

Issue 3

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Liver F.O.C.U.S

Factual, Open, Current, Useful, Straightforward

Welcome to *Liver FOCUS!* It will **inform** you about research taking place into liver disease at the National Institute for Health Research (NIHR) Birmingham Liver Biomedical Research Unit (BRU), provide **updates** on the progress of studies and **highlight** research activities, **whilst cutting through the medical jargon!**

IN THIS ISSUE:

- A family with NAFLD
- Warning Signs of Liver Disease
- Life After A Successful Liver Transplant
- Fatty Liver Disease: The Facts & Future
- Liver Disease Seminars
- Science is Fun!
- A Current Liver Clinical Trial
- FOCUS ON: Dr Phil Newsome, Liver Specialist
- The Ethics of Organ Donation
- I'm a Research Nurse!

My husband died from fatty liver disease and now my son has it. How new research is helping him to fight back

Caroline's* story of how her family has been affected by Non-Alcoholic Fatty Liver Disease



Non-alcoholic fatty liver disease (NAFLD) is on the increase in the UK due to the increasing number of diabetic and obese people. It is caused when the liver becomes diseased due to fat overload. It is already a huge issue in the USA which is one of the largest nations on the planet. Caroline and her family have experienced first-hand the devastating effect fatty liver disease can have, regardless of a person's age.

Caroline's story: Sebastian* was born in 1991. He was my second child and was always very active. From the age of about 18 months I noticed a difference in his behavior and at the age of 2 it was identified that he may be on the Autistic spectrum. At 9 years old Sebastian was diagnosed as having High Functioning Autism#.

I was advised by the National Autistic Society to give Sebastian a gluten free diet for several months which may help, but tragically his father died very suddenly and my world was thrown into disarray. Everyday tasks became a struggle so the gluten free diet stopped.

Sebastian's father had been clinically morbidly obese and the autopsy found cirrhosis of his liver. As both my son and daughter were slightly overweight, I raised my concerns with doctors and blood tests were performed at Birmingham Children's Hospital. My daughter was deemed healthy but a liver biopsy performed on Sebastian showed non-alcoholic fatty liver disease. His weight steadily increased over the following years and he was eventually classed as obese.

At 20 years old Sebastian was 5ft 8in tall (172cm) with a body mass index of 39. His future concerned me greatly and he was transferred in 2011 to the Queen Elizabeth Hospital Birmingham as they have a ground-breaking new piece of equipment called a Fibroscanner; this non-invasive machine can detect if the liver is scarred.

Following an assessment using the Fibroscanner the diagnosis confirmed that his liver was scarred and had progressed to non-alcoholic steato hepatitis (NASH) – this is the same disease his father had been diagnosed with. A second liver biopsy was performed under local anesthetic and the results gave doctors the information required to see just how scarred the liver was.



A Fibroscanner Machine

Despite NASH being a serious and life threatening disease, a light was offered to us. We were presented with a choice of two clinical trials to participate in. We decided to opt for the shorter 48 week trial which involved the daily injection of a drug already licensed as a treatment for diabetics.

Sebastian has now been on the trial** for a month and has shown great independence giving himself his daily trial medication, despite his dislike of needles and completing the daily diary.

Most encouragingly, his weight has reduced by nearly a stone. If this weight loss continues it will undoubtedly benefit his long term health.

With the determined efforts of Sebastian and the support of the Queen Elizabeth Hospital the future seems much brighter for my son and my family. Thankfully, Sebastian has not allowed his liver problems or autism to hinder his education and is now in his second year at College where he is specialising in BTEC 1 & 2 computing and life skills, and is progressing well.

* Names have been changed to protect identities

The National Autistic Society views Autism as "a lifelong developmental disability that affects how a person communicates with, and relates to, other people. It also affects how they make sense of the world around them". www.autism.org.uk

** Actual trial drugs, or pretend drugs (known as placebos) may be allocated during clinical trials. Please email LiverRessearch@contacts.bham.ac.uk for more information

Liver Disease: The Warning Signs

by Dr Andrew King



An unfortunate aspect of liver disease is that there are few early warning signs. The liver is able to cope with damage up until a very late stage without any noticeable symptoms.

