



# ICP Support

**Trustees' Annual Report for the  
period 1 April 2018–31 March 2019**



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# Reference and administration details

|   |  |
|---|--|
| <b>Charity name</b>   | <b>ICP Support</b>                               |
| <b>Registered charity number</b>                            | 1146449  |
| <b>Charity's address</b>                                    | 69 Mere Green Road,<br>Sutton Coldfield, B75 5BY |
| <b>Names of the charity trustees who manage the charity</b> |  |
| <b>Trustee name</b>   | <b>Office (if any)</b>                           |
| Judith Gray   | Chair  |
| Jenny Chambers  | Trustee<br>CEO                                   |
| Sian Eaton  | Treasurer  |
| Peter Dixon   |  |
| Aileen Morrison – Appointed 9 February 2019                 |  |
| Magdalen Rees – Resigned 26 August 2018                     |  |
| 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

2018/19 continued to be a busy and challenging year during which time we successfully weathered the difficult financial conditions we faced through a combination of fundraising activity and additional measures to monitor our financial position.

Despite our financial constraints, we know from the feedback from the families we support, the professionals we speak to and the research that



is under way that the work we do is vital if we are to achieve our vision that every ICP baby is born safely.

I was reminded of this when, along with Jenny Chambers, I was interviewed by a second-year journalism student who is the son of a mother Jenny supported over 20 years ago. He produced a very moving radio documentary, *Breaking the Silence on Stillbirth*, and it served as a timely reminder of the importance of our work.

We simply could not do all that we do without the support of our fantastic volunteers, be it fundraising, social media or helping with the many activities that take place throughout the year, often in all weathers – on behalf of all the ICP Support Trustees, thank you.

I am also grateful to all our patrons for their continued support. If you were fortunate enough to have secured a ticket for our Afternoon Tea hosted by Helen George I hope you would agree with me that it was a fabulous way to spend an afternoon.

*Jude Gray (Chair)*

## Summary of the year from the CEO

Running a small charity was never going to be an easy task, and as CEO you have to work with the downs as well as the ups (and sometimes there are more downs than ups!). However, I am delighted to report that this year, despite the financial difficulties we faced, we can now see a glimmer of light at the end of the tunnel.

This has been due to an increase in monthly donations from our supporters, who responded as soon as they knew we had financial issues, as well as donations from companies such as John Lewis. Other individuals held fundraising events (including afternoon teas and tarantula holding(!)) or took part in sporting challenges. I am incredibly grateful to them all and I am optimistic that this trend will continue.

A big thank you also to our volunteers, who work so hard to ensure that the women in our social media Facebook support groups have constant access to them and to those who help with the administration of the charity. We are always scouting for more help, so if you would like to get involved do please contact us! A thank you must also go to Susan, our office manager, who, although part-time, manages to complete a phenomenal amount of work in the time she does have, and who has made my life much easier since she came on board. We hope to add to the number of staff we employ as we continue to grow our charity.

I have been able to continue my work in delivering presentations on ICP throughout the UK, and the highlight for me was a webinar to Australian



midwives after being asked to do this by the Australian College of Midwives. It was my first webinar, but I enjoyed it very much!

However, my proudest moment of the year came via the publication in *The Lancet* of a meta-analysis on bile acids and risk of stillbirth by Dr Caroline Ovadia. Her work shows that 90% of women can be reassured about the safety of their babies if their bile acids remain below 100  $\mu\text{mol/L}$ , which will reduce anxiety for many women with ICP. I'm proud because some of the data included in Ovadia's paper has been from women recruited via our charity, and it's immensely satisfying to know that we have been able to be involved so directly in research. My thanks go to all the women who took part.

So the work continues. We have our plan to grow the charity, and I hope to report more good news in our next Annual Report.

*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 4188 members, an increase of 502 from last year. The Facebook page had 4756 followers, an increase of 868.

The Australia and New Zealand group also continues to grow: up 76 from 419 in 2018 to 495 in 2019.

We also launched a set of regional Facebook groups, with the intention of encouraging people to meet each other and organise events in their local area, and a further group for healthcare professionals.

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

Information is also disseminated through Twitter and Instagram, where engagement has been increased substantially by a volunteer who has provided a steady flow of new and regular content.

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 75% of visitors (up from 73%) doing so, continues. Changes continue to be made to the site to increase its usability on smartphones.

### ***Support and Information Line***

The charity runs a telephone support line that operates Monday–Friday, 9 a.m. to 9 p.m. 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 phone calls. The callers are mainly women with the condition, although there have also been calls from fathers and grandmothers, and 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,

stillbirth  
gallstones  
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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, in particular concerning 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. In December 2018, a caller at 38.6 weeks of pregnancy with severe itching had been refused bile acid tests as her hospital trust doesn't perform them. This caller had nowhere else to go for help and support.

## 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.

### *Media*

This year we were approached by the television series *Trust Me I'm A Doctor*, and two of our Trustees took part in production. Our relationship with the programme dates back to 1998 and provides us with the opportunity to raise awareness based on the most up-to-date research into the condition.

