

ICP Support



Trustees' Annual Report for the period
1 April 2013–31 March 2014

Reference and administration details

Charity name	ICP Support
Other names charity is known by	Formerly known as OC 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	Vice-Chair
Sian Eaton	Treasurer
Jenn Deasington – Resigned 20/03/14	
Peter Dixon	
Andy Edgecombe - Resigned 31/12/13	
Victoria Geenes	
Judith Gray	
Karen Grundy	
Rachael Rawlings - Resigned 27/04/13	
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) – also known as obstetric cholestasis (OC) – is a liver condition of pregnancy that affects around 5,000 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:

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

Our work focuses on ensuring that all pregnant women and health professionals are aware of ICP together with a knowledge of what is considered to be 'best practice'. We want to provide support to all people affected by the condition and ensure that research into understanding the condition continues. Our hope is that all of this will us to achieve our vision that: *"Every ICP baby is born safely"*

We are guided by recommendations from the Charity Commission and to ensure that the aims of the charity are met, the trustees meet twice yearly and have been further divided into three sub-committees: Policy & Strategy, Finance & Fundraising and Media & Communications. These groups aim to meet (or hold telephone conferences) every two months. 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 generic leaflet continues to act as a signpost for information about the condition (and contains pertinent facts about ICP). During 2013-2014 it was handed out at conferences, a baby show and at fundraising events around the UK.

An information booklet on ICP is currently being written with an anticipated launch time of autumn 2014.

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.

Information is also disseminated through social media such as Twitter, Facebook groups and a Facebook page. The open Facebook group is the most active and it is here that the most information is given out. The numbers have risen from 500 in January 2013 to the current number of 1,121. This rise also mirrors an increase in the visits to the website (see below). The open Facebook page is primarily used to update members about fundraising activities and any research or new research findings on the condition.

We receive an average of 5 emails a week requesting information about the condition. Many of these are asking specific questions about the condition because women know that the Chair works in a research group investigating the condition.

Support

The charity has a telephone support line that operates Monday–Friday, 9am to 9pm. Anyone affected by the condition can contact it for support. There are presently two volunteers who answer the phone. It is not a medical advice or counselling line but both volunteers have experience of the condition and one is a trained counsellor. We were still contacted by just over 45 people (including

health professionals) and this figure is comparable to the previous year's.

Contact for support via emails 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).

The majority of support and information is given via social media. We have four Facebook groups that provide support. We currently have:

- An Open* group, 'ICP Support' that has over 1,100 members. It is open so that anyone can see the posts and glean information about the condition without ever having to join.
- A new Secret* group, 'ICP Support Private' 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. This is much smaller and was introduced as a replacement for the forum which was less accessible. For those people who do not use Facebook there is still the scope to email the charity for information and support as well as to contact it by phone.
- A Closed* group, 'Precious Memories' that is for anyone who has been affected by the loss of a baby through ICP. This has also replaced the forum which was also less accessible. Like the other groups people who do not use Facebook can still access us by email or phone.
- A Closed* group, ICP Support South Africa.

*as defined by Facebook

All of these groups are monitored by volunteers. 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 who can signpost them to this support should they want it. She is also able to offer supervision to the other volunteers as required.

To raise awareness of the condition (advancing education)

Leaflets

The generic leaflet has helped to raise awareness about the condition, as it has been distributed at fundraising events and health professional conferences. It has also been sent out to people who have requested it, including several people from America and South Africa.

The new information booklet is being written with an anticipated launch time in the autumn of 2014

Media

The Media & Communications Committee had set a target of one media article every two months and to date this has been achieved and exceeded (12 articles in total) through baby magazines, newspapers and midwifery journals such as, The Daily Mail, Practical Parenting & Pregnancy, Essentially MIDDIRS and local papers. It was also featured in a South African journal through an article written by one of the Facebook group members with the oversight of our Chair. All articles have contained factual information about the condition together with signposting to support for people affected by the condition via the charity. A positive consequence of this was the sharing of the Daily Mail article close to 4,000 times. The article was also translated into several languages.

