



# ICP Support

**Trustees' Annual Report for the period  
1 January 2021–31 December 2021**

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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	
Jenny Chambers	CEO
Peter Dixon	
Jenny Hastings	Co-Chair
Aileen Morrison – resigned 26/04/2021	
Katy Crabbe	
Tracey Smith	Co-Chair
Emily Rees – appointed 08/02/2021	Treasurer
Asha Strong – resigned 17/08/2021	

## Structure, governance and management

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

Following a very different but rewarding 2020, 2021 proved to be more challenging. Continued lockdowns in the UK during the global pandemic challenged us to come up with different ideas for fundraising, as all our sporting events (which typically raise around £26,000) were cancelled.

It was, however, the charity's 30th Anniversary and we were excited to work together not only to raise funds for ICP Support, but also to pledge a minimum of 40% of what was raised through our appeal for much needed research.

Raffles, competitions, quiz evenings and individuals taking on challenges to raise funds became a big part of our fundraising focus. Jenny Chambers was instrumental in focusing our year and personally receiving pledges from followers and supporters of ICP Support, many of whom have supported us over many years. We also received some international donations and it's fantastic to know that we are reaching so far afield! Jenny's fundraising activities also included her dying her hair purple as a challenge. Thank you to our many supporters who donated to all of our events – as always, we couldn't do this without the support of you all.

We originally set a very stretching target of £100,000, and while we raised just under £50,000, we are delighted with this result given the challenging year that we, and so many other charities, have had. 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 able to report on the successes and look forward to many more in 2022, and in future years.

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

# Summary of the year from the CEO

January 2022 – and I'm writing this report, still working from home, and still having to find ways to be creative with our fundraising!

As our Co-Chairs have reported, last year was even tougher than 2020 in terms of raising the finance we need to keep our charity running. Despite all this, our income for 2021 was just over £100,000 – the first time we have achieved this since the charity was registered. Our 30th Anniversary Appeal has meant that we've been able to fund more research into ICP through an award of £25,000 made in December 2021 to Professor Catherine Williamson, King's College London. How this funding will be utilised can be found further on the report.

We've achieved this through a lot of hard work by everyone involved with our charity, whether they be staff, trustees, volunteers, fundraisers or anyone who has made a financial donation to us. As the Co-Chairs also say, we really couldn't have done this without your wonderful support!

With the £31,100 that Helen George won for us in 2020, we've been able to increase our staffing hours a little further and this has resulted in more help with producing posts for fundraising as well as to increase our reach. We can already see the results of this through an increase in people asking to join our support groups.

In April last year, we were able to invest more time to secure grant applications, resulting in £13,542 for our Information and Support Hub. These grants are vital to help us to continue our work and reach more people affected by ICP, and we are very grateful to the organisations who have supported us. We aim to increase funding from grant applications during 2022.

I have been able 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.

Excitingly, ICP Support is also supporting the trial of a new medication for the treatment of ICP. Launched by Mirum Pharmaceuticals, it will be testing the use of volixibat, which it is hoped will reduce both itch and potentially harmful bile acids. You can read more here: <https://www.icpsupport.org/ohana.shtml>



I hope to report back next year with a further increase in our income as we continue to grow our little charity and work towards ensuring that our vision of every ICP baby being born safely becomes a reality.

*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 2021 the main group had 6,859 members – an increase of 26%. This compares with 18% for 2020. The Facebook page had 6,080 followers, an increase of 600 from 2020.

Membership of the regional Facebook groups has grown slowly. The pandemic means that there has continued to be no progress in using these groups to facilitate in-person meetings.

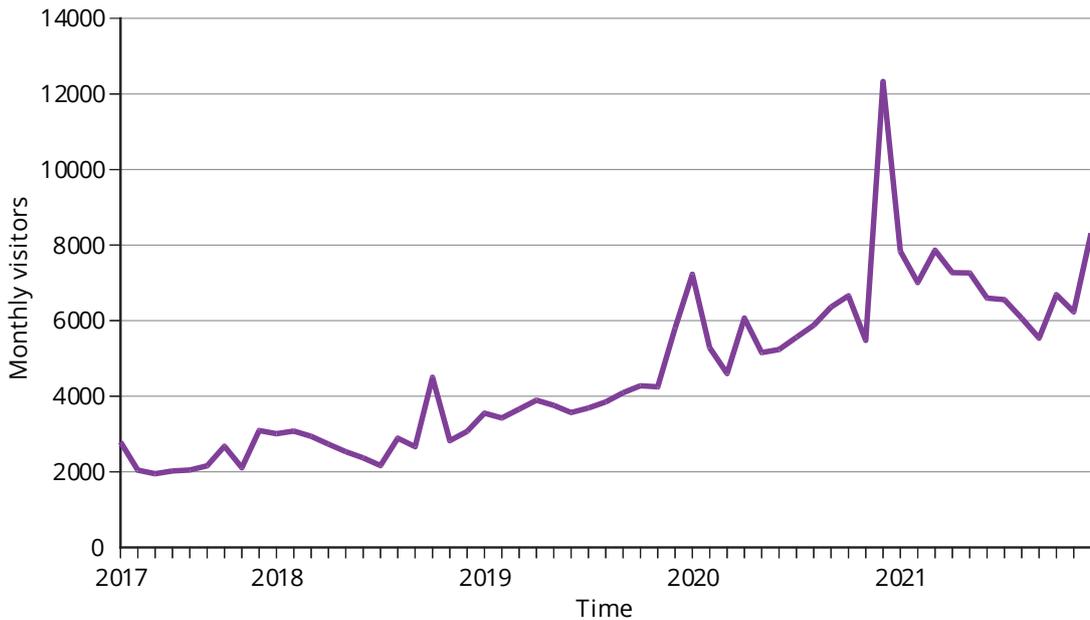
The postnatal Facebook group (1,080 members) which we have now re-named Beyond Birth has continued its success, its membership rising by 350% from 240 at the end of 2020 thanks to additional promotion of the group. It aims to support women who continue to have ICP-related issues after their babies are born right the way through to menopause. The Health Professionals group grown from 225 members to 344, but activity is still light.