### *Conferences and talks*

We had a stand at or took part in the following conferences and events:

- ◆ BMFMS conference, Brighton, April 2018
- ◆ Webinar on ICP to Australian midwives hosted by Australian College of Midwives, May 2018
- ◆ Primary Care Conference, Birmingham, May 2018
- ◆ Presentation on ICP/Pre-eclampsia overlap APEC – Liverpool (John Moores), May 2018
- ◆ ARM Conference – Birth in the Balance, December 2018
- ◆ Maternity and Midwifery Festival, London, February 2019
- ◆ BMFMS conference, Edinburgh, March 2019

### *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
- ◆ Tommy's Midwives
- ◆ RCOG Women's Voices Involvement Panel
- ◆ Action on Pre-Eclampsia (APEC)

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 the 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*

The NIHR (National Institute for Health Research) has an expectation that research conducted in the UK involves the patients (or patient organisations) representing the condition being researched. This is referred to as PPI (Patient and Public Involvement), and ICP Support has been at the forefront of PPI since the charity's inception in the 1990s. This takes the form of being involved with the design of studies into ICP, conducting surveys that help researchers to know whether their research intentions are feasible and facilitating the recruitment of participants to the actual studies. This year has seen our continued involvement in a major trial called PITCHES, which is testing the efficacy of a drug regularly used to treat ICP. We know that some of the women in our social media support groups participated in the trial and we will have an important role to play in helping to disseminate the results when they are in.

Dr Caroline Ovadia's paper showing that the risk of stillbirth due to ICP is only increased when bile acid levels rise above 100  $\mu\text{mol/litre}$  was published in February. This work was funded in part by ICP Support.

### *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.

- ◆ Award for iPads to Professor Catherine Williamson for use by research midwives recruiting to her studies into ICP
- ◆ Funds granted for selenium testing at Nottingham University Hospitals NHS Trust to identify whether women with ICP have lower levels of selenium, as has previously been suggested

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- ◆ Approval for £1,500 towards consumables for conducting Professor Catherine Williamson's OC Research Study

### Afternoon tea with Helen George

ICP Support's new patron, actress Helen George, hosted an Afternoon Tea for ICP at the Lanesborough Hotel in London, raising over £2,000.



### Running events

Running events continue to be an excellent source of funds. Official Great Run events this year saw no fewer than 16 people raising money for us at the Birmingham and Bristol 10 km runs and the Great North Run half-marathon.

A further eight individuals also took part in individual events around the country – as well as (in one case) Cyprus. Overall, just over £6,000 was raised by Team ICP's runners.

### Miscellaneous events

Emily Harvey braved her arachnophobia and raised £2,500 by holding Rosie the tarantula for 60 seconds.



education  
support  
pruritus  
symptoms  
scratch  
itchy  
risk  
information  
awareness  
fundraising  
UDCA  
genetics  
pregnancy

ElleVie Beauty Salon in Boldmere, Sutton Coldfield, held a fundraising evening at the salon that raised £710.



## Financial review

The charity started the year with cash reserves of £15,530, of which £3,548 constituted restricted funds, leaving £12,162 unrestricted and available to finance the day-to-day operations of the charity. This represented about three months' expenditure and the trustees felt that this needed to be increased, to ensure that there were sufficient available funds to finance any contingencies.

As a result there was a significant fundraising push by the CEO, using her position on social media and personally to generate more giving by those people who the charity is in contact with. This was very successful and unrestricted income rose to £59,129, an increase of over 50% on 2017/18.

During this period we kept close control of expenditure, so during the year the charity actually spent £2,712 less than the previous year.

In summary, 2018/19 has proved to be a successful year financially, in that we, with significant focus from our staff, were able to move our income to another level, whilst maintaining our expenditure.

This means that by the end of 2018/19 the charity had cash reserves of £24,145. This is sufficient to fund the Trustees' plans for the immediate future and to give a platform for our future activities.

Finally, as a result of the Chief Executive Officer's 2018 60th Birthday Appeal, in which she pledged to give all monies raised to research, £3,584 was raised and placed in our restricted reserves. During 2018/19 a further £2,552 was given to the charity for the specific purpose of giving to research. Of the £6,100, £3,000 was given to Nottingham City Hospital and £2,500 was given to Imperial College, London.

stillbirth  
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## Policy & Reserves

An average unrestricted cash balance of at least three months' expenditure will always 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:

|                     |                |            |             |
|---------------------|----------------|------------|-------------|
| <b>Full name(s)</b> | Jenny Chambers | Sian Eaton | Judith Gray |
| <b>Position</b>     | CEO            | Treasurer  | Chair       |
| <b>Signature(s)</b> |                |            |             |

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|              |           |           |           |
|--------------|-----------|-----------|-----------|
| <b>Date:</b> | 9/11/2019 | 9/11/2019 | 9/11/2019 |
|--------------|-----------|-----------|-----------|