



# ICP Support

**Trustees' Annual Report for the period  
1 January 2022–31 December 2022**

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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
<b>Names of the charity trustees who manage the charity</b>	
<b>Trustee name</b>	<b>Office (if any)</b>
Judith Gray	
Jenny Chambers	CEO
Peter Dixon	
Jenny Hastings	Co-Chair
Katy Crabbe	
Tracey Smith	Co-Chair
Emily Rees – resigned 09/11/2022	Treasurer

## 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 Co-Chairs of Trustees

2022 has proved to be a very challenging year for ICP support in terms of fundraising. Coming off the back of our 30th Anniversary year, where £50,000 was raised, the small charities sector finds itself affected by the ongoing cost-of-living crisis and a difficult climate in which to secure grants. ICP Support has continued in its efforts and also tried to cut its costs to ensure that the charity continues to deliver on its aims. We thank all of our supporters who have donated to ICP over 2022 – we could not provide the services we do without your help – and it means we can continue to help fund research, support women and their families, and enable us to fulfil our aim that every ICP baby is born safely.

As Co-Chairs who took over this role in April 2020, we can honestly say that this last year has definitely been a tough one, but we remain honoured to be a part of such a fantastic charity and look forward to 2023 with positivity and optimism.

*Jenny Hastings and Tracey Smith (Co-Chairs)*

# Summary of the year from the CEO

After the financial challenges of 2021 I didn't think it could get any harder to raise money in 2022 – but it did!

Yet while our income for 2022 was only half of what we had for the previous year we were still able to deliver our services with some great 'firsts' and highlights.

In February, BBC1's 'Call the Midwife' featured ICP in the penultimate and final episode of Series 11. I had been contacted over a year before to be told that the writers wanted to feature the condition and would appreciate my help in ensuring that the storyline was as accurate as it could be for the period in which it was being set (1968). This included using the correct name for the condition, as the only country in the world at that time using the term OC (obstetric cholestasis) was Australia, whereas the rest of the world was using ICP. I was delighted to do the research, but it was very hard keeping everything a secret – I was not allowed to tell anyone! The episodes reached an average of just under 8 million viewers in the UK and resulted in a spike of website visits of almost 1,000 visitors – five times the normal daily amount.

As part of our aims to reach health professionals I am delighted that we have been able to work with universities to deliver presentations on ICP to student midwives that encompass the history of ICP in the UK and an overview of the condition, and which also explore how charities can work with health professionals to support them, in and out of the clinical care space. By the end of 2022 I had given 13 presentations on ICP attended by just over 600 student midwives with great feedback from them.

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*Jenny was fantastic – engaging, dynamic, really informative and inspiring in sharing how her own personal experience spurred her on to move into research and awareness raising re ICP.*

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The charity was involved in helping to bring together the new EASL Clinical Practice Guidelines on the management of liver diseases in pregnancy, and this will be published in 2023.

I have continued to attend online meetings for organisations that ICP Support belongs to, such as the Pregnancy and Baby Charities Network, the Baby Loss Awareness Week group, EASL (European Association for the

study of the Liver, and others. I have been delivering presentations on ICP to student midwives, and these have been well received.

We ended the year with a Christmas Appeal, 'Not Every Baby Cries', and exceeded our (modest) target of £5,000 by raising £6,487. I want to thank Charlotte and Simon Baker who so very kindly led the appeal by sharing their own devastating experience of stillbirth caused by ICP.



We will continue to work hard to ensure that anyone affected by ICP can access our services and we hope that 2023 will see us sustain the level or services that we currently supply.

*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 five 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 2022 the main group had 8,790 members – an increase of 29%. This compares with 26% for 2021. The Facebook page had 6,562 followers, an increase of 482 from 2021.

Membership of the regional Facebook groups has continued to grow slowly. Despite the much-reduced influence of the covid-19 pandemic, there has continued to be no progress in using these groups to facilitate in-person meetings.