The signs of early liver disease are usually vague and can be confused with other health problems, these include:

- Fatigue and general weakness
- Loss of appetite, nausea, weight loss
- Abdominal discomfort
- Itching

As liver disease progresses the liver is no longer able to cope with the demands placed upon it and is unable to perform its many functions.

The following signs may indicate severe damage to the liver and medical attention should be sought at once:

- Yellowing of skin or eyes (Jaundice)
- Swollen abdomen (can be due to a build up of fluid in the abdomen)
- Vomiting blood or passing black, tarry stools (can be a sign of internal bleeding)
- Dark coloured urine and/or pale stools (may indicate a blockage in the drainage of bile from the liver)

Many cases of liver disease are detected by blood tests so if you are concerned by any of these symptoms, then seek advice from your GP who may arrange blood tests to check the liver.

Health and Life After a Successful Liver Transplant

From a lifesaving organ donation in 2011, to conquering Snowdon in 2012!



In 2011 Chris Williams was taken seriously ill during a family holiday. For 20 years he had suffered with an autoimmune disorder that mistakenly attacks and destroys healthy body tissue, which led to the development of Primary Sclerosing Cholangitis (PSC). Unfortunately, this subsequently led to organ failure and a liver transplant was necessary to save his life.

It's now a year since Chris underwent a liver transplant and with the support of his wife, daughters and the Queen Elizabeth Hospital's Liver Unit, he has gone from strength to strength. So much in fact that he has just completed a 70 mile charity bike ride from his home in Shrewsbury to Mount Snowdon on the first anniversary of his transplant, and then climbed to the summit the next day. This has raised an incredible £7,278 for the Liver Foundation Trust at the QE and increased awareness of liver disease and the importance of organ donation.

Chris was discharged from hospital 10 days after his transplant and returned to work early in 2012. Chris is all too aware how the amazing gift of organ donation can transform lives, and will be eternally grateful to his donor and their family.

You can still donate: www.justgiving.com/Chris-WilliamsSnowdon

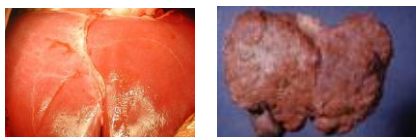
Fatty Liver Disease: The Facts & The Future

Liver disease is now the fifth biggest killer in England & Wales. It is the only disease in the top 5 that is still increasing year-on-year.

Fatty liver disease is commonly due to either excess alcohol, or non-alcoholic causes such as type 2 diabetes, obesity and high blood cholesterol (known as non-alcoholic fatty liver disease).

Identifying patients with no symptoms or 'silent' advanced liver scarring is difficult to do and has been a major challenge in general practice. Performing an invasive liver biopsy to assess scarring is not without risk to the patient.

Unfortunately, most patients do not develop any symptoms of advanced scarring until it has resulted in significant liver damage and complications.



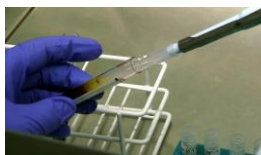
A healthy liver and an unhealthy liver

Liver function blood tests (LFTs) are frequently requested as part of routine chronic disease check-ups by GPs. If the result is an abnormal LFT with no obvious cause this is a trigger for further investigation.

The 'BALLETS' study is a UK funded project that is shedding new light on the meaning of 'abnormal LFT' in patients with no previous history of liver disease.

The Birmingham group of study patients was established in 2006. Many patients recruited for this study

either had no explanation for their abnormal LFTs, or were found to have excess fat collecting in their liver.



Are simple blood tests effective for identifying liver problems?

Developments in liver scanning and special blood tests have opened up new possibilities of identifying patients at risk without the need for a liver biopsy.

Using a Fibroscanner (a non-invasive and very accurate piece of equipment) and new blood tests, patients in the study will be invited back for further comprehensive health and liver assessments. This should allow doctors to establish what proportion of the patients have significant liver scarring, possible causes and whether original LFTs were suggestive of liver disease or not. It is hoped to see if the amount of liver scarring estimated in 2006 using LFTs, accurately predicted the development of any liver complications (such as liver cancer) over the following 7-8 years. It is crucial to establish whether these 'simple' LFTs are effective in helping GP diagnoses as the new tests and scans are very expensive and can only be requested if liver disease is seriously suspected.

