



ICP Support

**Trustees' Annual Report for the
period 1 April 2015–31 March 2016**



Contents

Reference and administration details	3
Structure, governance and management	3
Description of the charity's trusts	3
Summary of the year	3
Objectives and activities	5
The focus of our work and how we demonstrate public benefit	6
To provide information and support to people affected by the condition	6
To raise awareness of the condition (advancing education)	7
Promoting, supporting and raising funds for research	9
Additional details of objectives and activities	10
Volunteers	10
Website	10
Financial review	11
Policy & Reserves	12
Declaration	13



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
Charity's correspondence address	69 Mere Green Road, Sutton Coldfield, B75 5BY
Names of the charity trustees who manage the charity	
Trustee name	Office (if any)
Jenny Chambers	Chair
Judith Gray	Vice-Chair
Sian Eaton	Treasurer
Peter Dixon	
Victoria Geenes – Retired 11 July 2015	
Magdalen Rees	
Alice Tuson – Retired 11 July 2015	
Jenny Hastings – Co-opted 29 October 2015	
Tracey Smith – Co-opted 29 October 2015	

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

Summary of the year

Our charity is slowly expanding, and as a result so too has the workload of the Trustees. An earlier project with The Cranfield Trust, an organisation



that gives advice to developing charities, had already highlighted the need for two things: an office to allow the Chair to reclaim her home again, and an employee who would be able to shoulder some of the increasing administration that accompanies growth. So in May 2015 we moved into our first office and in October 2015 we appointed an Office Manager. Although their working hours are relatively low (1.5 days a week), this appointment is making a real difference and has meant that we can take on new projects.



Our biggest project, a training module in ICP for midwives, was completed at the end of 2015 and approved by the Royal College of Midwives for their continuing education programme called i-learn. This is a platform for all midwives who are members of the RCM to update their knowledge of midwifery-related conditions such as ICP. Written by the charity and approved by Professor Catherine Williamson, King's College London, it was launched in March 2016 and we will have feedback on its progress at the start of 2017.

We continue to support people affected by ICP, and this has led to growth in the number of people who contact us. Every day 10 new posts are made in our Facebook groups that require answers; every day someone contacts us via email wanting information or support; and every other day someone gets in touch with us through our support line. Although many people access our website for information, we know that people want that personal contact which can make so much difference to how they are coping with ICP.

Other highlights of our year include being shortlisted for an RCM Award for our website, the introduction of running events, such as the Great North Run, the Birmingham 10 km and half-marathon, and Virtual Runs. The latter are a great idea for 5 km runs or walks that all the family can take part in. They can be completed at any location and all the person has to do is send in evidence of their run or walk (smart phones are a wonderful invention!). Not only do these events raise funds for the charity, but they also bring people together and raise awareness of the condition.

The other event that will achieve the same result is our 25th Anniversary project, which will last for the whole of 2016. It celebrates 25 years of what started as an information and support line and has developed into a registered charity. Many of our supporters have signed up to celebrate with us by taking part in our Afternoon Tea for ICP and running events, and some will join us in a Gala Ball to be held in September 2016.



The medal awarded to the runners who completed our first Virtual Run.

We remain committed to collaborating with other charities and organisations whose aims are similar to ours and to promoting research into ICP. We are proud to be the conduit for women to be able to take part in research, and this year over 50 women – one a week – participated,

stillbirth
gallstones
intrahepatic
URSO
cholestasis
hormones
families
bile acids
liver
heredity

“Thank you all so much for the push, the words of encouragement and the no judging zone. You women rock and I will forever be grateful!”

via the charity, in various trials being conducted by Professor Williamson at King’s College and Imperial College, London.

