visits (up 12,018; 46%) and the number of individual users (up 12,052; 68%) have risen significantly over the year (down 10,236; 8%), but the number of individual pages visited has fallen. However, all three comparisons are strongly affected by the changes noted in the introduction. In particular, the number of page views is down because the 'Important information about ICP' section of the website was reduced from 14 pages to one page (retaining all the information), and the '10 things you need to know' section was reduced from 11 pages to one page (again without changing the information presented). In both cases, expanding and collapsing paragraphs were used to present the information in a compact way on a single page. Furthermore, the increases in visits and users are mostly accounted for by the Thunderclap promotion in Awareness Week. The underlying trend is a small but steady increase in both categories.

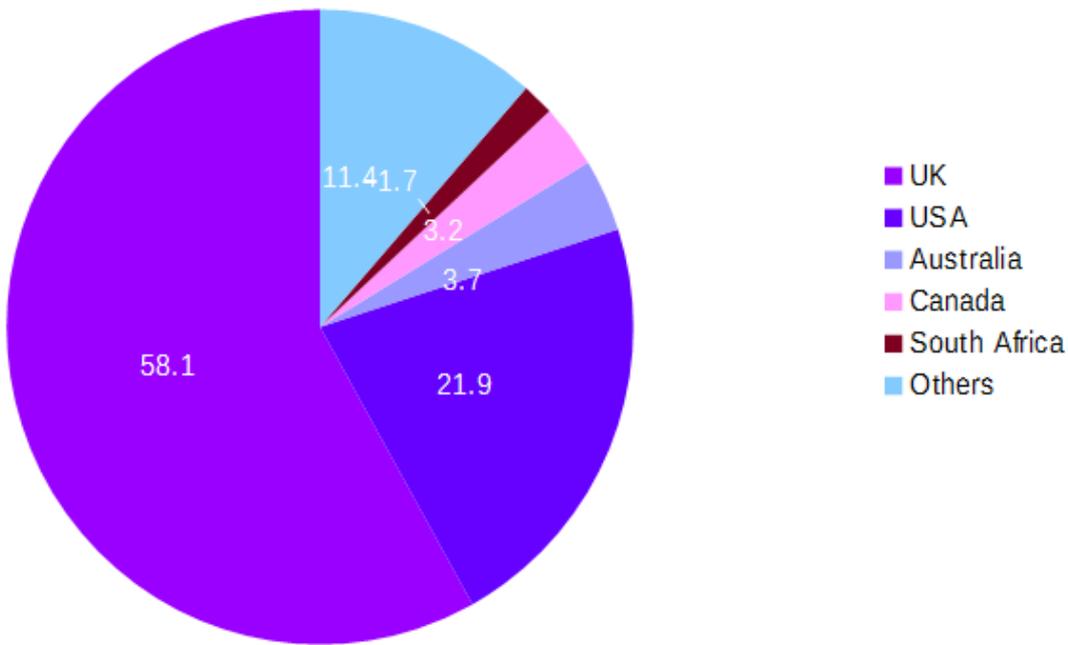


A comparison of the 2014 and 2015 Awareness Week website statistics is shown in the Awareness Week section of this report, above.

