

Patient, Carer and Public Involvement and Engagement



Professor David Adams, Centre Director "One of our key aims is to increase the interaction between patient groups and researchers as their input is invaluable and enhances our work"

Liver Focus newsletter: Research, clinical trials and stories:

- [Liver Focus Issue 5 \(/Documents/college-mds/centres/liver/Liver-Focus-Issue-5.pdf\)](#): (January 2015) Clinical trial participation by 19 year old Katharine, Hepatitis C drug breakthrough, PSC support, free events, Haemochromatosis support
- [Liver Focus Issue 4 \(/Documents/college-mds/centres/liver/Liver-Focus-Issue-4.pdf\)](#): A breakthrough for transplantation - livers are kept 'alive' outside the body
- [Liver Focus Issue 3 \(/Documents/college-mds/centres/liver/Liver-Focus-Issue-3.pdf\)](#): My husband died from fatty liver disease, now my son has it
- [Liver Focus Issue 2 \(/Documents/college-mds/centres/liver/Liver-Focus-Issue-2.pdf\)](#): Organ transplantation can change your life!
- [Liver Focus issue 1 \(/Documents/college-mds/centres/liver/Liver-Focus---issue-1.pdf\)](#): A current clinical trial for treating NAFLD

Liver Focus is produced twice a year by the Liver Patient and Public Involvement Panel.

2015 Future Events ...

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Queen Elizabeth Hospital Research Showcase Day, Wednesday 20th May 2015, 10am-3.30pm

Cost: FREE

This event just gets bigger and better every year! In 2014 there were giant inflatable organs, a Commonwealth Athlete and countless interactive stands! 2015 promises to be even better so come along and join in the fun, and find out what groundbreaking research we are doing right here in Birmingham to help improve the health of the nation, and the world. Activities are suitable for all ages and everything is completely FREE! Whether you're a patient, student, carer or just have a free day, then pop along. It all takes place in the main entrance of the new Queen Elizabeth Hospital. A map of all stands will be provided when you arrive.

PSC Support Day, Saturday 18th July 2015

Cost: FREE

See the 'PSC Annual Support Meetings' tab for full information.

Past Events ...

2014 Events



Meet the Scientist at Thinktank Science Museum, Thursday 30th October 2014

We hopefully inspired a future Marie Curie or Alexander Fleming by wowing children with some fantastic interactive experiments and games, driving their desire to have lots of fun, and learn about science!

Lecture: Your Astonishing Liver - Disease Investigation to Transplant Innovation. 11th September 2014



The British Science Festival came to the University of Birmingham in September 2014 and there were hundreds of activities taking place during this week long extravaganza of science and fun. Research scientists and surgeons from the UoB and the Queen Elizabeth Hospital presented a lecture on the history and development of liver disease, and an exciting new clinical trial we are involved with which could revolutionise the future of organ transplantation.

Photo above: Mr Barney Stephenson, surgeon, introducing the audience to a groundbreaking piece of equipment which is being developed for potential use in liver transplantation (image courtesy of Jon W Mueller)

University of Birmingham Community Day, 7th September 2014

The annual community day was moved this year (normally in June) to coincide with the British Science Festival. The team from the Centre for Liver Research saw about 400 people at their stand - in just one day! They unveiled new experiments and activities to help adults and children learn why their liver is so essential for life. 144 children took part in an experiment showing how bile works, and 237 adults learnt how diet can potentially lead to liver disease.

Queen Elizabeth Hospital Research Showcase Open Day, 20th May 2014

Commonwealth Athlete Somto Eruchie was the guest of honour at this event and he spent the day giving advice on how to get the body and health of an athlete. This was day brilliant for adults who also had the chance to talk with doctors, scientists and nurses about clinical trials we are running, cutting edge scientific news and liver disease. There was a £100,000 machine on show which is part of a trial to prolong the life of livers awaiting transplant into a patient. Visitors also had the chance to participate in some interesting activities which resulted in few raised eyebrows and visitor exclamations of "oh my goodness, I really need to rethink how much I eat!"

Haemochromatosis Enlightenment, 27th March 2014

A representative of the Haemochromatosis West Midlands Support Group met at the last Patient and Public Involvement meeting. Haemochromatosis can be a debilitating disease which impacts daily life, but support is available. To find out more see the [Haemochromatosis WM Support Group website](http://www.haemochromatosiswm.org.uk) (<http://www.haemochromatosiswm.org.uk>) or email them at info@haemochromatosiswm.org.uk (<mailto:info@haemochromatosiswm.org.uk>).

Research Awareness Day - Queen Elizabeth Hospital Birmingham 15th January 2014



Researchers and nurses from the University of Birmingham had a research awareness stand in the new Queen Elizabeth Hospital (QEH) recently to highlight the research they are undertaking, the clinical trials they run and the progress being made into understanding liver disease.