To the best of our knowledge, this type of study has never been undertaken before and will provide important new information for the NHS. Furthermore the study will provide valuable guidance for GP's when managing patients with fatty liver disease and patients with unexplained LFTs.

The Latest Research Presented at a Free Public Seminar

by the **NIHR Birmingham Liver Biomedical Research Unit**

Three of the regions' most up and coming liver researchers recently held a free seminar on the clinical trials they are involved with. Dr Chris Corbett, Dr Matthew Armstrong and Dr Ian Rowe presented talks in a very interesting, clear and concise way so that everyone was able to understand their research and how it may affect the future of liver disease.

The seminar was hosted by the prominent liver specialist and researcher, Professor David Adams, and was held at the new Queen Elizabeth Hospital. Everyone was welcome including general members of the public, patients, transplant recipients and doctors. *Would you like us to run this seminar again? Email Liverresearch@contacts.bham.ac.uk*



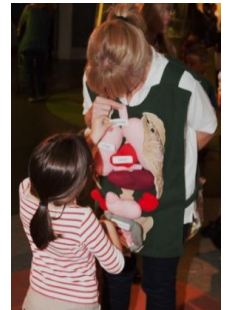
L-R: Drs Corbett, Armstrong & Rowe

Crazy Experiments and Gooley Madness: Science is FUN!

That was the message which scientists and nurses from the Centre for Liver Research were passing on at Birmingham's Thinktank museum recently. The team are passionate in 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.



Adults took part in games that highlighted the hidden calories in drinks from coffee shops – even the 'low fat' options! They also had the opportunity to show how well they know their alcohol by measuring a unit of wine, beer and spirits. Unsurprisingly, most over-estimated a unit and poured twice the actual amount!



Top: Nurse Sharon Wyatt educating where organs live. Left: Dr Janine Youster supervising experiments.

The team from the Centre for Liver Research.

A Current Clinical Trial Involving Stem Cells to Treat Severe Liver Scarring *(as featured on BBC News)*

Trial Name: 'REALISTIC'

Repeated Autologous Infusions of Stem Cells in Cirrhosis

REALISTIC is being undertaken at centres in Birmingham, Nottingham and Edinburgh and aims to look at the effectiveness of two new treatments in patients with severe scarring of the liver. The study will assess whether the new treatments help to improve the function of the liver, and reverse any damage which has occurred.

The Two Treatments

The first treatment involves an injection of a substance called GCSF, which helps release stem cells from the bone marrow tissue, and allows the stem cells to circulate around the body.

The second treatment is a variation of the first; GCSF is injected, but stem cells are then filtered from the blood and returned to the body. The hope is that the stem cells will make their way to the liver and help reverse any damage.

Patient Recruitment

The aim is to recruit 81 patients. So far, 30 patients have been recruited between the three centres. The study is due to end in 2016.

Taking Part

If you have liver scarring and would like to take part in this study then please email Liverresearch@contacts.bham.ac.uk. Doctors would be very happy to advise whether you may be eligible, and provide detailed information as to what is involved with participating in a clinical trial.

BBC News link: <http://www.bbc.co.uk/news/uk-england-birmingham-12095466>



FOCUS ON: Dr Phil Newsome

Liver Specialist at the Centre for Liver Research, University of Birmingham and the Queen Elizabeth Hospital

Dr Philip Newsome is a Senior Lecturer in Hepatology and Consultant Hepatologist in the Liver Unit at the Queen Elizabeth Hospital Birmingham. Phil has a long-standing research interest in the use of stem cells to promote liver regeneration and is the Head of Cell Therapy at the University of Birmingham. His clinical interests are liver transplantation and non-alcoholic fatty liver disease (NAFLD).

As well as his research and clinical responsibilities, Phil is Chief Investigator on a large clinical trial of adult stem cells in patients with liver cirrhosis, and on many drug trials in NAFLD.

