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Useful Contacts

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Chronic disease diagnosis inspired clinical trial participation

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PSC is a disease of the bile ducts in and around the liver. They become inflamed and obstructed which in turn causes scarring and hardening of the bile ducts (fibrosis).

It is a chronic progressive disease commonly found alongside Inflammatory Bowel Disease (IBD), which Katharine also has.

The cause and cure for PSC is unknown. As it is progressive, it can sometimes lead to liver failure which means a liver transplant could be required.

Despite the disease being in its early stages, Katharine was experiencing symptoms which impacted on her daily life including fatigue and discomfort around the liver area.

Many different medications were tried but unfortunately they had a negative effect on her IBD.
So, in early 2013 she was invited to participate in a clinical trial involving a new drug to hopefully ease the symptoms of PSC.

The drug concerned was also being tested to see if it could help with fibrosis of the lungs, as well as the liver. Katharine’s grandfather had been diagnosed with lung fibrosis so the dual-purpose of this drug encouraged her to apply in the hope it could be revolutionary for them both, as well as many others.

Before being accepted on a trial there is a screening process that takes place to ensure a participant is suitable. As a young adult, Katharine also had concerns how the trial would impact on her life at university and any possible side effects, so wanted to have these questions answered beforehand.

“At first I was dubious - the trial was two years long, did I really want to commit to something for that length of time?”

A consultant reassured her that life would hardly be affected during the trial and virtually no side effects were expected. The only problem was a weekly self-injection; something she dreaded but knew she could overcome.

After going through the screening process Katharine was accepted on to the trial. The first appointment was a daunting experience but Katharine recalls “I met my trial nurse who was lovely and very reassuring”.

“One of Katherine’s biggest fears was self-injecting”.

“I had never injected myself, so had to be taught. I was so worried and my nurse had to do it for me. Now, I never thought I’d be doing it so quickly and easily - I can do it on my own with no trouble at all”.

Katharine is now 19 years old and is still participating in the trial. “I’m really proud of myself for sticking it out! I’ve learned I can do something important, even if it does involve needles”.

Being diagnosed with a chronic condition is never easy, especially at such a young age, and clinical trials are not suitable for everyone. For those who are suitable, it is an empowering and motivating way to take part in revolutionary research that could benefit so many. Or as Katharine states,

“T’m not just taking part in this for myself; I’m doing it for everyone with my condition, their families and the people close to them”.

Could you be a ‘Katharine’? Speak to your consultant to find out what clinical trials are taking place, or email liverresearch@contacts.bham.ac.uk

QUICK LIVER FACTS:
Your liver acts like a chemical processing factory; it sorts out what your body needs, and what is toxic. It performs over 500 functions every day. Your liver is the only organ that can repair itself - but only to a certain point so don’t take advantage of its remarkable talents!

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In isolation, or in combination, it can cause arthritis, diabetes, chronic pain, loss of libido, liver disease, mood swings, heart disease, skin bronzing, chronic fatigue, muscle and joint pain, and abdominal pain.

Knowledge of this disease is not widespread, therefore sadly it is not understood by everyone. For most people, your diagnosis will be the first time they have heard of the illness.

As this is such a complex disease which can link to many areas of medical specialisms, its treatment can be difficult. A good GP is a huge asset so don’t be afraid to ask your GP what they know about Haemochromatosis.

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You can also join our volunteer group who work with us in a range of ways from preparing items for this newsletter, to advising on patient information sheets used in clinical trials. You don’t need any experience or special skills to volunteer, just an interest in liver disease. For more information on joining this group, please email liverresearch@contacts.bham.ac.uk. You can also visit www.birmingham.ac.uk/clr-ppi. The time commitment is about 20 hours per year, half of which is done from your own home via email.

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Countries such as Spain and Austria have an ‘opt out’ system which means that unless individuals have specifically stated they do not want their organs transplanted, it is assumed they automatically consent to donate.

