

ICP Support

(Formerly OC Support)



Trustees' Annual Report for the period 20 October 2011–12 March 2013

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	
Peter Dixon	
Andy Edgecombe	
Victoria Geenes	
Judith Gray	
Karen Grundy	
Rachael Rawlings	
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 therefore to provide support and information to people affected by ICP, raise awareness of the condition and promote research into it to achieve our vision that: *'every ICP baby is born safely'*.

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*

Our work therefore focuses on ensuring that all pregnant women and their health professionals are aware of ICP together with a knowledge of what is considered to be 'best practice'. We want to provide support to those people affected by the condition (and this includes other family members) and to ensure that research into understanding the condition continues so that the risk of stillbirth from the condition is eliminated.

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 & Strategies, 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

Name Change

In November 2012 it was decided by the Trustees to change the charity's name from OC Support to ICP Support. The principal reason for this change was to better reflect the correct scientific name for the condition (ICP) and also because most people abroad use the term ICP (the charity's constitution also allows for work abroad). Although the condition can also be referred to as OC it was felt that it was simpler for all women to know it by the one name as women from all over the world contact the charity and access the website for information.

Information

It was agreed that a general leaflet containing details about the charity and how to access support together with key facts about the condition would be designed. This was achieved in March 2013. This leaflet will be sent to anyone interested in the condition, used at fundraising events and distributed as appropriate at public events such as baby shows or health conferences. It was also agreed to produce an information booklet, with a target date of summer 2013. Both the leaflet and information booklet would be based on known research to ensure that the public had clear and accurate information regarding the condition. ICP Support's involvement with one of the world's leading research groups, based in London, would help to ensure this.

The website has also been specifically designed to incorporate research-based, written information about the condition as well as an accessible information film. At present all this information is in English but future plans will incorporate the need to meet the requirements of people whose first language is not English.

Support

The charity has a support line that operates Monday–Friday. Anyone affected by the condition can contact it for support. There are presently three volunteers who answer the phone. It is not a medical advice or counselling line but all the volunteers have experience of the condition and two are trained counsellors. There is also an active 'support' Facebook group and two Google forums, all of which are monitored by volunteers who offer support (a listening ear as opposed to formal counselling) and information (based on research). People can also contact the charity for support by email.

To raise awareness of the condition (advancing education)

Leaflets

The general leaflet will help to raise awareness about the condition, as it will be used at fundraising events and health professional conferences. It has already been sent out to people who have requested, it including several people from America. It has also been accepted into one large teaching hospital in London and future aims are to have it generally available in more hospitals. The same aims will exist for the information booklet.

Media

The Media & Communications Committee had set a target of one media article every two months and to date this has been achieved through baby magazines, radio and newspapers such as, The Telegraph, The Practising Midwife and Practical Parenting & Pregnancy. All articles have contained factual information about the condition together with signposting to support for people affected by the condition via the charity.

Conferences and talks

The charity was represented at an international medical conference on ICP at Imperial College London in September 2012. A talk was given by one of the trustees and a brief film was shown that helped attending scientists and health professionals to better understand the debilitating effects of the condition. Those attending the conference reported that they felt they would have better empathy for their patients and now had somewhere to signpost them for further support. This talk was repeated to midwives at a local hospital where it was also well received.

Awareness day

A national awareness day called 'Pounds in the Pot' was held in March. This was a relatively low-key event to test interest in such a day, but raised just over £2,000. It resulted in more people becoming aware of the condition (through the 'Tea Parties' that were held). It is anticipated that it will be held again in 2014, possibly as an awareness 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 website, giving the general public access to these research papers. The charity also uses its Facebook page to report on the research 'in action' to show people how the scientists work and what is done with their samples.

Raising funds for research

The charity aims to raise funds for research into the condition. In March 2012 ICP Support (under its former name) donated £5,500 to the Genesis Research Trust. At the end of the charity's first financial year, it will be proposed that a percentage of future annual income is donated to groups conducting research.

Additional details of objectives and activities

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, or have been, involved in research into ICP.

The charity's website could also not function without the generosity of its webmaster who has taken the website through two design changes. He provides reports to the charity on the demographics of the visitors to the website so that the charity can see how far reaching its effects are. The website currently attracts approximately 500 visits a week that come from all over the globe. It is able to use surveys to canvas the opinions of the people that visit the site. One survey has involved women in the design of a new study that will look at identifying how the baby's heart may be affected by the condition. A second has collected their views on a potential new trial that will look at the use of a particular medication currently used in the

treatment of ICP but which needs a large trial to confirm its efficacy so that it can be formally recommended by organisations such as the RCOG (Royal College of Obstetricians & Gynaecologists) and NICE (National Institute for Health & Care Excellence).

Achievements and performance

This year we have:

- Produced our first generic leaflet
- Been featured in the media every two months.
- Been a guest speaker at an international conference into the condition
- Held our first awareness day and identified what we need to have in place for next year's awareness day/week
- Supported hundreds of people on the support line and the website
- Helped to recruit 47 women to research
- Booked our presence at the RCM conference and Baby Shows for 2013
- Broadened our international reach through the name change from OC Support to ICP Support

Financial review

The Charity was formed on 20 October 2011. It received an initial donation of £5,318 from its predecessor organisation: OC Support. Much of this amount was raised through a successful Charity Ball in November 2011 and £4,472 of these monies formed part of the first research donation of £5,500 to the Genesis Research Trust. Subsequent financial strategy has focused on building up a level of cash reserves with increased fundraising. In the period to 31 March 2013, excluding fundraising relating to the Ball, £10,435 has been raised, with 59% of this being received in the last six months. All of this fundraising has come from members of the public. There has been an emphasis on increasing the regular giving amongst its supporters, to establish a sustainable, predictable source of funds. These funds are in place to further the long-term aims and objectives of the charity.

At the first AGM of the Charity on 27 April 2013 it will be proposed that at least 10% of all fundraising in a period will be given to support further research into ICP. Future expenditure is anticipated to cover

- Payment of day to day operational costs
- Production of the information booklet
- Attendance at medical and baby-related conferences
- Financial support for research in 2013/14

Policy & Reserves

As the Charity develops, 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, apart from to spend them on the aims and objectives of the Charity.

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	Judith Hibbert
Position	Chair	Treasurer	Vice-Chair
Signature(s)			