In 1991, when the charity was first started, I don’t think anyone could have envisaged that 25 years later we would still be in existence. What started as a need to raise awareness of this potentially devastating condition of pregnancy soon turned into something more as research gradually began to show that not only was stillbirth a cause for concern, but that the condition has longer term effects that scientists are only just beginning to uncover – for example, the increased risk of biliary disease, such as

gallstones, for affected women and the potential for the children (male and female) of mothers with ICP also to be affected. We now know that the daughters of affected women have around a 14% chance of developing ICP in pregnancy and males may have an increased risk of obesity. Clearly, our work is not finished and we will continue to support anyone affected by ICP as well as funding the research to better understand the condition. I hope that by the time we are celebrating 50 years of existence we’ll have more answers and that stillbirths have become a thing of the past in ICP. With the help of our much valued volunteers and supporters, I feel sure they will.

Jenny Chambers (Chair)

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, 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 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

Our most popular point of access for information on ICP is through our social media groups. We have five Facebook groups and a Facebook page. At the end of our financial year the main open group had over 2300 members, an increase of 28% from last year. The Facebook page can best be described as our 'shop front', as it is used to update members about fundraising activities and research or new research findings on the condition. We currently have 2386 followers, an increase of 44% since last year.

Other sources of information continue to be through our website and our generic information leaflet. The content of our planned information booklet has been incorporated into the website and we are still considering our options with regard to printing the booklet.

Information is also disseminated through Twitter and Instagram. On Twitter, our followers rose by 11% (from 516 to 574) after appointing a volunteer to manage the account midway through the period. Our tweets were viewed 58,700 times, with 327 clickthroughs and 245 retweets.

Support

Our telephone support line continues to provide a daily service. The frequency of calls has been steadily increasing, with a peak in early 2016. The callers are mainly women who have ICP, although there have also been calls from fathers and grandmothers, as well as a few international calls. The calls are often quite lengthy – at least 25 minutes and sometimes an hour long – and it's clear that the care given to women around the country and sometimes in neighbouring hospitals varies significantly. This seems to compound the anxiety experienced by women, and they are often quite distressed by the time they make a call to our support line.

stillbirth
gallstones
intrahepatic
URSO
cholestasis
hormones
families
bile acids
liver
heredity



Telephone support

In addition to the telephone line, we facilitate an email support line where we 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).

The majority of support is still provided via social media and we respond to posts on a daily basis. The posts are generally from women

with ICP, but we also receive posts from family members. We have five Facebook groups that provide support, one of which is specifically for bereaved parents. On average we respond to 10 new posts every day that are made by women seeking support or information.

Much of our information and support is provided by volunteers (called moderators) and we are very grateful to those women who give up their spare time to do this. They are mindful of their limitations, in that they are not counsellors or health professionals and their role is to listen and empathise and provide research-based information where needed. Some of the posts ask complex questions about the condition that require

specialist knowledge of ICP. This is where our charity is unique in that our Chair also works as part of a research group investigating the condition and one of our other trustees is the senior scientist within that research group. The Chair of the charity is a trained counsellor and is able to identify people affected by ICP who may need additional support and can signpost them to organisations that can provide this should they want it. She is also able to offer supervision to the other volunteers as required.

"This group is a life saver, day or night the support was incredible when I wanted to tear my hair out with the itching."**"**

To raise awareness of the condition (advancing education)

25th Anniversary

Our last Awareness Week was in March 2015. As the charity was originally formed in 1991 (as a support and information line) we have taken the decision to use 2016 as the year to celebrate our achievements and to use this as an opportunity to raise awareness and fundraise. This will be described in in our next report.



Training module for midwives – i-learn through the RCM

We were delighted to submit our training module on ICP for midwives to the RCM (Royal College of Midwives) and this was formally accepted and launched at the beginning of March 2016. Approved by our Patron, Professor Catherine Williamson of King's College London, this module ensures that all midwives who are members of the RCM can access this training and use it not only to improve their knowledge of ICP but to submit as part of their continuous development (revalidation). We should have some statistics on its use at the beginning of 2017.

Leaflets

The generic leaflet has helped to raise awareness about the condition, as it has been distributed at fundraising events and health professional conferences. This year we took the opportunity to update the leaflet before reprinting it.

Media

This year has been challenging to sustain our presence within the media, as our two volunteers have been busy with a new baby and a move to Australia! However, we have still been able to feature ICP in the local press. In Australia, Channel 9 News featured the condition.