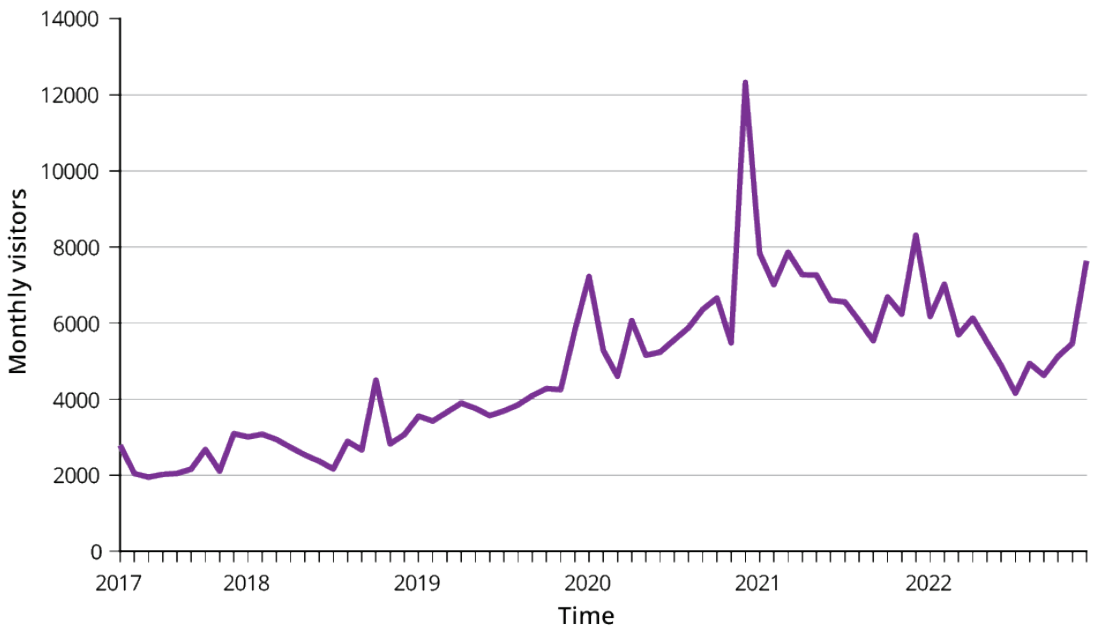
The Beyond Birth (postnatal) Facebook group (1,852 members) has continued to grow rapidly, its membership rising by 71% from 1,080 at the end of 2021. There is clearly a demand for providing support to women who continue to have ICP-related issues after their babies are born, right the way through to menopause. The Health Professionals group has grown from 344 members to 394, but activity is still light.

Information is also disseminated through Twitter and Instagram, where engagement continues to increase substantially. Twitter followers have

increased from 1,239 to 1,440 (16%), while the number of Instagram followers has grown significantly, up by 32% from 2,620 followers to 3,102.

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

The number of visitors to the website (see chart) fell during the middle of the year but appears to have recovered. The reason for this is unknown.



*ICP Support website visits*

The trend towards accessing the website by mobile phone appears to have halted, with 80.7% of visitors doing so (compared with a peak of 82.2% in 2021. However, this is still well ahead of the 73% who used smartphones in 2017). Apple’s iPhone share remains unchanged at 65.4% of mobile visits. Minor changes continue to be made to the site to improve its usability.

### ***Infographics***

We have continued to fulfil our aims of raising awareness and providing information on ICP to anyone affected by ICP, and these infographics continue to be well received. Many infographics are now available on the website for use by others, subject to due acknowledgement of ICP Support as the source.




### Non-fasting bile acid test

**FALSE** *'You should fast before a bile acid test'*

**TRUE** If you fast, bile acid concentrations will be at their lowest and the diagnosis of intrahepatic cholestasis of pregnancy could be missed.

**TRUE** Bile acids peak (are highest) after eating. You need to know what your peak bile acids concentrations are to assess the safety of your baby in ICP.

 If health professionals advise you to fast, refer them to: Mitchell et al. (2021) <https://doi.org/10.1111/1471-0528.16669>

[icpsupport.org](https://www.icpsupport.org) #FoodNotFast #EatPeakRepeat

### Diagnosis of ICP

Other causes for the itch will be ruled out. You'll be asked about your family history and may be offered a liver ultrasound.

**Blood tests** Used to diagnose and monitor intrahepatic cholestasis of pregnancy

**Bile acid test** For a diagnosis of ICP, you must have raised bile acids.

**Liver blood test** Assesses how well your liver is working. 20% of women with ICP will have normal liver blood test results.

*It is important to repeat these tests if results are normal but you continue to itch*

[icpsupport.org](https://www.icpsupport.org) Supporting you every itch of the way

### Stillbirth risk in ICP

The risk of stillbirth in intrahepatic cholestasis of pregnancy is 3.44% when bile acid concentrations are  $>100\mu\text{mol/L}$   
Dvadia et al. (2019). The Lancet. [https://doi.org/10.1016/S0140-6736\(19\)31877-4](https://doi.org/10.1016/S0140-6736(19)31877-4)

**Assessing the risk of stillbirth**

Non-fasting bile acid tests are required. Results must be available within 24 - 48 hours to allow any necessary action to be taken. It is essential to monitor bile acids with at least weekly testing, particularly when concentrations are  $>40\mu\text{mol/L}$

**Induction of labour recommended:**

From 35 weeks with bile acids of  $>100\mu\text{mol/L}$   
Sometimes earlier, depending on individual circumstances or other pregnancy complications

Around 38-39 weeks with bile acids of  $<100\mu\text{mol/L}$   
When there are no other pregnancy complications and the itch can be tolerated

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### Coping with the itch in ICP

**Keep Cool**

- Wear loose, breathable clothing
- Keep rooms ventilated
- Freeze a bottle of water, wrap in a towel and place on the skin

**Rest & Relax**

- Try to find time to relax
- Do something to distract yourself
- Try to sleep during the day if the itch is worse at night

**Soothe the Skin**

- Apply aqueous cream with menthol from the fridge
- Bathe in oatmeal

**Talk to Us**

- Join our Facebook group, contact our support line or online drop ins
- We're here to support you. Don't suffer alone!

