# ICP Support

## Trustees' Annual Report for the period 1 April 2017–31 March 2018

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# Reference and administration details

| | |
|---|---|
| **Charity name** | **ICP Support** |
| **Registered charity number (if any)** | 1146449 |
| **Charity’s address** | 69 Mere Green Road,<br>Sutton Coldfield, B75 5BY |

**Names of the charity trustees who manage the charity**

| **Trustee name** | **Office (if any)** |
|---|---|
| Judith Gray | Chair |
| Jenny Chambers | Trustee<br>CEO |
| Sian Eaton | Treasurer |
| Peter Dixon | |
| Magdalen Rees | |
| Jenny Hastings | |
| Tracey Smith | |

# Structure, governance and management

## Description of the charity’s trusts

| | |
|---|---|
| Type of governing document – dated 1/11/16 | Articles & Memorandum of Association |
| How the charity is constituted | Company Limited by Guarantee |
| Trustee selection methods | Elected by members |

# Foreword by Chair of Trustees

The past year, 2017–18, marked a historic moment for ICP Support, as we secured Charity Commission approval to appoint Jenny Chambers as our first CEO, in addition to her responsibilities as a Trustee of the charity and volunteer.

Our current levels of funding place limitations on the ambitions we have to deliver our charitable aims, and whilst we have been able to employ a CEO, we recognise that this has had to be on a part-time basis, and this does not reflect our future plans nor the demand that this places on the role. During the past twelve months we have spent some time developing our strategy to grow the income of the charity so that we can make a step change in our ability to deliver on our mission that all ICP babies are born safely. This year has taught us that many small charities like ours are grappling with the issue of funding. We have embarked upon a strategy to grow the income we receive through regular donations, as well as targeting events throughout the year to boost our profile, increase awareness of the condition and generate much-needed funds for research. I am enormously grateful to all our regular donors and fundraisers: thank you, and please do continue to spread the word and keep up the great work that you do for the charity.

I would also wish to say a big thank you to our small army of volunteers, who undertake a variety of activities to enable us to provide support to the women and the families affected by ICP – be this through our array of social media channels or cheering on our ICP Support runners – thank you.

Finally, this year we also welcomed actor Helen George as an ICP Support patron. Helen joins Professor Catherine Williamson and Kim Medcalf as our third patron and we look forward to their support in the months and years ahead.

*Jude Gray (Chair)*

# Summary of the year from the CEO

As our chair, Jude Gray, has already mentioned in her foreword, charities face an uphill struggle to secure sufficient income to ensure that they can continue to fulfil their aims. ICP Support is no different from any other charity responding to these issues, and for the first time in our history we have had to consider whether we can continue as a charity. Some of our financial issues have been the result of an increase in our expenditure following my appointment as CEO, and some of it has been due to a decline in fundraising activities and income from our supporters. We have no statutory funding or grants at present, so any drop in financial support has a big impact on us; we have already had to curtail some of our activities, such as attending conferences where we get to speak to many health professionals about ICP.

But if we are to reach even more women with ICP and continue to offer the first-class support we are known for providing, as well as raising awareness and improving education amongst health professionals, we will not only need to have sufficient income to maintain our current support, but will require further income to help us cope with the additional operational tasks that will accompany our growth.

It's a dilemma that all charities face at some stage as they grow bigger, and we are addressing how we can improve our income streams. We have already shared our challenges with supporters and they have responded positively – it's a lesson learned that we shouldn't assume that those we support are always aware of our financial well-being (or lack of it) and reminds us that communication with our stakeholders is vital.

We should not forget that we have still had financial support, especially from our running events (managed by a Trustee of the charity, Jenny Hastings). These have been very successful – in particular the Manchester Great Run, which took place just a week after the Manchester bombing. I was overwhelmed that our runners still wanted to take part and I was honoured to be able to attend the day, which was emotional but extremely positive, filled with hope and optimism for the future.

I, too, am optimistic that with our supporters' help and that of our new patron we will see 2018–19 being a more stable year for ICP Support. I am confident that our report next year will reflect this and I very much hope that you will join us in our journey in helping us to ensure that we can continue to provide support and information to anyone affected by ICP, raise awareness of the condition and promote and fund research into it.