Conferences and talks

We were able to have stands at the RCM Conference in Telford and the Primary Care Conference in Birmingham and were delighted to be able to use both events as a platform to highlight our training module for midwives on ICP (see above). We now have the additional support of our new office manager at these conferences – something that is vital if we are to continue our presence at these events.



Jenny Chambers with our new promotional display at the RCM Conference.

Collaboration

We believe that collaboration is key to the success of our charity's aims. By working with other organisations we can not only raise our profile and reach more women, but also support other charities with the same aim: the safe arrival of unborn babies.

We are actively involved with organisations such as:

- ◆ The NIHR (National Institute for Health Research) speciality group, which helps to support the delivery of all the current research projects that involve reproductive health.
- ◆ MBRRACE-UK (Mothers and Babies – Reducing Risk through Audits and Confidential Enquiries across the UK), which is part of the NPEU

stillbirth
gallstones
intrahepatic
URSO
cholestasis
hormones
families
bile acids
liver
heredity

(National Perinatal Epidemiology Unit), whose focus will include perinatal mortality.

- ◆ James Lind Alliance – an organisation that brings patients, carers and clinicians together to identify and prioritise research questions that are felt to be a priority, but which are also of the most practical benefit to those people affected by the area being researched
- ◆ Sands, Count the Kicks and Mama Academy – all charities working towards the same aim as us: the reduction of stillbirths.
- ◆ The RCM (Royal College of Midwives). As previously mentioned, we were delighted to be able to work with the RCM (Royal College of Midwives) and our training module on ICP was launched using the RCM's i-learn, an integral part of continuous professional development for those midwives registered with them and wishing to improve their knowledge of certain conditions.

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. This year over 50 women took part in varying studies via the charity and over 500 women contributed to two surveys by the charity that helped to produce statistics on the itching women with ICP experience. The two resulting infographics have been used on the website and within the training module for midwives on ICP.

Raising funds for research

Our commitment to research remains an important part of our charitable aims. This financial year we will add to the reserves we keep for research and at least 50% of the money raised during our 25th Anniversary year will be ring-fenced for this purpose. In January 2017 we will give these reserves to an appropriate research body.



Additional details of objectives and activities

Volunteers

All the charity's trustees are volunteers, and there are a further 14 volunteers carrying out the following roles:

- ◆ moderating the Facebook support groups (managed by the Chair, who is a trained counsellor)
- ◆ providing support for the fundraising manager
- ◆ providing IT support
- ◆ helping to manage the charity's online shop
- ◆ running the charity's social media platforms

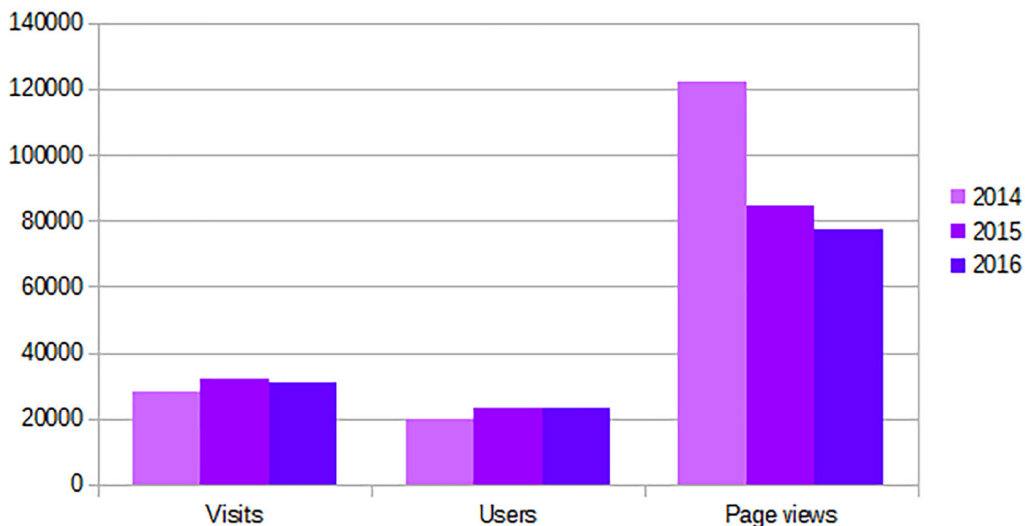
Website

We are very proud of our website and this year it was shortlisted by the RCM for one of their Annual Awards. We strive to make the content research-based but at the same time user-friendly. At the beginning of this year we also made the transition to a mobile-friendly site.