The severity of the itch in intrahepatic cholestasis of pregnancy is not directly related to bile acid concentrations. You may have low bile acids with an intense itch or high bile acids with mild itch

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## 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. We also provide online support and email support. We are grateful to the James Tudor Foundation and the Eleanor Rathbone Charitable Trust for their support in helping to continue this service.

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

### Leaflets

Our generic leaflet has primarily become a digital leaflet. It continues to help raise awareness of ICP, and provides up-to-date information on the condition. Printed leaflets are still available and can be distributed at

conferences. We are currently working to source funding that will enable us to translate our leaflet into different languages to meet the needs of the diverse communities who access our support.

### ***Conferences and talks***

We have continued with delivering information about ICP to health professionals via online presentations and will continue with this approach during 2023.

### ***Collaboration***

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

- RCOG Guidelines Committee
- Tommy's
- Sands
- Pregnancy and Baby Charities Network
- Baby Loss Awareness Week Consortium
- EASL (European Association for the Study of the Liver)

## **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 we worked with Professor Catherine Williamson from King's College London and Mirum Pharmaceuticals to give feedback on a potential new medication (Volixibat) for treating ICP. We have also continued our work with Professor Bill Hague from Adelaide, Australia, and our founder Jenny Chambers has been invited to speak at the Society of Obstetric Medicine of Australia and New Zealand (SOMANZ) Conference in October 2023.

### ***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. This year we were unable to fund any research due to the financial challenges we faced, but we hope that this will change soon.

### ***Grant Awards to ICP Support***

We are very grateful to the following organisations for grants received this year which support the running and development of our Information and Support Hub.

James Tudor Foundation: £5,000



Eleanor Rathbone Charitable Trust: £1,000

## **Financial review**

The charity started the year with unrestricted cash reserves of £112,065 available to finance the day-to-day operations of the charity, the balance being higher than usual due to the higher reserves retained from the covid-19 pandemic time, and also boosted by a large donation via Helen George (Patron) who competed in a television programme on our behalf. This left cash reserves representing approximately 17/18 months expenditure.

The charity's focus for 2022 continued to be on fundraising to try to ensure that the operational costs to the charity were met and to provide a basis for growth in the future. Income for 2022 was £51,602, which was substantially lower than the previous year. This was due to a downturn in fundraising and grant monies received. 2022 was a challenging year for ICP Support, as indeed it was for many other charities, large and small. The cost-of-living increases and changes to the amount of funds available through grant providers made fundraising especially difficult. As ever, we are proud of the amount raised and thankful for the continued generosity of our donors and patrons, particularly in such a difficult year in the charity sector.

The trustees continue to operate with a Finance Committee that oversees and discusses the financial objectives of the charity, looks at pay and remuneration, and monitors future income and expenditure. The committee continues to meet approximately two weeks before each Trustees meeting, where any final proposals are approved, and where the Chair summarises the discussion points from the Finance Committee meeting.

Staff continued to work as normal during 2022. Two notable differences were that the Engagement Officer was on maternity leave for the majority of 2022 and a new member of the team was recruited at the beginning of the year in the role of Support and Engagement Officer. Unfortunately, due to family and other work commitments, she resigned and left at the end of 2022. Expenditure continued to be on operational activities overall, with less spent on fundraising activities, as per 2021. It is worth noting, however, that some of the sporting fundraising events have started to return.

Overall, the charity had a deficit of income over expenditure of £60,978, which takes into account donations of £31,384 made to research projects, funded from the large reserves gained in 2021 due to the anniversary appeal and which was always earmarked for research. This means that at the end of 2022 the charity had cash reserves of £51,087. This gives ICP Support sufficient funds to continue to support our aims in 2023. In line with the Trustees' pledge that 10% of any surplus of income over expenditure is earmarked for research, it was agreed at the Finance Committee and Trustees' meetings to transfer £3,626 into a restricted reserve. This will be distributed when a suitable application is received.

It is the opinion of the Trustees that the charity ended 2022 in a strong financial position, but mindful that raising funds in the future may still prove to be challenging. It ensured that there is enough current and future cashflow to ensure that the operational activities can continue.




## **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	Jenny Hastings	Tracey Smith
<b>Position</b>	CEO	Co-Chair	Co-Chairs
<b>Signature(s)</b>			
<b>Date:</b>	28/09/2023	28/09/2023	28/09/2023