*Jenny Chambers (CEO)*

# 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
- to raise awareness of the condition
- to 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 by 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 we meet four times a year. In between those times we also hold telephone conferences 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

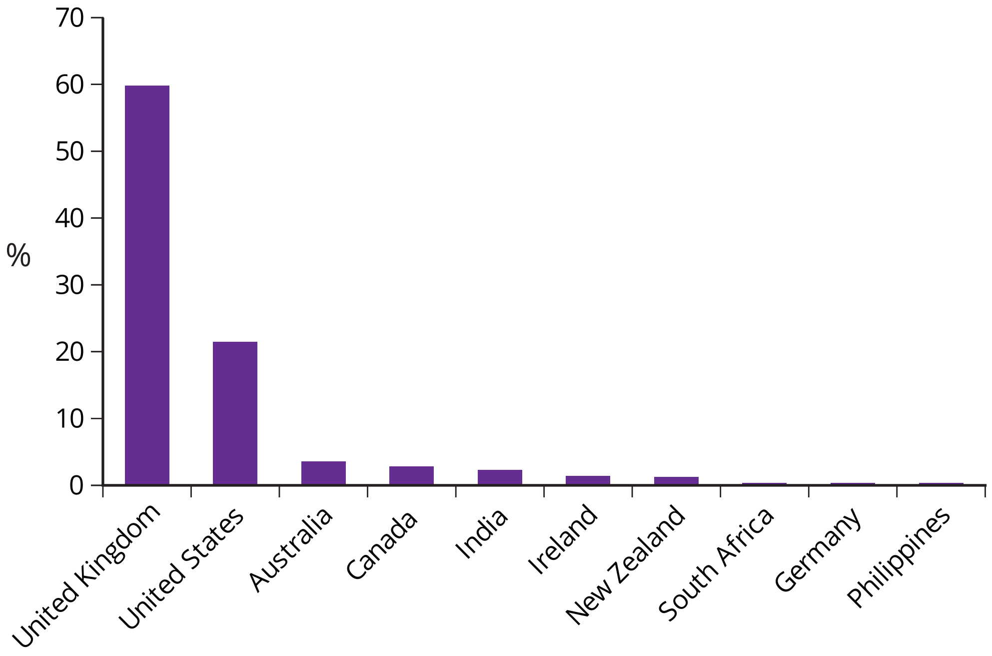
Social media and our Support and Information line continue to be the channels through which we provide information and support and deliver public benefit.

Our most popular point of access for information and support on ICP is still through our social media groups. We have four Facebook groups and a Facebook page. At the end of our financial year the main open group had over 3621 members, an increase of over 700 from last year. The Facebook page had 3829 followers, an increase of about 800 since last year.

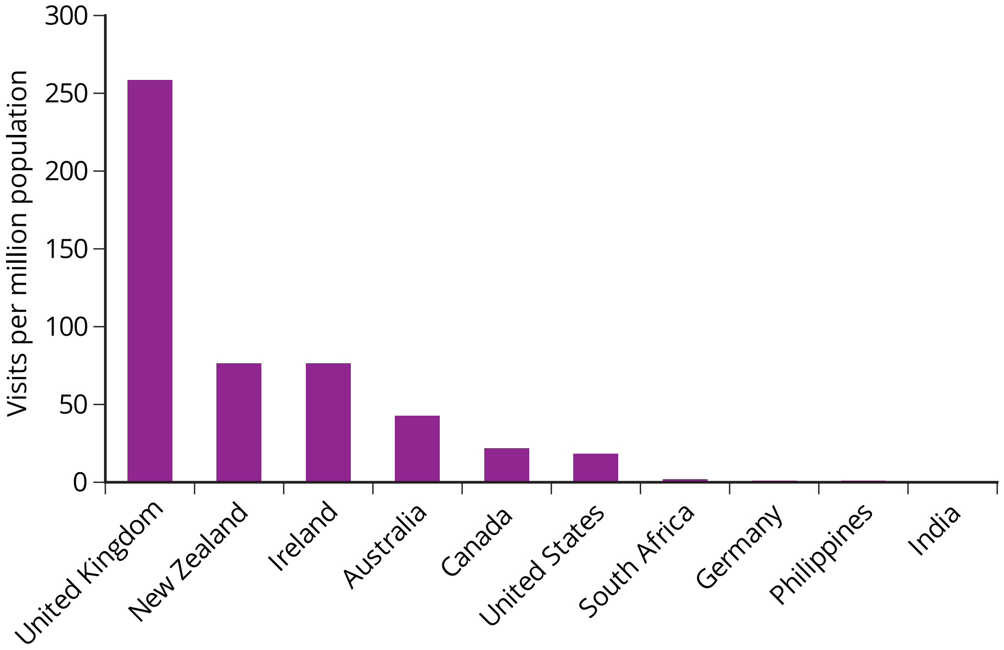
Other sources of information continue to be through our website and our generic information leaflet.

Information is also disseminated through Twitter and Instagram.

Our international reach is shown in the following chart, which shows the top 10 countries from which the website receives visits.



However, when adjusted to take account of population size, the order changes:



This shows clearly the dominance of English-speaking countries, which is to be expected (the other countries are effectively invisible at this scale). It is notable that there are nearly twice as many visitors per head of population from New Zealand as from Australia.

The number of visitors to the website, which in recent years has changed very little, jumped up by 31% this year, possibly because our Facebook moderators have been actively referring more people to the website.

The trend towards accessing the website by mobile phone, with 73% of visitors doing so, continues. Changes have been made to several sections of the site to increase its usability on smartphones.