Although figures vary, research available does seem to indicate that countries where presumed consent is in operation tend to have up to 30% higher donation rates than those where explicit consent is required.

Perhaps more contentious is the issue of authorisation from relatives. In England, even if a person has signed up to the donor register, relatives can prevent organs from being used.

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My PSC support group & me

By Kevin McCabe, PSC Sufferer

I was diagnosed with the autoimmune liver illness Primary Sclerosing Cholangitis (PSC) in 2003.

Living with a chronic illness raises many questions and medical professionals are well placed to answer many of them, but there is no substitute for the experience of others.

The first time I was inspired by another PSC sufferer was a few days after my diagnosis. The doctor who gave me the life-changing news explained that I may one day need a liver transplant. I had never heard of PSC before so after several failed internet searches (misspelling the disease!) I finally found some information. It wasn’t good and predicted a gloomy future. However, amongst it all was a blog from a man who also had PSC. He cycled a lot and had been diagnosed over twenty years ago. I cycled too so thought “if he can just get on with life, so can I”.

Following diagnosis I discovered ‘PSC Support’, which has a growing number of experienced members and an active online forum for questions and debate. A support group is a great resource of experiences and guidance on dealing with everyday challenges of life such as: How do I tell my employer? Where do I get travel insurance?

Being able to discuss issues with people who have actual experience is priceless. Medical experts are great at explaining the intricacies of the disease, but can never truly understand life as a sufferer.

The inspiring effect of others has continued right up to my recent transplant where a ‘thumbs up’ from a fellow patient as I was wheeled into the operating theatre really gave me strength. I’m so proud how PSC Support has helped my life, I even bought their sweater!

Martine Walmsley, Chair of PSC Support says: “The exchange of information and personal support between patients face-to-face at PSC Support meetings and in our online forums is inspiring.” Visit www.pscsupport.org.uk.

For liver related groups visit the British Liver Trust Website www.britishlivertrust.org.uk. The University of Birmingham also run an annual PSC Support group meeting hosted by clinical scientists. Details can be found at www.birmingham.ac.uk/clr-ppi.

FOCUS ON:
Dr Gideon Hirschfield

Gideon is a Senior Clinical Lecturer at the University of Birmingham and Queen Elizabeth Hospital Birmingham. He specialises in autoimmune liver diseases such as PSC, PBC and AIH. Alongside his clinical responsibilities and treating patients, Gideon works with a team of research scientists at the University of Birmingham who are looking into the causes of liver disease and possible new drugs or treatments.

Why did you decide to become a doctor?
Because it is an interesting job; it is one of those few jobs where even on your last day at work before retirement you may encounter a new challenge.

Why did you specialise in liver?
I was very lucky to do my clinical training as a student in Cambridge. My first medical attachment at the start of the clinical course was with the academic medicine team which included liver medicine, and then with the academic surgical team. It seemed pretty obvious to me at that point that I should do Transplant Hepatology as a career.

What is most gratifying about your job?
I am most satisfied after seeing patients with complex autoimmune liver disease, spending time answering their questions and educating them about their disease and the best treatments for them.

What upsets you about your job?
Admin … I’m not very good at filing or filling in forms. Seems such a waste of time!

What is the best piece of advice anyone has ever given you?
Try and finish what you start.

Why do you think medical research is important?
Whether you look after patients with common or rare diseases, patients need new treatments and we’ll deliver those new treatments only if we continue to do basic and applied medical research.

If you were 16 years old, what alternative career might you have chosen?
Tricky but probably a Lawyer.

What single advancement in liver treatments or research would you like to see in your lifetime?
Rational and effective treatment for autoimmune liver disease, preferably as a result of research conducted in Birmingham!

You can see Gideon and his colleagues talk about their scientific research and their work with patients in a new video which has been made by the National Institute for Health Research (NIHR) Birmingham Liver Biomedical Research Unit (BRU).

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References:  1 Abadie & Gay, 2006; Neto et al, 2007, Bilgel, 2012

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