



# ICP Support

**Trustees' Annual Report for the  
period 1 April 2019–31 March 2020**



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## Reference and administration details

Charity name	ICP Support
Registered charity number	1146449
Charity's address	69 Mere Green Road, Sutton Coldfield, B75 5BY
Names of the charity trustees who manage the charity	
Trustee name	Office (if any)
Judith Gray	Chair
Jenny Chambers	CEO
Sian Eaton	Treasurer
Peter Dixon	
Aileen Morrison	
Jenny Hastings	
Tracey Smith	
Asha Strong – appointed 1 November 2019	

## 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

What a year of contrasts this has been. We started the year in a relatively stable, yet still challenging, financial position and despite our size we have shown enormous creativity and fortitude to raise much-needed funds to support vital research and to provide help and advice to families affected by ICP. We may be small, but we have big ambitions, and I would like to



thank all of our fundraisers who have worked with us and continue to support us in this endeavour.

One of the standout moments of this year has been the long-awaited study on the impact of ursodeoxycholic acid on women with ICP. ICP Support was involved in this study, and the research paper published in *The Lancet* has had a far-reaching impact, making the work done by our ICP Support team a vital service to the women and families affected. You can download this study from our website: <https://www.icpsupport.org/pdf/Chappell-et-al-2019.pdf>.

We end the financial year during the COVID-19 pandemic and acclimatising to life in lockdown. We know this will affect our ability to manage a whole raft of planned fundraising activities and we also know that our small ICP Support team will continue to work tirelessly to raise awareness and provide support to families. This is going to be tough for us; many charities will not survive, and if I could ask you to remember to do just one thing, please use Amazon Smile ([smile.amazon.co.uk](https://smile.amazon.co.uk)) when you make your online purchases so that we at ICP Support can benefit and put those funds to very good use.

*Jude Gray (Chair)*

## Summary of the year from the CEO

I ended last year's report with the words '*... the work continues. We have our plan to grow the charity, and I hope to report more good news in our next Annual Report*'.

It is somewhat surreal, then, that I am writing this year's report during a pandemic that has costs the lives of thousands of people and resulted in the UK currently being in lockdown. I can't go out unless it's to get food, and even if I do, I have to keep 2 metres away from anyone I may come in contact with. If this were a script for a film, I am not sure anyone would find it believable.

The sadness at the loss of lives and the worry about COVID-19 make it seem almost inappropriate to be writing about fundraising and donations; yet as a charity we are needed more than ever. Calls to our support line have increased and the questions in our social media groups are coming in thick and fast as women come to us for information and support about ICP, which their own health professionals are currently unable to give because

stillbirth  
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of a reduction in hospital visits. And while the demand for support has risen, we anticipate a loss in income of some £26,000 from fundraising events that were due to take place during lockdown. Once again, our little charity is back in challenging waters.

But we will get through this and I will write this report. We are busy fundraising to make up the shortfall of income and I am humbled at the response we are receiving from people. These are often from the same people who supported us during 2019 with their regular donations (the life blood of this charity), purchase of lottery tickets, fundraising events such as the Norwood Park Golf Club, who raised £5,092.56 for us, the Launceston Young Farmers, who raised £1,500 and of course all those who took part in sporting events, which raised a collective total of just under £9,000.

I want to thank them and everyone else who has supported our charity – we cannot survive without your generosity.

This comes on the back of what was a steady year for us, during which we continued to attend conferences to raise our profile, give talks to health professionals on ICP, and collaborate with other organisations. We have worked with pregnancy charities to highlight the need to continue the drive to reduce stillbirth, and we are currently working with the RCOG on their revised Guideline for ICP – we can promise you that it's completely different from the existing Guideline and will benefit many women with the condition. The biggest surprise of the year came from a large trial, called PITCHES, in which I represented the charity as a Lay Investigator. It showed that the drug ursodeoxycholic acid, which has been used for the past 20 years to treat ICP in the UK, doesn't work as well as we had thought it did – so much so that we are now having to rethink what drug could be used to treat the condition. We are currently in discussion with a drug company about a potential new medication for treating ICP, and although this may be subject to delays because of COVID-19, I am optimistic that trials on the drug will eventually go ahead once we are through the pandemic. This shows just how important it is for research into ICP to continue, and supporting research remains one of our aims.

As I finish typing this report, NHS staff are fighting to keep people alive, and they, together with key workers such as supermarket staff, postal staff and all the other workers in the services we need to keep the country functioning, are putting their own health at risk. We want to thank them for doing this, and like them and so many charities, we will also continue to fight for our future so that we can still be here to support you and your families during the rest of this year and beyond.



