July 2015

St George's University Hospitals MHS

ICIOIC

NHS Foundation Trust

Park

Contact details:

If you would like to contact me I am based in the renal department at St George's hospital.

Telephone: 0208 725 1919



Unfortunately it looks like the picnic in the park event on the 12th July wont be going ahead. We haven't received enough interest from young adults and so Guys and the Royal Free have had to pull out. We will definitely be rescheduling a ioint event for the near future but in the mean time I will get thinking about an event specifically for St Georges patients. It would be really handy if you could give me ideas of the sort of thing you might like so that I can cater to you guys.

Email: marielouise.turner@stgeorges.nhs.uk

facebook.

I'm really keen to get started on the Facebook group but I haven't had much response from you guys yet. It would be great if you would let me know the kind of things you would like this group to be used for.. And I would love it if people could send in suggestions for a name as I feel this should come from you.

I am looking for an editorial team!

I will monitor the page to make sure everything on it is appropriate but it would be great if anyone wanted to volunteer to be involved as group admins. Mainly I would want you help to make sure there is content going on to the group so that it remains interesting and relevant.

Ravenstor Weekend Away – Peak District

The Ravenstor weekend away has now been confirmed! And will be for three nights across the weekend of the 18th, 19th & 20th September.

The trip is FREE but places are limited so please let me know ASAP if you are interested in coming! This is open to young adult renal patients across the UK so places will be given on a first come first served basis.

It's a great opportunity to come away with other young adults from across the country. There will be a wide range of fun workshops and activities such as; archery, canoeing, walking, cycling. I will be going too so if you have any questions or want to have a chat with me about it just give me a ring or send me an email!

The **St George's Kidney Patient Association Mid Summer Ball!**

On Saturday it was time for the mid summer ball at the Oval cricket ground. I managed to fill our table with some of you guys and a few members of staff. It was a lovely sunny evening and everyone looked great! The KPA raises money for all areas of the renal unit—from the free TVs to the special equipment used in surgery. It's a fantastic cause and hopefully lots of money was raised. I'd like to say a big thanks to all those who came and hopefully we will have more YA events so those who couldn't join can get involved.



I saw these two articles in the Metro and the Evening Standard on my way home from work.. I thought it was interesting to see two news stories about kidney transplants in the same week so decided I'd attach them to the newsletter in case any of you fancied giving them a read. Its nice to hear about other people stories. I may see if I can catch the documentary 'Transplant tales' on iplayer. I'll let you know what I think, if it's worth a watch. If any of you want to tell your story or write an article about anything you think is relevant then I would love to include it in the newsletter! It doesn't have to be about kidneys!



Transplant: Charlotte Archer-Gay with her father Phil, who donated his kidney to her

Girl, 15, receives 'incompatible' kidney from dad in breakthrough

Ross Lydall Health Editor

A TEENAGE girl has told how her life was transformed after medical advances allowed transplant surgeons to give her an "incompatible" kidney from her father.

Charlotte Archer-Gay, 15, suffered from kidney failure and spent two years being hooked up to a dialysis machine four days a week, observing a severely restricted diet and unable to take part in sport and other activities.

But a pioneering method at Great Ormond Street Hospital for Children of "washing" her blood to remove antibodies and prevent it rejecting the kidney allowed the organ to be provided by her father, Phil Gay.

About a third of parent-to-child transplants are normally incompatible because of different blood groups, leaving the child having to wait years for a new organ. Charlotte's transplant is one of only 12 such operations carried out at Great Ormond Street.

Nizam Mamode, the consultant transplant surgeon, said: "I think this is the way forward if there is no other option. There are good outcomes and there is a very high chance of success," He added: "I can't tell you how

He added: "I can't tell you how satisfying it is when you see a child whose transplant is working well and who has been able to get back to a normal life and live life to the full. These children, and Charlotte is a very good example, have such potential. That potential is denied when they are on dialysis."

Charlotte, who lives near Romford. received the transplant in February. She is now back at school every day.

Her father's kidney was removed at Guy's hospital and immediately transported to Great Ormond Street. He was wearing a Bobby Moore T-shirt on the day in honour of his hero, the England captain who died of liver and bowel cancer, and Charlotte has named her new kidney Bobby.

Charlotte said: "Since receiving my dad's kidney my life has changed completely. I get to spend much more time with my friends and doing the things I love. I feel a lot more normal and makes me so happy.

"I can't put into words how grateful I am for what my dad did for me. It gives us a connection that not many people have and to say I am thankful would never be enough."

Mr Gay, 48, said: "I feel very privileged and very proud to be able to donate my kidney to help my daughter. Our hearts have been broken over the last four years seeing our beautiful daughter fight a terrible condition. The transplant's been a brilliant success and it's great to see Charlotte and the whole family living a normal life again. "We've benefited from first-class care

"We've benefited from first-class care and expertise from the transplant team and I hope our story helps to show the importance of organ donation." @RossLydall Swap op: Gary Robertson was able to get a kidney because of his wife Susan's donation PICTURE CASCADE

My wife had a surprise gift for me... a new kidney

by BILL GIBB

SUSAN ROBERTSON has given her husband Gary the biggest surprise of his life – a new kidney.

The 42-year-old hairdresser knew he would never ask, so announced her intention to donate when they arrived for a medical appointment.

'She was really my only potential live donor but it was a real shock,' said Mr Robertson, 45, who is the third generadon in his family to suffer from polycystic kidney disease.

'When she makes her mind up, though, it's very difficult to get her to change.'

Mrs Robertson said: 'Even before he went on dialysis I'd already decided I'd do whatever it took, and that included donating one of my kidneys.'

The couple were placed in a 'pooled' donation chain – in which matching donors swap organs – with two other A CANCER sufferer with only days to live has made a remarkable comeback thanks to a new wonder drug. Bill Sedgley, 73, was bedridden after his cutaneous T-cell lymphoma spread to his lungs and liver. However, the Warwickshire granddad recently enjoyed a fourmile stroll after one of the first successful UK trials of brentuximab.

couples. Helping her husband might mean denying a lifeline to the Edinburgh couple's two boys – Murray, 13, and Sean, aged ten – who have a 50/50 chance of needing a kidney.

'I don't know what the future holds,' Mrs Robertson added.

After the operation, her husband said: 'I've got my life back.'

Their story features in Transplant Tales on BBC One Scotland tonight.