This event focussed on NAFLD, which is a form of liver disease that is on the increase in the UK and can be caused by obesity. [See the QEH's own write up on this event!](http://www.uhb.nhs.uk/news/research-awareness-day-proves-popular.htm) (<http://www.uhb.nhs.uk/news/research-awareness-day-proves-popular.htm>).

2013 Events

Meet the Scientist at Thinktank, Millennium Point, Birmingham 31st October 2013

Scientists, nurses and doctors from the University of Birmingham and Queen Elizabeth Hospital descended on [Birmingham's Thinktank at Millenium Point](http://www.thinktank.ac/page.asp?section=47§ionTitle=Visit+Us) (<http://www.thinktank.ac/page.asp?section=47§ionTitle=Visit+Us>) for one day only to show young visitors how viruses work and the how the liver functions. There were loads of hands-on activities for children to take part in and even some experiments!

A Virus in My Liver: Royal Society Summer Exhibition, July 2013



(<http://royalsociety.org/events/2013/liver/>). The prestigious Royal Society in London was where [Dr Zania Stamataki](http://www.birmingham.ac.uk/staff/profiles/iaudi/stamataki-zania.aspx) (<http://www.birmingham.ac.uk/staff/profiles/iaudi/stamataki-zania.aspx>) spent time presenting to children, teenagers and adults of all ages about the liver: how it keeps you alive, how it filters blood, how it can heal itself (!), and how viruses 'use' the liver. You can view one of Dr Zania Stamataki's talks by visiting the [Royal Society website](http://royalsociety.org/events/2013/liver/) (<http://royalsociety.org/events/2013/liver/>).

University of Birmingham Community Day, 9th June 2013

On a blisteringly hot day the campus at the University of Birmingham was full of the sounds of children as local families poured on site. Year upon year this event gets bigger and better with an estimated 12,000 people attending

this FREE day out.

The Centre for Liver Reserch stand was in the spectacular and grandiose setting of the Great Hall. Visitors from young children to adults took part in some fabulous new experiments designed by our scientists, and learnt why the liver is so vitally important to body health and that liver disease has many causes - it's not just alcohol!

Queen Elizabeth Hospital Showcase Day, 20th May 2013



The Showcase Day at the new Queen Elizabeth Hospital highlighted some of the innovative and revolutionary research being undertaken, much of it in collaboration with the University of Birmingham.

There were 33 different exhibition stands with some very amusing (and some very gory) activities.

2012 Events

Meet the Liver Scientist at Birmingham's Thinktank, 22nd October 2012

Crazy Experiments and Goey Madness: Science is FUN!

That was the message scientists and nurses from the NIHR Birmingham Liver BRU and Centre for Liver Research were passing on at Birmingham's Thinktank museum. The team are passionate about showing that science is fun and their enthusiasm was very infectious. Hundreds of children had the opportunity to dress up like a scientist and take part in real experiments. They learnt how the liver works and why we need it, felt a mock scarred (cirrhotic) liver, participated in games, made badges and asked questions to doctors, nurses or scientists.



L-R: Children guessing where body organs live, and visitors undertaking REAL laboratory experiments!

Seminar on Liver Research and Trials, 20th September 2012

The National Institute for Health Research (NIHR) are the research side of the NHS, it funds many initiatives throughout the UK and is driving research from bench to bedside for the benefit of patients. The NIHR Birmingham Liver Biomedical Research Unit hosted a free seminar on the 20th September 2012 focussing on some current studies funded by the NIHR. If you missed this seminar and would us to host another, then please [let us know](mailto:liverresearch@contacts.bham.ac.uk) (<mailto:liverresearch@contacts.bham.ac.uk>). You can still [view a summary of the talks \(Documents/college-mds/immunity/NIHR-Seminar-Summary.pdf\)](#) * in a PDF document. Academics (researchers), clinicians (medical doctors) and **members of the public** attended and talks were suitable for all levels of knowledge.

University of Birmingham's FREE Community Day, 10th June 2012



Each year the University welcomes our campus and find out what we do, as well as take part in some fun activities. Outside there were bungee robes, a myriad of giant inflatables, mini golf course, helter skelter, rock climbing wall and fairground stands.

Inside the Great Hall, our liver stand had lots of hands-on and interesting activities to fascinate, captivate and stimulate brains of all ages, and which showed the range of liver research undertaken at the University.

Research Open Day at the Queen Elizabeth Hospital, 9th March 2012

The NIHR Birmingham Liver BRU and Centre for Liver Research once again took part in this popular annual event. Many visitors came and tried our 'guess the units' game and learnt just how many calories there are in alcohol! Visitors also learnt more about our research.

