



LCP Support

**Trustees' Annual Report for the
period 1 April 2016–31 March 2017**



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Reference and administration details

Charity name	ICP Support
Registered charity number (if any)	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)
Jenny Chambers	Chair
Judith Gray	Vice-Chair
Sian Eaton	Treasurer
Peter Dixon	
Magdalen Rees	
Jenny Hastings – Co-opted 29 October 2015	
Tracey Smith – Co-opted 29 October 2015	

Structure, governance and management

Description of the charity's trusts

Type of governing document – dated 20/10/11	Articles & Memorandum of Association
How the charity is constituted	Company Limited by Guarantee
Trustee selection methods	Elected by members

Summary of the year

I am delighted to report that it's been a bumper year for ICP Support in terms of fundraising. This is due to the success of our 25th Anniversary celebration and in an increase in the number of people wanting to fundraise for the charity. In September 2016 we held our 25th Anniversary Gala Ball in London and we were overwhelmed at the support for it. Held at The Lansdowne Club in London, it raised £21,000 – an amazing amount! Other fundraising events included our popular, 'Afternoon Tea for ICP', with events bringing in over £1,600, school fairs over £2,800, and book royalties





A view of the Lansdowne Club at the 25th Anniversary Ball

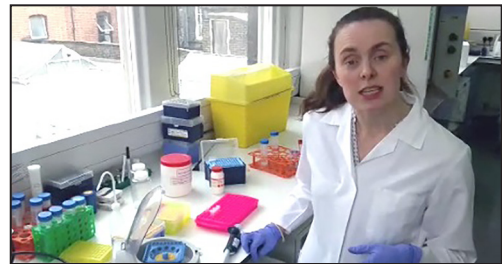
more than £1,050, as well as our usual running events.

Regular giving has continued to rise, from £3449 in 2015–16 to £4377 in 2016–17: an increase of 27%.

We have also seen an increase in company engagement, with events held at the workplace and matched funding raising over £1,100, and an incredible donation from The Wilmington Trust of £10,000 subsequent to a recommendation from a member of staff!

As our income has grown, so too as our ability to fund research and we were very pleased to approve research applications for:

- ◆ The purchase of a freezer at Nottingham University Hospitals Trust (City Campus) to store samples collected for ICP research
- ◆ The work of Dr Caroline Ovadia, Clinical Research Fellow at King's College London, who is investigating the metabolic pathways of ICP
- ◆ A data entry research midwife to start the input of data into a new database for all the ICP participants in Professor Catherine Williamson's study



Dr Caroline Ovadia

In total, we funded just over £30k towards research and we are thrilled that we have started to fulfil our aim of supporting and funding research into the condition.

In December, we co-hosted a conference on ICP with Professor Catherine Williamson that was attended by many doctors, midwives and researchers. This was a very successful conference and I was pleased to be able to share the views of women by presenting a short film on what women think about ICP research. The film, made 'in-house' and at very little expense, was well received by the audience and has been requested for use as a research training film within hospitals.

Our work with other organisations saw ICP featured in two films that were launched by Tommy's and Best Beginnings, meaning that thousands more women will learn about the condition and the importance of reporting itching in pregnancy.

Of course, as always, our primary aim is about supporting anyone affected by ICP and we continue to do this through our social media groups and support lines. We could not provide this vital support without our wonderful volunteers. As well as answering questions in the social media groups and looking after the support lines, we also have volunteers who run our social

stillbirth
gallstones
URSO
cholestasis
hormones
families
bile acids
heredity
liver
intrahepatic

media platforms (Facebook, Twitter and Instagram) and others who focus on fundraising. It is a big commitment to be a volunteer within the charity and we are incredibly grateful to everyone who gives up their time for us.

But we are also very grateful everyone else who supports the work we do, because without their input we wouldn't be where we are today. My thanks go to everyone involved who helped to make this such a successful year and we look forward to another bumper year!

Jenny Chambers (Chair)

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

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 over 2900 members, an increase of 600 from last year. The Facebook page had just over 3000 followers, an increase of more than 600 since last year.