Website usage

The data in this section cover the period 1 April to 31 March in each year. It is difficult to make direct comparisons with previous years because of the impact of specific promotional events and changes to the structure and content of the website

Website usage



The number of distinct visits to the site (31,138 in 2015/16) and the number of individual users (22,959) have been steady over the last three years. The number of separate page views has fallen because we have reduced the number of pages on the site (while retaining the same content), which means that visitors have to load fewer pages to obtain the same information. We have also made it easier for people to reach key pages, so they do not have to pass through an intermediate page as often.

Geography

There have been small shifts in the origins of the website's visitors. The UK continues to decline slowly as a percentage (which we would expect), while the USA and Canada have grown. South Africa, which was our fifth most common source of visitors two years ago, is now ninth, surpassed by India, Ireland, New Zealand and Brazil. Absolute numbers for South Africa have fallen to almost a third of where they were a year ago. This may reflect the lack of activity in the South Africa Facebook group following the moderator's move to the UK.

Technology

People access the website via three general types of device: desktop/laptop computers, mobile phones (smartphones) and tablets. Smartphones account for around 60% of visits. The proportion of visits from tablets (iPads etc.) has declined, most likely reflecting the increased capabilities of smartphones.

Financial review



In the last year the financial resources of the charity have continued to grow. During 2015/16 our income was £29,918, a significant increase of about £10,000 over 2014/15. Regular giving to the charity has continued to rise and one-off donations have also risen, with many supporters raising funds for the charity on a local basis.

Operating expenditure has increased to £27,348. As part of the Trustees' strategic plan for growth the decision to move to an office and appoint our first employee was taken. In May 2015 the charity rented an office in Sutton Coldfield, and in October

2015 the Trustees engaged a part-time office manager, firstly for one day per week and then, after a formal review of the success of this, to one and a half days a week in January 2016.

Supporting ICP families is at the heart of what the charity does, and increasingly this support is given through social media and our website. In the latter part of 2015 a significant project was undertaken to make the website fully compatible with all electronic devices, at a cost of £3,270. Another significant item of expenditure was on attendance at conferences, allowing us to engage with health professionals and raise awareness of the



condition. This increased in 2015/16 in line with one of the key objectives of the charity.

There was a surplus of £2,570 in 2015/16. During 2015/16 the Trustees created a formal designated reserve; this contains all the monies raised specifically for donating to medical research. The 2014/15 profit surplus of £2,800 was ring-fenced here along with other monies specifically donated for research. At the AGM it will again be agreed that a minimum of 10% of this year's surplus be transferred to the Research Fund.

In 2015/16 the 25th Anniversary Appeal was started and 50% of all the proceeds being donated will be added to the Research Fund. At the end of the 25th Anniversary period the whole of the Research Fund will be given to an appropriate body.

At the end of the financial year the charity has unrestricted cash reserves of £17,254. The reserves are sufficient to continue the work of the charity and to continue its strategic plan into 2016/17.

Future expenditure is anticipated to cover:

- ◆ Payment of day-to-day operational costs
- ◆ Financial support for fundraising activities
- ◆ The development of the support line
- ◆ The implementation of short films on ICP to reach more women who may be affected by the condition
- ◆ 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.

The Designated Reserve contains those monies set aside for medical research into ICP.

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 Gray
Position	Chair	Treasurer	Vice-Chair
Signature(s)			

		
---	--	---

Date:	17/9/2016	17/9/2016	17/9/2016
--------------	-----------	-----------	-----------