Big Bang at the NEC, Birmingham, 17th March 2012

This event was aimed at children aged 5-18 years to show how exciting science and engineering can be. 29,000 children attended, many of whom were fuelled up on the free sweets being handed out. Our activities included an 'I'm A Celebrity' style box where children could blindly feel a normal liver compared to a cirrhotic liver (actually jelly filled with popcorn in!). Children learnt where organs live on our special organ tunic, and found out learnt why Homer Simpson may have a liver problem!



PSC Annual Support Meetings...

PSC Support is a patient led support group for people suffering from the inflammatory liver disease primary sclerosing cholangitis (PSC).

Support group meetings are hosted annually by the University of Birmingham with some of the world's leading researchers (who just happen to be based in Birmingham!) presenting and taking your questions. In 2015 this event will take place on Saturday 18th July in the new Queen Elizabeth Hospital Birmingham. If you wish to find out more or reserve your place and attend, please contact Martine Walmsley, Chair of PSC support, on martine@pscsupport.org.uk (<mailto:martine@pscsupport.org.uk>). Dr Gideon Hirschfeld will be one of the key speakers at this event. Gideon was featured in the latest issue of [Liver-Focus \(/Documents/college-mds/centres/liver/Liver-Focus-Issue-5.pdf\)](#) talking about his work and what inspires him, and one of his talks from the June 2014 PSC support meeting can be viewed below.

<https://www.youtube.com/watch?v=jVFmBzrtPvk> (<https://www.youtube.com/watch?v=jVFmBzrtPvk>)



(<https://www.youtube.com/watch?v=jVFmBzrtPvk>) At the 2014 meeting Prof David Adams, Dean of the University of Birmingham's Medical School, updated on our current research including the trials portfolio established through the NIHR Birmingham Liver BRU.

Birmingham are also a participating centre for the National PSC Genetics study.

The PSC Support [newsletter \(/Documents/college-mds/centres/liver/PSCGeneticsStudyNewsletterQ22011.pdf\)](#) has up-to-date information for all events and includes contact details.

Clinical Trials and Research Videos ...

The NIHR Birmingham Liver BRU undertake continual research into the causes of liver disease, and potential new drugs or treatments.



(<https://www.youtube.com/watch?v=Tg-ctAuc-6Q&list=PL7N0D2Uw2l0xlmwslSyausmuCOKQgexIW&index=10>) This video is the perfect introduction to the liver, what it does, why you need it, and the diseases that can cause liver problems. It also gives you a quick introduction to the work of our researchers. If you are interested in finding out even more, then visit <https://www.futurelearn.com/courses/liver-disease>



(<http://www.youtube.com/watch?v=lid2ZwGDG20&feature=youtu.be>) This is a more in-depth look at our work. Researchers from the NIHR Birmingham Liver Biomedical Research Unit introduce you to their work with patients, clinical trials, and the basic laboratory science being undertaken. This is an insight into a world leading liver research facility. If you want to find out more, email liverresearch@contacts.bham.ac.uk.



(http://www.youtube.com/watch?v=SRK1jC_ufJQ) Information on current and past current trials can be found in this short video which discusses (1) non-alcoholic fatty liver disease, (2) the use of stem cells to repair liver damage, and (3) blocking Hepatitis C particles infecting a new liver after transplantation.

To find out more about all our current clinical trials, [click here](#) (<http://www.research.uhb.nhs.uk/trials/>)

Get involved - your views are important!

Our grateful thanks go to the **Liver Patient and Public Involvement Panel** for their valuable contribution to Liver Focus, and for their dedication to the Panel's activities. If you would like to join the Panel, please complete the form at the bottom of this page.

We know that **your** views and opinions can help us to develop a better research programme. Our Patient and Public Involvement panel is a small group of volunteers who come together twice a year to listen to presentations from doctors on the latest liver research and hear how current clinical trials are progressing. They also suggest future research plans, help review patient information sheets and help produce articles for Liver FOCUS. We greatly value their ideas, suggestions and opinions. They also advise how we can best communicate our research findings to the public.

To find out more about this panel, and joining it, please complete this form:

GET INVOLVED! Review Panel Application Form:

Title

Mr

Name

Address

Address Line 1

Address Line 2

City

County / State / Province

Postcode / Zip Code

Country

Email

Telephone

I am interested in finding out more about the Liver Patient and Public Involvement Panel

I would like to receive initial information by email

Do you have any specific questions?

It would help us to know why you are interested in the Liver Patient and Public Involvement Panel. If you are happy to do so, please provide this information below

[*This is a summary of independent research funded by the National Institute for Health Research (NIHR)'s Birmingham Liver Biomedical Research Unit programme. The views expressed are those of the author(s) and not necessarily those of the NHS, the NIHR or the Department of Health]

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