Conferences and talks

The charity had a stand at the Royal College of Midwives (RCM) Annual Conference in November 2013. This was hugely successful in raising awareness both of the charity and the condition. We spoke to over 150 health professionals and a poll of just under 100 midwives resulted in data that showed that this cohort of health professionals do not have a comprehensive understanding of the condition. For example, fewer than 1:5 midwives knew that the condition can present as early as 8 weeks. This is supported by what we have learnt from women on the Facebook group because they report being turned away for important diagnostic tests when they itch earlier than the 'norm'.

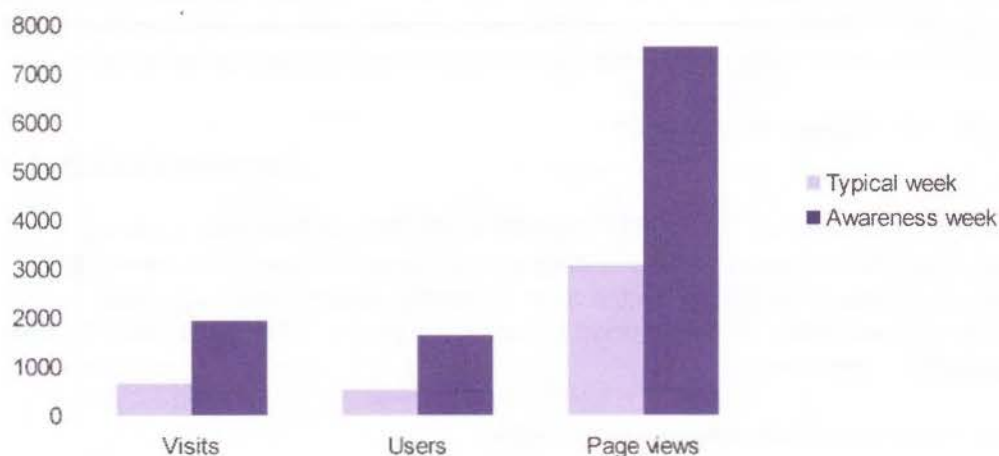
This shows the importance of us attending such conferences and we plan to attend the RCM conference again in November 2014. We are also scheduled for a stand at the Primary Care Conference in May 2014 where our target audience will include GPs and Health Visitors.

We attended the St Albans' Baby Show with a view to assessing whether it is useful for us to be present at baby shows. We found that by and large women do not want to be aware of conditions that can result in stillbirth and that they attend these shows for the positive aspects of approaching parenthood. As the cost of this show was very small £50 it was a worthwhile exercise and we have decided to focus on the health professional conferences instead. We will re-visit this decision in the future when we have more funds and more people to run the stands.

Awareness Week

Following on the success of last year's Awareness Day it was decided to extend this to a week to include a fundraising target of £5,000. 25 people held events (compared with 4 last year) and we raised just over £5,000. We had a few local media articles and we also saw traffic to our website increase. The following chart compares Awareness Week (1st – 8th March) with the third week in March, after the Awareness Week traffic had died away.

Awareness week comparison



In percentages, visits were up 198.3%, users were up 214.2% and page views were up 145.9%. There's no doubt that we reached a lot more people that week.

Promoting, supporting and raising funds for research

Promoting and supporting research

Through ethical approval given to Professor Catherine Williamson's studies based at Imperial College, London, ICP Support is able to encourage and identify women interested in taking part in that research. They are given information about what the research entails with the clear guidance that they are not obliged to participate. Women have reported back to the charity that they feel that taking part may not only help them but may help other women for the future and gives them a sense of purpose. Published results from the studies are reported on the ICP Support website, giving the general public access to these research papers. The charity also uses its open Facebook page to report on the research 'in action' to show people how the scientists work and what is done with their samples.

We actively seek their opinions on what they want to see happening in research and involve them in trial designs.