Geography

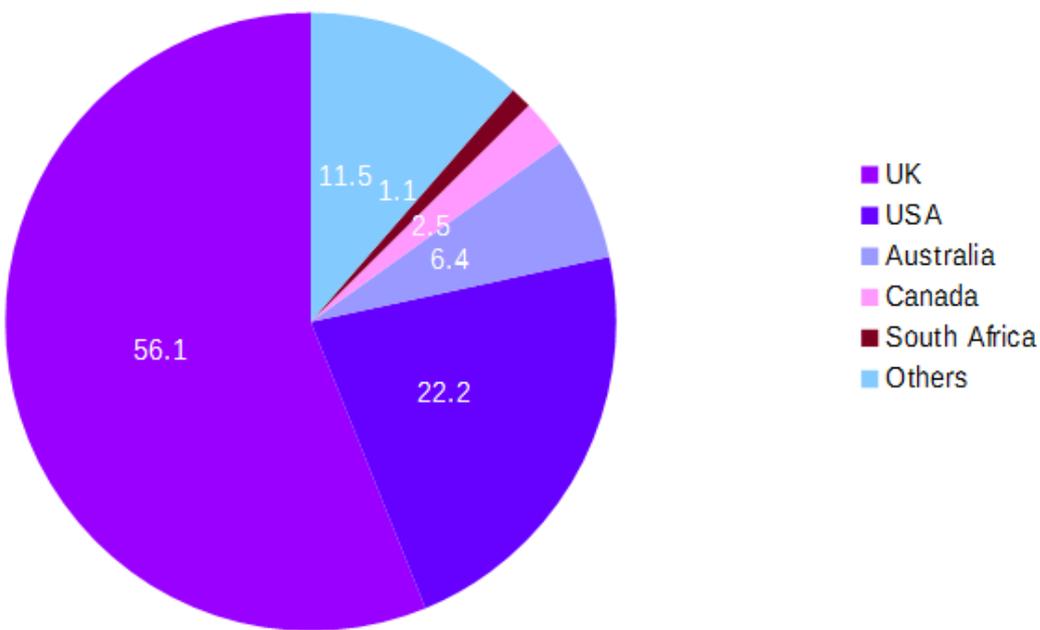
There have been small shifts in the origins of the website's visitors over the year. This chart shows 2013–2014:

Visits 2013–2014



And the percentages for 2014–2015:

Visits 2014–2015



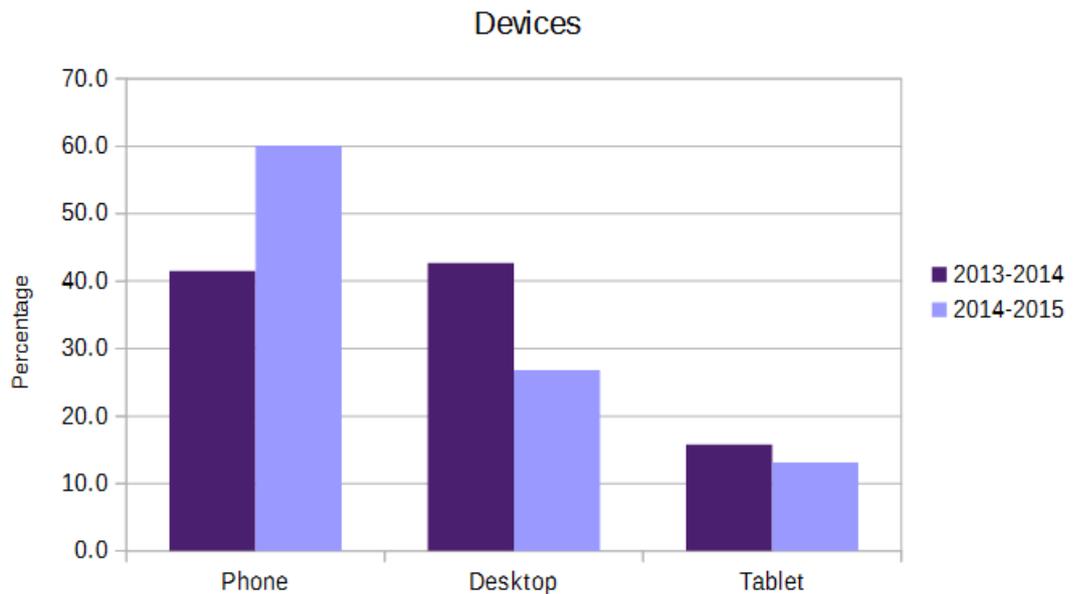
Australia has increased significantly relative to other territories.



The absolute numbers of visitors from each of the top five countries have risen, so the UK's percentage fall is only relative.

Technology

People access the website via three general types of device: desktop/laptop computers, mobile phones and tablets. This year's figures show a big change:



Facebook

At the time of last year's report, there were 1,121 members of the main Facebook group. This had risen to around 1,800 this year. There are also 171 members in the Australia/New Zealand group and 22 in the South Africa group (with some overlap between the latter two and the main group).