Food For Thought: The Ethics of Organ Donation

By Greg Moorlock

From an ethical perspective organ donation may appear simple and clear-cut: donating organs allows patients to receive live-saving or life-improving transplants. If this is such a good thing, isn't it best to have as many organs donated as possible?

There are many things that might increase the number of donated organs but some are regarded as ethically dubious. For instance, paying people to donate their organs might encourage more people to donate but also raises concerns about exploitation and organ trafficking.

Some groups have argued that consent for organ donation is not important and that organs should be routinely retrieved from the deceased. This has raised strong concerns about respecting people's wishes and decisions about their bodies.

The current 'opt-in' donation system limits the amount of organs available. Moving to an 'opt-out' system where everyone must donate their organs (unless they 'opt out'), might increase the number of donated organs, but

raises some concerns about consent and personal wishes being respected.

There are many other arguments for and against organ donation and whilst generally speaking it is good to increase the number of donated organs, this must be done within the limits of what is considered ethical.

Saving and improving lives is important, but so is consent, respecting wishes, and avoiding exploitation. How these considerations are balanced is always open to debate which is why organ donation can prompt strong and conflicting opinions.

The UK organ donation system relies upon the generosity and goodwill of the public, so engaging the public in these ethical debates is vital when assessing the suitability of suggestions to increase donation rates.

For more information on organ donation, or to register to be an organ donor:
www.organdonation.nhs.uk

What do you think of the Liver FOCUS Newsletter?

- ✚ Are there any questions you want answering in Liver FOCUS?
- ✚ Do you wish to share an experience about liver disease?
- ✚ Have you undertaken any fundraising work for liver research?
- ✚ Do you want to suggest an item for the next edition of Liver FOCUS?
- ✚ Would you like more information about joining our Patient and Public Involvement panel (we reimburse travel costs)

Please contact Liverresearch@contacts.bham.ac.uk.

You can also visit www.birmingham.ac.uk/clr-ppi for further information

Other useful weblinks: www.birmingham.ac.uk/liver,

www.britishlivertrust.org.uk, www.northamptonshireliversupport.org

Who are the Clinical Trials Research Nurses in the NIHR Birmingham Liver Biomedical Research Unit?

Senior Research Nurse, Diana Hull

On leaving school my career choices were catering or nursing - I have now been a nurse for over 16 years. I actually became a research nurse by accident; whilst working on a busy haematology unit I was passed some information about a post in research nursing. I applied and the rest is history! My job satisfaction is from helping patients and trying to make a difference with their diagnosis, it can be a humbling experience as patients allow me to enter into their lives during traumatic periods. It's also fantastic to work in a team of diverse individuals with such outstanding skills. Out of work I am quite energetic (running marathons, playing badminton, climbing Machu Picchu etc), and also love to read thriller and horror books.

Research Nurse, Sharon Wyatt

I have been a nurse for 14 years, specializing in accident and emergency and intensive care work. Research studies are often carried out in critical care areas (e.g. A&E) which gave me an insight into research nursing. I was recently presented with the chance of a being research nurse role and jumped at it! I love being able to help others and make a difference. Out of work I belong to a running club, am a chocoholic and like reading autobiographies and spending time with my amazing friends.



Research Nurse, Kathy Guo

I have been in nursing since 1979 and am experienced in respiratory medicine, general surgery, urology, cardiac and liver critical care. I became interested in research nursing whilst undertaking an Msc in health sciences and have been a research nurse for the last 3 years. The thing I like most about the job is holistic care. We are able to spend more time with the patients and get to know them better than nursing staff on general wards. We try to help the patients not only from the clinical trial perspective, but also with their psychological needs. I'm currently working on 6 liver clinical trials, including REALISTIC and LEAN. I'm addicted to knitting and crochet in my spare time and also enjoy adrenaline kicking time in the Gym, especially Zumba classes!

The NIHR Birmingham Liver Biomedical Research Unit is a partnership between the University Hospital Birmingham NHS Foundation Trust and the University of Birmingham.

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We would like to acknowledge the Wellcome Trust Clinical Research Facility where many trials take place.

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