From the day I suffered my first stillbirth I have never lost hope that if people come together they can achieve great things. I believe that still to be true, because with your help we have achieved great things as a charity, and I know that we can continue to do so.

Stay safe everyone; I hope to be writing the next report in a very different climate!

*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 currently meet four times a year. In between those times we also hold telephone conferences to plan activities that 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 several Facebook groups and a Facebook page. At the end of our financial year the main open group had 4,948 members – an increase of 18.1% from last year. The rate of growth is accelerating – in 2018/19 the increase was 13.6%. The Facebook page had 5,189 followers, an increase of 433.

The Australia and New Zealand group also continues to grow: up 52 from 511 in 2019 to 563 in 2020.

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. While these groups have grown steadily in size, they have not yet led to the stated goals.

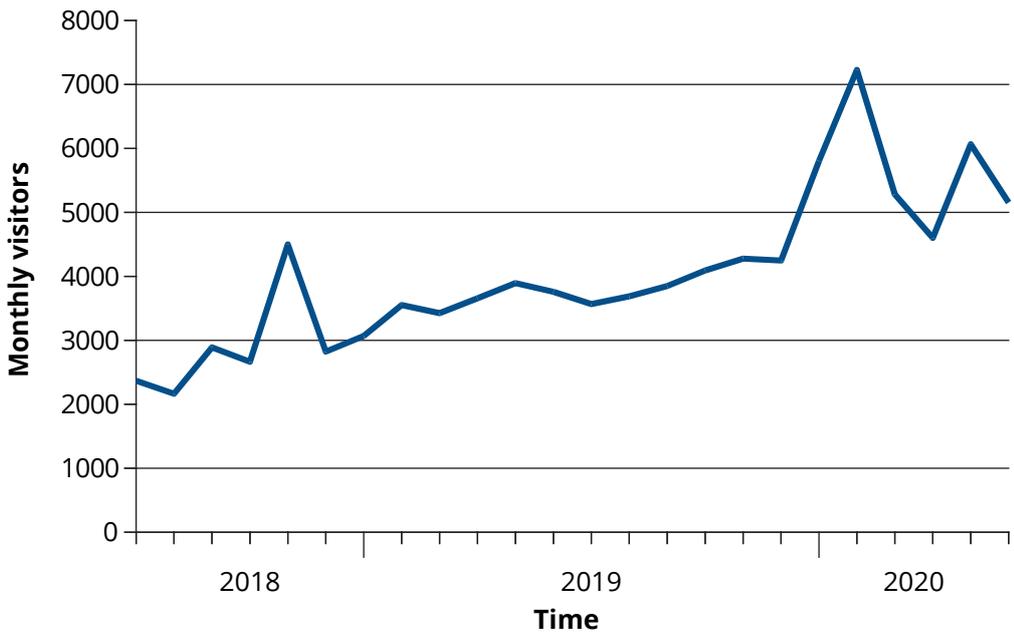
The postnatal Facebook group (184 members) has been successful, supporting women who continue to have ICP-related issues after their babies are born. The health professionals group (108 members) is growing, but is not particularly active as yet.

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 continues to increase substantially. Twitter followers have increased from 931 to 1,086, while Instagram followers have grown dramatically, from 1,169 to 1,734 (+48%)

The number of visitors to the website, which rose by 31% in 2018/19, following several years of slow growth, has seen an even greater increase: up 46% (see chart). The sharp peak in January 2020 coincides with the broadcast of *Trust Me, I'm a Doctor*. The continued rising trend in February to April suggests that the COVID-19 pandemic had no discernible impact on visits to the website. Links to authoritative resources for treatment of





*Growth in ICP Support website visits*

pregnant women during the pandemic were added to the website and kept current.

The trend towards accessing the website by mobile phone continues slowly, with 76.4% of visitors doing so (compared with 75% in 2018/19 and 73% in 2017/18). In sharp contrast to the general smartphone market, which is dominated by Android devices, Apple's iPhone is responsible for almost 60% of mobile visits. Changes continue to be made to the site to improve its usability.

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

The charity runs a telephone support line that operates Monday–Friday. We do not give medical advice; nor do we provide counselling, but the person who currently takes the calls is a trained counsellor. The calls are often quite lengthy: at least 25 minutes and sometimes more. Although we do not receive as many calls as we used to (because our Facebook support groups take most queries), we know that some women just want to talk to someone and hear a human voice. Sophie says: 'I nearly didn't ring, but I am so pleased I did because after speaking to you I feel much more reassured and less anxious about the condition'.



## 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*

Last year we were approached by the television series *Trust Me, I'm A Doctor*, and two of our Trustees took part in production of a segment on ICP. The show was broadcast on BBC2 in January 2020. 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.



