



# ICP Support

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



# Contents

Reference and administration details	3
Structure, governance and management	3
Foreword by Co-Chairs of Trustees	3
Summary of the year from the CEO	4
Objectives and activities	5
The focus of our work and how we demonstrate public benefit	6
Financial review	9
Declaration	11



## 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 – retired 06/04/2020	Chair
Jenny Chambers	CEO
Sian Eaton – resigned 23/09/2020	Treasurer
Peter Dixon	
Aileen Morrison	
Jenny Hastings appointed Co-Chair 06/04/2020	
Tracey Smith appointed Co-Chair 06/04/2020	
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 Co-Chairs of Trustees

What a year it has been. March 2020 saw the UK shut down during a global pandemic, and as a charity all the fundraising events we rely upon for donations were cancelled. It could have meant disaster, but as we



always do as a small but mighty charity, the team rallied together, and our lockdown loyalty fund was created.

We had to think of new ways to fundraise, from the 2.6 Challenge to raffles, virtual afternoon teas, cake competitions, and our ongoing virtual quiz evenings. As always, we couldn't do this without the support of you all and we exceeded our target, which we are so incredibly grateful for. 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.

The year ended with many of you tuning in on Christmas Eve to watch our Patron Helen George win £31,100 on *Celebrity Catchphrase* for our charity. It couldn't have been a better and more exciting end to the year and how many of us were shouting 'what we could see' at the TV.

As Co-Chairs who took over this role in one of the most challenging of years, we are honoured to be able to report on the successes.

We look forward to our 30th Anniversary year celebrations in 2021.

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

## Summary of the year from the CEO

We changed our financial year end in 2020 so that it runs from January to December. This means that I am reporting on a shorter financial year this time, and, sadly, also means I am still writing to you during a pandemic.

But there is more positive news given the UK's vaccine rollout, and I very much hope that by the time of our next Trustees' Report things will be looking very different for us. As a charity we also have positive news to report. During the last nine months we have managed to raise sufficient funds to cover the shortfall from loss of event income during Covid-19 (£26k) and we had the most wonderful surprise in December when Helen George, our Patron, secured a further £31,100 when she took part in *Celebrity Catchphrase* and won!

We were also able to secure two Covid-19 grants to help us cope with the increase in demand for our services during the pandemic, and our thanks go to the National Lottery Awards For All and the Charities Aid Foundation for their support.

I have been able to attend online meetings for organisations that ICP Support belongs to, such as the Pregnancy and Baby Charities Network,





*Celebrity Catchphrase: Jordan Banjo, Stephen Mulhern, ICP Support Patron Helen George and Harry Redknapp*

as well as the Baby Loss Awareness Week group. I have been delivering presentations on ICP to student midwives, and hosted two Facebook live presentations on ICP, with Dr Caroline Ovadia who discussed her meta-analysis on stillbirth risk in ICP, and with Dr Peter Dixon who talked about the genetics of the condition.

It's been sad to say goodbye to our Treasurer, Sian Eaton, who helped set up ICP Support as well as supporting me back in 1994 when I started to raise awareness of ICP. I am sure that Sian will be enjoying her well-earned rest! Jude Gray, our Chair, has also retired as Chair (but remains a Trustee) and I am delighted to welcome Tracey Smith and Jenny Hastings as our new Co-Chairs.

Next year I look forward to reporting back on our 30th Anniversary and letting you know how our Appeal to raise £100,000 has gone. It's not going to be easy, given the continuing climate, but whatever we raise will be used to fund our work of supporting and providing information to anyone affected by ICP, raising awareness of the condition, and supporting and funding research into it.

*Jenny Chambers (CEO)*

pruritus  
symptoms  
scratch  
itchy  
risk  
ICP  
research  
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awareness  
fundraising  
education  
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UDCA  
genetics  
pregnancy

## 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 (31 December 2020) the main open group had 5,443 members – an increase of 10% in nine months, equivalent to an annual increase of 13.3%. This is in line with the growth rate in recent years. The Facebook page had 5,480 followers, an increase of 291.

The Australia and New Zealand group also continued to grow, but slowly: up 18 from 563 in May 2020 to 581 at the end of the year.

stillbirth  
gallstones  
liver  
intrahepatic  
URS<sub>2</sub>O  
cholestasis  
hormones  
families  
bile acids  
heredity