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

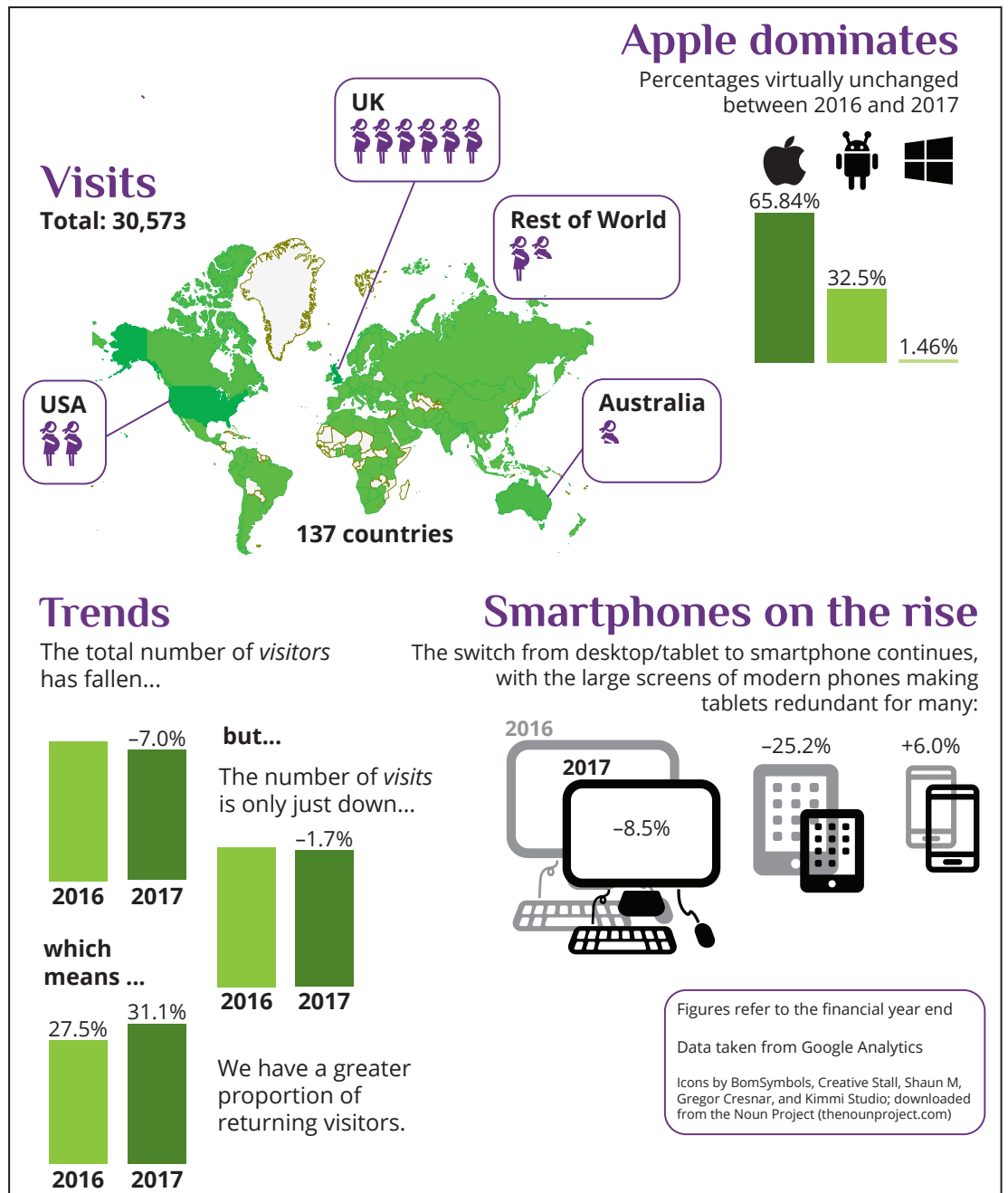
Information is also disseminated through Twitter and Instagram. The infographic opposite shows some of the trends observed from visits to our website.

Our Support and Information Line also continues to reach out to people in a unique way compared to the popular Facebook group. Our volunteer, Magdalen, who answers the calls, reports that the calls come in 'waves' with no apparent pattern, and she often deals with complex conversations. She takes care to ensure that callers do not think she is medically trained and she does not offer medical advice. Callers will confide difficult personal or family circumstances in addition to speaking about ICP, so it is also important that they know that what they tell her is confidential and if she needs to seek clarification about something she will let the caller know this. Our telephone volunteer has been answering these calls since 2011 and makes a point of never switching off the phone, so that callers always hear a ring and a friendly message even if it's not possible to answer immediately.

Over the last year, there has been a little over 40 calls, many of which last for 45–60 minutes. A steady theme is the lack of seriousness with which hospital doctors regard the condition and a continuing trend to ignore bile acids or insist that they are taken under fasting conditions.

Quite often, a father, grandparent or other family member will ring, because they can see their loved one suffering and find ICP Support after searching for further help and information.