*Still image from Trust Me, I'm a Doctor (BBC2)*

### *Conferences and talks*

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

- ◆ Presentation on ICP at Birmingham Heartlands Hospital, May and November 2019
- ◆ Presentation on ICP/Pre-eclampsia overlap APEC – Northampton, July 2019
- ◆ Maternity and Midwifery Festival, Cardiff, September 2019
- ◆ Maternity and Midwifery Festival, Dublin, 2020. At this conference we discovered that midwives were advising women with ICP to fast for their bile acid tests, something that is completely wrong to do! This is

because you need to know how *high* bile acids rise to assess stillbirth risk to the unborn baby, but fasting gives doctors the *lowest* reading. We were able to correct this misinformation and midwives were returning to their hospitals with the aim of changing this practice.



*The ICP Support stand in Dublin*

## **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 College London and Tommy's
- ◆ Tommy's Midwives – Live Facebook session with our Patron Helen George in June 2019
- ◆ RCOG Women's Voices Involvement Panel
- ◆ Action on Pre-Eclampsia (APEC)
- ◆ Pregnancy and Baby Charities Network

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, mentioned previously in this report. We know that some of the women in our social media support groups participated in the trial and we were able to report on the findings of this trial through our website and social media groups.

### *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.

There has been no direct donation to research this year, so our committed 10% of surplus income will be restricted for any funding applications that are received during the next financial year. However, we are still supporting research through our members, who sign up to take part in studies such as PITCHES and Professor Catherine Williamson's (King's College London and Imperial College London) OC Research Study.

### *Running and cycling events*

This year saw Team ICP taking part in not just running but also cycling. Sporting events are a fantastic fundraiser for ICP Support and we were very lucky to gain places in the Prudential Ride London event in August. Prior to this a team had taken to the streets of Manchester to run the popular Great Run 10K event, proudly wearing their ICP vests.



August saw six Team ICP members take part in the 100 mile challenge for Ride London. This impressive event brought some of our dads together to cycle and raise money for our charity, which was absolutely fantastic. The team together raised over £4,000 for us and we extend our thanks to them.

The final organised event of the year for Team ICP was the ever-popular Great North Run. Three excited yet apprehensive team members completed the event and raised a significant amount of money for the charity, while also telling us they had great fun.



During the year we have also been very lucky to have runners choosing to enter their own events and raise money for us, such as the Edinburgh Marathon and the Southampton 10K. We are incredibly grateful to these members who decide to put on their ICP vest and run individually for us. If you fancy setting yourself a challenge for the coming year then don't forget: you can contact us and we will support you in doing so.

It is fantastic to report that our running events have raised around £9,000 for our charity this year.

## Financial review

The charity started the year with unrestricted cash reserves of £24,145 available to finance the day-to-day operations of the charity. This represented about six months' expenditure and was higher than in previous years. It was the result of a deliberate policy to increase the level of cash available to fund the charity, with the objective of expanding its operational capacity.

The charity is focused on raising income, but this was less of a focus in 2019/20. As a result, total income was £56,011, 9% less than in the previous year, but still substantially higher than in 2017/18.

There remains a desire to keep close control of expenditure. However, there was also a need to start to plan for expansion. This came in mid-2019/20 with the employment of two part-time employees, which led to

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an 21.7% increase in salaries. The full impact of this will not be felt until 2021/22 (2020/21 being affected by the COVID-19 pandemic – see below). This was the first step in a long-term plan, releasing the CEO to concentrate on core charity objectives.

Overall, the charity had a surplus of income over expenditure of £7,136. This means that by the end of 2019/20 the charity had cash reserves of £31,281. This is sufficient to fund the Trustees' plans for the immediate future and to give a platform for our future activities. In line with the trustees' pledge that 10% of any surplus of income over expenditure is earmarked for research, at the July 2020 Trustees Meeting it was agreed that £714 be transferred into a restricted reserve. This will be distributed when a suitable application is received.

The COVID-19 pandemic lockdown started at the end of 2019/20. The trustees acted promptly to safeguard the cash resources. It was soon apparent that one of the key sources of income would be lost with the cancellation of all running and cycling events. The two new administrative employees were furloughed at 80% of salary in line with the government scheme. The CEO then went into fundraising mode, with a number of grant applications and a fundraising campaign with a £26,000 target.

Both of these strategies have been highly successful, with the grants funding the additional COVID-19 work, and by the end of the financial year good progress had been made towards the fundraising target.

It is the opinion of the trustees that the immediate action taken by the CEO and trustees is sufficient to protect the cash reserves of the charity at this very difficult time. Even if the running and cycling events do not return until 2021/22 and there is an economic downturn, there is enough current and future cash inflow to ensure that the operational activities can continue into the future, in line with the charity's objectives.

## 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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