### *Support and Information Line*

We are the only UK charity to run a telephone support line for women with ICP. The support line 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, has worked closely with the charity and has been answering the line for over seven years. She is supported and supervised by a trustee of the charity who has had counselling training. Over the last year there have been 42 new calls, with many of these callers making repeat calls. The callers are mainly women with the condition, although there have also been calls from fathers, grandmothers and a few international callers. 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. The volunteer observes that the care given to women around the country and sometimes between neighbouring hospitals is quite varied: namely an inconsistency in the testing of bile acids. 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.

We have also operated a support line in Australia since 2016. Although our Australian Facebook group is smaller than our UK group, women expressed a need for someone to talk to directly, and it is well utilised. The number of calls reflects a smaller membership in Australia, but the feedback is positive. We have on average two callers per month, but typically multiple calls will be had with the same person. Text messages will also be exchanged. It is a vital service and many women tell us that they feel their experience has been safer and more positive because of the help received via the support line.

## To raise awareness of the condition (advancing education)

### *Leaflets*

The generic leaflet continues to help raise awareness of ICP and it has been distributed at fundraising events and health professional conferences. Our plan to move forward with distribution into hospitals has not been realised owing to financial constraints but we would still like to secure funding to be able to do this. We will revisit this during the next financial year.

### *Media*

Although it’s been relatively quiet in this area because of capacity issues, we were delighted to have an article on ICP, written by Jenny Chambers

and Alice Tuson, accepted in the Australian Midwifery press. This was a first for the charity.

## *Conferences and talks*

We had a stand at the following conferences, which were attended by just over 2,000 delegates, giving us plenty of opportunity to speak to many health professionals about ICP and the work of the charity:

- Maternity & Midwifery Festival, Manchester, September 2017
- Maternity & Midwifery Festival, Edinburgh, November 2017
- Primary Care Conference, Birmingham, May 2017

## *Collaboration*

We have continued our collaborative work with other organisations, and this year the organisations we have worked with include:

- 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
- King's London and Tommy's – we were delighted to be in the development and launch of a short film called 'Always Ask' that encourages pregnant women to speak up about any concerns they have with their pregnancies
- Tommy's Midwives – we took part in a live Facebook Q&A session on ICP with the Tommy's Midwives, Professor Catherine Williamson, Dr Peter Dixon and Dr Caroline Ovadia

- RCOG Women's Voices Involvement Panel – Jenny Chambers was involved in the *Specialists of Tomorrow Public Insight Workshop*, which looked at what people who use O&G services really want and need from their doctors.

Through our leaflets, attendance and presentations at conferences and collaboration with other organisations we raise awareness of the condition and deliver public benefit. Our leaflets, for example, act as a signpost to support that we can provide for women with ICP, many of whom who have no one to turn to. This is why we are keen to ensure that our leaflets are in as many hospitals as possible and we will continue to work towards achieving that aim.

## 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 just over 50 women took part in varying studies via the charity. This was lower than last year because of capacity issues.

### *Raising funds for research*

Promoting, supporting and raising funds for research enables us to deliver public benefit, as the work carried out may have a direct benefit for women suffering from ICP. For example, the research supported this year involved potential drug treatments for women with the condition.

# Financial review

The charity started the year with cash reserves of £23,873. This cushion was needed to help finance a significant increase in expenditure with the appointment of our first paid Chief Executive Officer on a part-time basis. The Trustees understood that to fund this and maintain existing expenditure would require an increase in income generated.

The unrestricted income for the year to 31 March 2018 was £37,778. This was lower than the previous year, reflecting the fact that the previous year had benefited from funds generated through the 25th Anniversary Appeal and the Ball. Encouragingly, the underlying year-on-year trend shows a steady, albeit modest, growth in our income.

Likewise, the unrestricted expenditure for the year also showed an anticipated and significant increase rising to £49,679 in this last financial year. The Trustees were acutely aware of the operating deficit and whilst operating within our policy of reserves equivalent to three months’ expenditure, implemented a financial review that resulted in the curtailment of all non-essential expenditure and significant efforts put into fundraising.

In summary, 2017–18 has proved to be a challenging year financially and 2018–19 will require a continued focus on generating income to deliver on our objectives.

Finally, as a result of the Chief Executive Officer’s 60th Birthday Appeal, in which she pledged to give all monies raised to research, we are pleased to report that we will be able to provide £3,584 for much-needed research. These monies are being held in a restricted reserve until appropriate applications are made to the Trustees by research teams. During 2017–18 the charity provided £3,890 to Kings College London.

## Policy & Reserves

An average cash balance of three 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 | Sian Eaton | Judith Gray |
| **Position** | CEO | Treasurer | Chair |
| **Signature(s)** | JChambers | | J.Gray |
| **Date:** | 31/12/2018 | 31/12/2018 | 31/12/2018 |