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

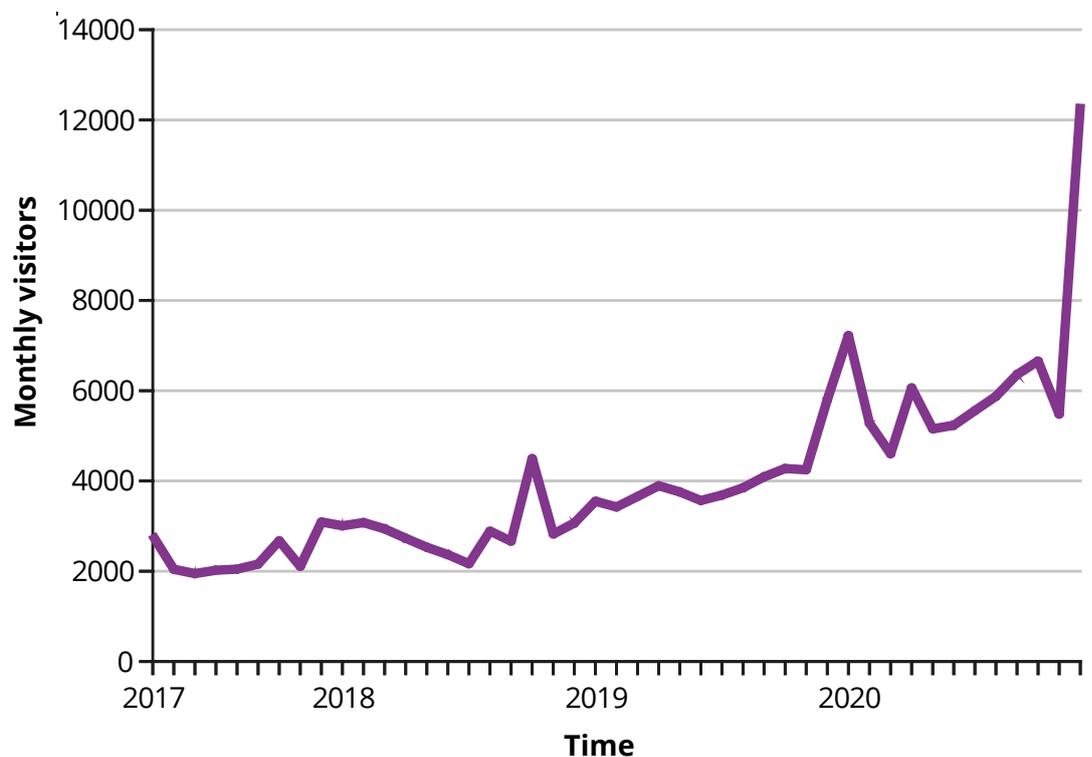
The Postnatal Facebook group (240 members) has continued its success, supporting women who continue to have ICP-related issues after their babies are born. The health professionals group has more than doubled in size to 240 members but activity is still light.

Information is also disseminated through Twitter and Instagram, where engagement continues to increased substantially. Twitter followers have increased from 1,086 to 1,140, while the number of Instagram followers has grown less dramatically than last year, rising from 1,734 to 1,990 followers.

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

The number of visitors to the website (see chart) rose at a similar rate to that in 2019/20; the exceptionally high number of visits in December 2020 is due entirely to Helen George's appearance on *Celebrity Catchphrase* on 24 December.

The trend towards accessing the website by mobile phone continues, with 80.5% of visitors doing so (compared with 76.4% in 2019/20, 75% in 2018/19 and 73% in 2017/18). Apple's iPhone is now responsible for just over 60%



Growth in ICP Support website visits

education  
support  
pruritus  
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pregnancy

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. During the pandemic calls to the support line doubled and we also implemented online meetings for women with ICP which women reported as being helpful to them. It was a great way for women to see a friendly face as well as being able to talk to other women online. One of our callers was from Australia!

## **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.

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

A very different approach was needed for giving talks on ICP. As Covid-19 prevented us from attending our usual conferences we switched to online presentations.

- ◆ Caroline Ovadia and Jenny Chambers gave a live presentation on Facebook discussing Caroline's meta- analysis and the criticism from other charities.
- ◆ Jenny gave a live online presentation at Midlands Maternity and Midwifery Festival.
- ◆ Jenny gave an online presentation on ICP and the importance of ICP Support to PBB (Pregnancy and Birth) Events.

### ***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

## 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.

### *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.



## Financial review

The charity started the year with unrestricted cash reserves of £31,281 available to finance the day-to-day operations of the charity. The level of

cash reserves represents approximately 7–8 months' expenditure. This was higher than the previous year, bearing in mind that the financial year end for the charity was changed to 31 December and only represented 9 months' income.

The charity's focus for this 9-month period was on fundraising, with the aim of raising income to ensure that the operational costs to the charity were met and to provide a basis for growth in the future. Income for the 9 months was £74,122, an increase of 32.33% on the previous 12 months – a fantastic achievement given the economic climate and the restrictions due to the global pandemic.

During this financial year the Trustees agreed to appoint a Finance Committee to oversee and discuss the financial objectives of the charity, to look at pay and remuneration and to monitor future income and expenditure. This first meeting of the Finance Committee took place on 5 August 2020 and the committee will meet two weeks prior to each Trustees meeting. The discussions and proposals will then be taken to the Trustees meeting for overall approval.

At the start of this financial year two of the administrative staff were on furlough at 80% of their salary, in line with the government scheme. This was done to ensure safeguarding of cash resources. During the pandemic, the charity was keen to keep close control of expenditure, given the uncertainty of retaining regular donors due to the volatile economic climate. However, it became apparent through June that the work that the administration staff had undertaken prior to furlough was imperative to the running of the charity, and due to good income streams obtained through successful fundraising they were taken off furlough on 1 July 2020. The aim of this was also to release the CEO to concentrate on the core charity objectives.

Overall, the charity had a surplus of income over expenditure of £44,170, meaning that by the end of 2020 the charity had cash reserves of £75,451. This gives ample funds to not only secure the immediate plans but also for future activities and growth. 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, both held in April, to transfer £4,417 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 2020, with the continued cancellation of running and cycling events. However, driven by the CEO new fundraising activities and grant applications ensured that the charity's £26,000 target was not only met but exceeded.



It is the opinion of the Trustees that the charity ended 2020 in a strong financial position. It ensured that there is enough current and future cashflow 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>	15/05/2021	15/05/2021	15/05/2021