How people access our website

To raise awareness of the condition (advancing education)

25th Anniversary

Our last Awareness Week was in March 2015. As the charity was originally formed in 1991 (as a support and information line) we made the decision to use 2016 as the year to celebrate our achievements and to use it as an opportunity to raise awareness. It was incredibly successful, raising just over £53,000 and we are very grateful to everyone who contributed to its success.



Leaflets

The generic leaflet has helped to raise awareness about the condition, as it has been distributed at fundraising events and health professional conferences. This year we took the opportunity to update the leaflet before reprinting it and we now have plans to ensure that our leaflet is available in all hospitals for women with ICP. We have pledged to provide the leaflet free of charge.

Media

Although it's been relatively quiet in this area because of capacity issues, we were delighted to have an article on ICP, written by Jenny Chambers and Alice Tuson, accepted in the Australian Midwifery press. This was a first for the charity.

Conferences and talks

We had a stand at the following conferences where we spoke to hundreds of health professionals about ICP and the work of the charity:

- ◆ Primary Care Conference, Birmingham
- ◆ Royal College of Midwives Conference, Harrogate
- ◆ European Midwives Association Conference, London
- ◆ ICP Conference, London
- ◆ London School of Obstetrics & Gynaecology (LSSOG)

Collaboration

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

- ◆ 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 – we were delighted to be in the development and launch of a short film called 'Always Ask' that encourages pregnant women to speak up about any concerns they have with their pregnancies
- ◆ Best Beginnings – The 'Our Chance' campaign has been hugely successful and ICP Support helped to organise the making of a short information film about ICP



The ICP Support stand at the EMA Conference

Promoting, supporting and raising funds for research

Promoting and supporting research

Through ethical approval given to Professor Catherine Williamson's studies based at Imperial College London, ICP Support is able to encourage and identify women interested in taking part in that research. This year over 100 women took part in varying studies via the charity.

Raising funds for research

Our commitment to research remains an important part of our charitable aims and as have previously mentioned this year we funded £30,650 towards research. Project include identifying the effect of ICP on the unborn baby's heart, looking at diet in ICP and funding a specialised freezer at Nottingham City for the storage of samples collected at that hospital for Professor Catherine Williamson's (King's College London) research into the condition, as well as for their own ICP research.



The ICP Support freezer at Nottingham City Hospital

Financial review

In the last year the financial resources of the charity have continued to grow, boosted by the 25th Anniversary appeal. As part of this appeal we made the commitment to give 50% of what was raised to research. The appeal raised £53,314, and 50% of this was placed in our restricted reserves. As a result, we were able to donate £30,650 (including the balance of unrestricted reserves) to three research projects. During 2016/17 our unrestricted income was £55,273, a significant increase of over 2016/17.

Operating expenditure has increased to £48,654. £8,000 was spent on paying for the Anniversary Ball, which raised such a considerable amount. There was also an investment in goods for resale, as the website upgrade allowed us to expand the use of the charity's virtual shop. The charity's office is well established and it is recognised that the cost of this will increase in 2017/18 as the office-share comes to an end. As part of the



Trustees' strategic plan for growth in January 2017 the office manager's hours were increased to two days a week. 2016/17 saw the first full year of this appointment, which commenced in October 2015, when the office manager was only working for one day a week. This accounts for the significant increase in salary costs.

At the end of the financial year we were able to appoint our first part-time CEO. This substantial funding commitment was fully costed and the Treasurer is confident that the charity has the resources to bear such an increase in expenditure.

Supporting ICP families is at the heart of what the charity does, and increasingly this support is given through social media and our website. The costs of maintaining this to our high standards have continued to rise, but this is in line with the Trustees' strategic objectives. We were pleased to deliver one of our key targets and spent £870 developing a short film on ICP. There was also a rise in the cost of attending conferences. Such events are expensive, but this is one of the main strands of communication between the charity and medical professionals.

There was a surplus of £6,619 in 2016/17. At the end of the financial year the charity has unrestricted cash reserves of £23,873. The reserves are sufficient to continue the work of the charity and to continue its strategic plan into 2017/18.

Future expenditure is anticipated to cover:

- ◆ Payment of day-to-day operational costs
- ◆ Financial support for fundraising activities
- ◆ The development of the support line
- ◆ Attendance at medical conferences
- ◆ Financial support for research

Policy & Reserves

An average cash balance of three months' expenditure plus any committed expenditure will 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:

Full name(s)	Jenny Chambers	Sian Eaton	Judith Gray
Position	Chair	Treasurer	Vice-Chair
Signature(s)			

		
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Date:	21/11/2017	21/11/2017	21/11/2017
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