Information is also disseminated through Twitter and Instagram, where engagement continues to increased substantially. Twitter followers have increased from 1,140 to 1,239 (9%), while the number of Instagram followers has grown rapidly up by 32% from 1,990 followers to 2620.

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

The number of visitors to the website (see chart) continues to rise steadily.





Growth in ICP Support website visits

The trend towards accessing the website by mobile phone continues, with 82.2% of visitors doing so (compared with 80.5% in 2020, 76.4% in 2019, 75% in 2018 and 73% in 2017). Apple’s iPhone is now responsible for 65.4% of mobile visits, compared with just over 60% in 2020. Minor changes continue to be made to the site to improve its usability.

### Infographics

At the beginning of 2021 we were able to employ a part-time Engagement and Development Officer who has been able to help us with the design of infographics that share bite-sized pieces of information about ICP on social media and our website. Where necessary, these are always approved by experts in ICP. These are being well received in our communities and have also been used by health professionals.

#### 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 #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 Supporting you every itch of the way

stillbirth  
 gallstones  
 liver  
 UTSO  
 cholestasis  
 hormones  
 families  
 bile acids  
 heredity  
 intrahepatic

## 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. During the pandemic calls to the support line doubled and we also continued to hold online meetings for women with ICP which women reported as being helpful to them.

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

### Leaflets

The generic leaflet continues to help raise awareness of ICP and is sent to hospitals requesting a supply. This is an important way for us to raise awareness of ICP and to provide up-to-date information on the condition. Although digital is replacing the need for many leaflets these days, we are aware that some hospitals prefer to have hard copies and we will continue to disseminate them where requested. We now hope to source funding that will enable us to translate our leaflet in to 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 2022.



## 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
- RCOG Women's Voices Involvement Panel
- Pregnancy and Baby Charities Network
- Baby Loss Awareness Week Consortium
- RCOG Guidelines Committee
- 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 has seen our continued involvement with researchers such as Professor Catherine Williamson from King's College London and with Professor Bill Hague from Adelaide, Australia.

## 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. During 2021, Facebook fundraising pages proved very effective.



*Thanking one of our Facebook fundraisers.*

At the end of 2021 we awarded a grant of £25,000 to Professor Catherine Williamson, King's College London. This grant will support:

- a scoping exercise to look at the feasibility of a longer-term impact of ICP (following women for several years after their pregnancy(ies))
- funding one of the researchers for work that she hopes will lead to investigating diet in ICP
- supporting the maintenance of the ICP database used by Professor Williamson's team.

This follows on from an online discussion held with people affected by ICP in October 2021 in which themes for research were identified. The results are summarised in the infographic below:



## 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.

- National Lottery Awards for All: £9,542



- Westfield Health: £1,000



- The February Foundation: £3,000

## The February Foundation

The impact of these awards is far-reaching. They have enabled us to employ part-time staff members to act as Engagement & Development Officers with a remit to broaden our reach among anyone who might be affected by ICP, for example, through the development of infographics to provide information on ICP, raise awareness of what we do, and to have more contact with our social media communities such as our Regional Groups. This is reflected in the increase of membership to our support groups as more people find us.



stillbirth  
gallstones  
UTSO  
cholestasis  
hormones  
families  
bile acids  
heredity  
intrahepatic  
liver

## Financial review

The charity started the year with unrestricted cash reserves of £72,460 available to finance the day-to-day operations of the charity, the balance being higher than usual due to the COVID-19 pandemic, and thus the level of cash reserves represents approximately a full year of expenditure.

The charity's focus for 2021 continued to be on fundraising, with a particular lens on both activities around ICP Support's 30th anniversary, ensuring that the operational costs to the charity were met and providing a basis for growth in the future. Income for 2021 was £115,962, an increase of 56% on the previous year's accounts – these were, however, accounts for only 9 months of the year due to a change in financial year. We are proud of the amount raised and thankful for the continued generosity of our donors and patrons, particularly in such an important year for the charity.

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, now run by the Treasurer, continues to meet approximately two weeks before each Trustees meeting, where any final proposals are approved, and where the Treasurer summarises the discussion points from the Finance Committee meeting.

Staff continued to work as normal during 2021, and no staff returned to being on furlough. Expenditure continued to be on operational activities overall, with less spent on fundraising activities, as per 2020, due to the pandemic. Year-on-year, the main difference in spend, besides the shorter financial year in 2020, will be due to salaries, where the charity has grown headcount and also did not benefit from the furlough scheme.

Overall, the charity had a surplus of income over expenditure of £36,257, meaning that by the end of 2021 the charity had cash reserves of £111,708. This gives ICP Support enough in funds to plan for both short-term and long-term activities. 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.

The COVID-19 pandemic continued to affect key sources of income during 2021, with the continued cancellation of running and cycling events. However, driven by the CEO, new fundraising activities and grant applications, and with a key focus on the charity's 30th anniversary, the charity continued to have the capacity to meet its objectives.



It is the opinion of the Trustees that the charity ended 2021 in a strong financial position. It ensured that there is enough current and future cash-flow to ensure that the operational activities can continue, and that the charity can look to expand in line with its future 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	Jenny Hastings	Tracey Smith
<b>Position</b>	CEO	Co-Chair	Co-Chairs
<b>Signature(s)</b>			
<b>Date:</b>	24/05/2022	24/05/2022	24/05/2022