There is an interaction between the website and the Facebook groups that is easy to observe, but hard to quantify. For example, people frequently ask questions on Facebook that could have been answered by reading the website. It is clear that many people's natural instinct is to search for a community on Facebook where they can get a quick answer, rather than spending time searching for and reading a website. Our Facebook moderators have become more ready to post a link to the relevant page(s) on the website over the past year, especially since the volume of traffic on the groups has grown significantly. Unfortunately, Facebook provides no way to monitor this traffic.

We are also unable to measure how many people find the answers they want at the website and never visit, comment or post on Facebook.



Achievements and performance

Overall, we are delighted with our progress, which reflects growth in the number of people we are supporting.

This year we have:

- ◆ Seen an increase of 46% in visit to our website
- ◆ Exceeded our media target
- ◆ Had a visible presence at two conferences that helped to raise awareness of the condition
- ◆ Supported a membership of just over 1800 people on the open Facebook group – this year we added 700 new members
- ◆ Maintained our telephone support for people
- ◆ Increased the number of organisations we collaborate with

Financial review

In the last year the financial resources of the charity have continued to grow. During 2014/15 income was £19,488. Regular giving to the charity has continued to rise. The trustees continue to encourage this form of donation by encouraging users of the Facebook groups to support the charity financially in this way. One-off donations have also continued to be received, with many supporters raising funds for the charity on a local basis.

The largest item of financial expenditure was the donation of £6,000 sent to Genesis Research Trust, making total donations to this organisation of £12,500 since the inception of ICP Support. The largest item of operating expenditure related to conference attendance. Other significant costs included website maintenance/hosting and telephone expenditure.

There was a surplus of £2,813 in 14/15.

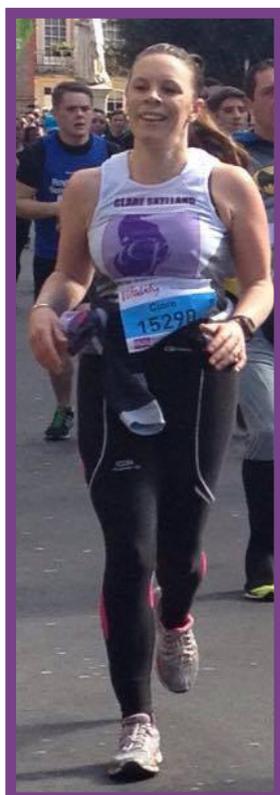
At the end of the financial year the charity has cash reserves of £17,484. The reserves are sufficient to continue the work of the charity and to grow its activities into 2015/16.

Future expenditure is anticipated to cover

- ◆ Payment of day-to-day operational costs, including a move to office premises
- ◆ Financial support for fundraising activities
- ◆ Printing of information booklet
- ◆ Attendance at medical conferences
- ◆ Financial support for research

Policy & Reserves

An average cash balance of 3 months' expenditure plus any committed expenditure will be maintained. There are no plans to invest any of the monies held.



Summary

We believe that through the website, social media groups and collaboration with other organisations we are continuing to deliver our aims as a charity. We are grateful to have been supported in this by the Cranfield Trust who has helped us to develop our strategic plan and deliver those aims.

Part of the strategic plan has identified a need to engage help to make grant applications on behalf of the charity. These applications will help us to conduct our work – for example funding for the information booklet or display stands for conferences. We hope to see the benefits of engaging this help this during the next financial year. The plan also identified the need for the charity to have an office from which to work as our growth means that we can no longer operate within our present confines.

We are delighted with our growth and would like to thank everyone who has helped to support this, in particular those people who have actively raised funds for us or supported the charity through donations.

Declaration

The trustees declare that they have approved the trustees' report above.

Signed on behalf of the charity's trustees:

| | | | |
|---------------------|---|--|---|
| Full name(s) | Jenny Chambers | Sian Eaton | Peter Dixon |
| Position | Chair | Treasurer | Vice-Chair |
| Signature(s) |  |  |  |

| | | | |
|--------------|-----------|-----------|-----------|
| Date: | 11/7/2015 | 11/7/2015 | 11/7/2015 |
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