Collaboration

This year we were invited to join a group that has been set up by the government as part of its remit to promote research within the UK. The NIHR (National Institute for Health Research) is the body that oversees this process and as a result speciality groups that focus on specific areas of health were formed. These speciality groups help to support the delivery of all the current research projects that include reproductive health and 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 were delighted to be asked to nominate a representative from the charity to sit on 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.

Raising funds for research

We continue to fund research into the condition and it was agreed that a minimum of 10% of our surplus could be donated for this purpose. In June 2013 a further £1,000 was paid to Genesis Research Trust (who direct the money to ICP research). This makes a total of £6,500 given to research since the formalisation of the charity.

This money has been used to help support the important genetic work being conducted by Professor Catherine Williamson at Imperial College London and King's College London. The findings may result in a greater understanding of the genetics of the condition and could help doctors to implement better treatments for women with ICP.

Additional details of objectives and activities

Volunteers

It is important to note that all the charity's trustees are volunteers and many have full-time jobs. However, they provide a richness of experience to the charity and three of them are involved in research into ICP.

As well as the trustees there are further 8 volunteers, five of whom were added after 31 Mar 2013. They act as:

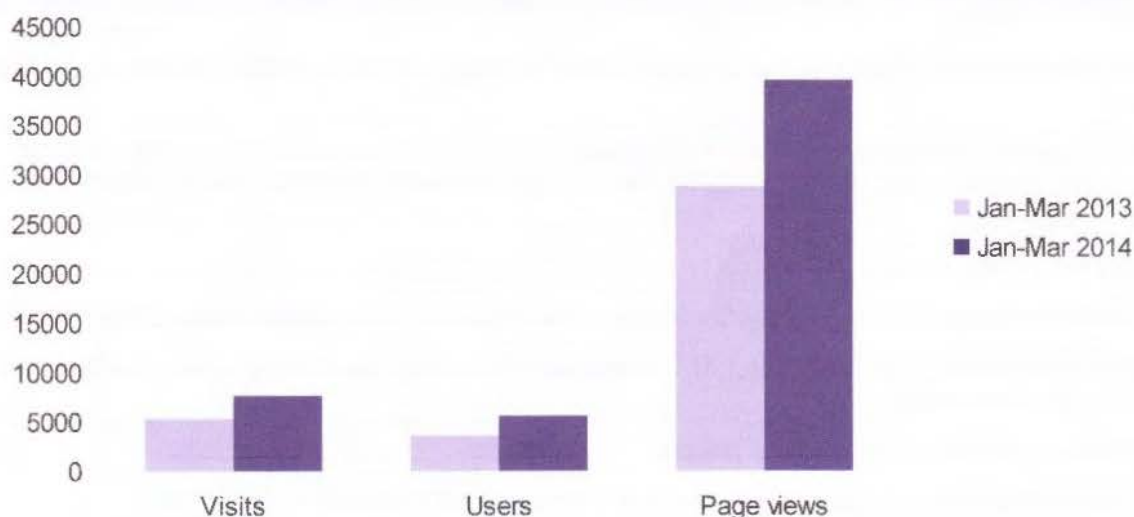
- moderators of the support Facebook groups (managed by the Chair who is a qualified counsellor)
- support for the media coordinator in her work
- support for the fundraising manager
- IT support

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.

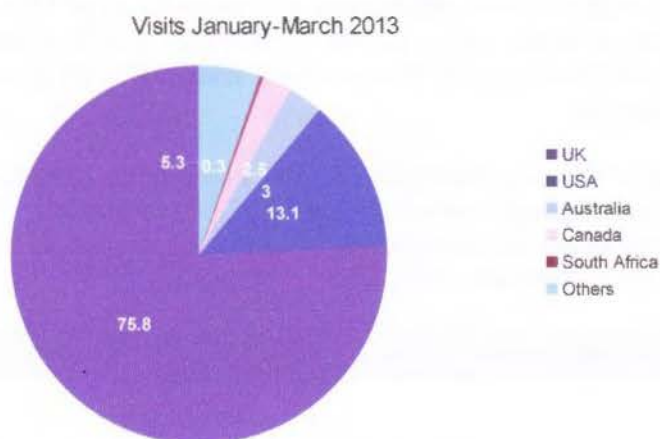
Last year we reported that we had changed our name to ICP Support to reflect the universal term for the condition and to be a source of information to women from abroad. We can see from the website the positive impact of our name change. We have data from Google Analytics for the website since the name change to ICP Support on 1 January 2013 and can see some changes since then by comparing the first three months of 2013 with the same period in 2014.

Website usage 1st quarter

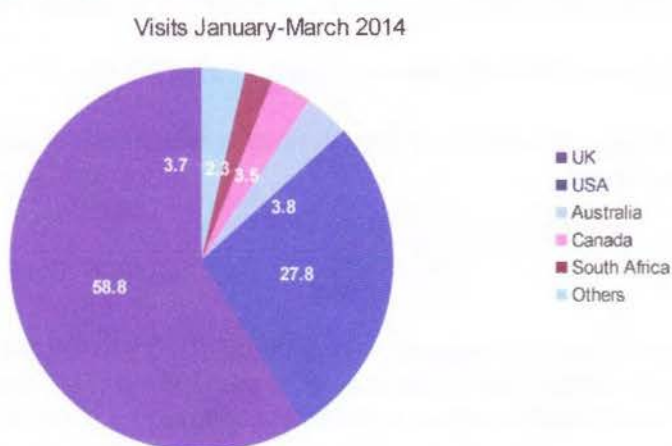


The 2014 numbers in this chart have been adjusted to remove the boost from Awareness Week in 2014 in order to give a like for like comparison. In percentages, visits were up 43%, users were up 55% and page views were up 37%.

Here are where our visitors came from in the first quarter of 2013 (percentages):



And here are the percentages for 2014:



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

In our first two years of operation, we have established the charity on a conservative procedural and financial footing while fulfilling our stated objectives. If we are to build our fundraising for research significantly, the charity is likely to need to expand. We have therefore put in motion the process of taking strategic advice from The Cranfield Trust, a charitable organisation which offers advice on strategy development and business planning to non-profit organisations.

Achievements and performance

Overall, we are delighted with our progress that reflects growth in the number of people we are supporting. This year we have:

- Built on last year's Awareness Day and held a very successful Awareness Week that saw our website traffic increase that week by 198%, the number of events held increase by 525% and our target of £5,000 met
- Exceeded our media target
- Had a visible presence at a midwifery conference that helped to raise awareness of the condition
- Supported a membership of just over 1,100 people on the open Facebook group – this year we added 620 new members
- Maintained our telephone support for people
- Booked our stands at the RCM conference and Primary Care Conference for 2014
- Been invited to sit on the NIHR Speciality Group as a PPI representative

Financial review

In the last year the financial resources of the charity have continued to grow.

- For the first time we have had the financial resources to attend professional conferences to increase awareness among medical staff regarding ICP
- The website has been maintained and developed by a professional, which has significantly improved how we communicate with sufferers of the condition
- Funding has been provided to ensure that trustees are up to date with best practice
- A further £1,000 was paid to an organisation researching into ICP, making total donations to ICP research £6,500 since the formalisation of the charity

Regular giving to the charity has increased substantially over the last 12 months. The first ICP Awareness Week was very successful, raising over £5,200.

At the end of the financial year the charity has cash reserves of £15,573. The reserves are sufficient to continue the work of the charity and to grow its activities into 2015.

Future expenditure is anticipated to cover

- Payment of day-to-day operational costs
- Financial support for fundraising activities
- Printing of information booklet
- Attendance at medical conferences
- Financial support for research in 2014/15

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.

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

Position Chair

Signature(s) 

Sian Eaton

Treasurer



Judith Hibbert

Vice-Chair

