

May 2017

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Deaf Awareness Week

15-21 May 2017

#DeafAwarenessWeek
actiononhearingloss.org.uk/daw



Lots of things coming up including social events and information days! Drop me an email or give me a call if you'd like to know more! =)

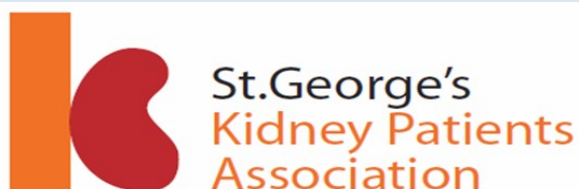
Polycystic Kidney Disease Information & Support Day!

When: Saturday 1 July 2017, 9:30 am to 4 pm — at St George's Hospital, the Monckton Lecture Theatre.

Hosted by: Dr Joyce Popoola, Dr Anand Saggarr and the PKD Charity

Everyone is welcome! Come to meet and share your experiences with others, put your questions to the experts and learn about ADPKD (Autosomal Dominant PKD), the latest research and the new drug, Jinarc (tolvaptan).

Lunch and refreshments included. There is no charge, but a donation is welcome to help cover the costs.



St George's KPA Annual General Meeting (AGM)

Saturday 20th May 2017

Time: 11am – 1.00pm

Where: H4.18c & 18d, Hunter Wing, St George's Hospital, Tooting, SW17 0QT.

Have your say! Discuss the current renal service situation, future plans and elect a new committee.

Speakers:



Gillian Norton
Trust Chair

Update on the St George's Foundation Trust Hospital & **its plans for the renal service.**



Daniel Jones
Head of the Renal Unit

The Renal Unit **achievements & plans**

Full agenda: www.sgkpa.org.uk

Young adult activity weekend

Ilam Hall – Peak District 2017

22nd to 25th September

If you're **18-30** and have had a kidney transplant or have a chronic kidney condition or are on dialysis you can come and enjoy an action packed **FREE** weekend at **Ilam Hall Youth Hostel**. Ilam Hall is an impressive country house in the heart of the Peak District.

- Meet other young adults from across the UK.
- Enjoy the wide range of activities that are on offer, including walking, arts and crafts, orienteering, rock climbing, bush craft, team challenges, karaoke, music, interesting workshops and lots of fun socialising.
- Weekend suitable for young adults with disabilities.*
- Staffed by experienced kidney nurses and youth workers.



"Awesome weekend away, met some great people and now have some epic memories. Can't wait for the next one."



How do I book my place?

To book or for more information email Kidney Care UK at info@kidneycareuk.org, write on the [young@NKF](https://www.facebook.com/young@NKF) Facebook page or contact the Young Adult Worker at your unit:

Marie-Louise Turner (Renal Young Adult Worker)
phone: 0208 725 1919 or email: marielouise.turner@stgeorges.nhs.uk

*The weekend is suitable for people with mobility issues and some disabilities. Please check with your young adult worker for more detailed information.

Stephen's Story

Cycling on Peritoneal Dialysis (PD)

I had dreaded this for months, but finally my renal consultant said: "It's time to start dialysis". Sleeping badly, poor appetite, feeling lethargic and rotten, I was facing peritoneal dialysis or PD - meaning the end of a normal, pleasurable life. In an act of bloody-minded belligerence, I bought a bike.

My first ride was soon after fitting the PD catheter. A wobbly 3 minutes 400m, but with 100m downhill where I felt the same 'whooshing' sense of freedom I did as a child.

After cycling a few months, I felt much fitter and healthier. A bit concerned about overdoing it, I spoke to my nurse and consultant. They said 'do as much as you like'. I could get on with life!

I live in the beautiful Lake District and used the hilly terrain to my advantage. Cycling can be tough, but only as tough as you want it to be. I cycled when I felt like it. I dialysed overnight and carried no fluid during the day, so PD didn't restrict my cycling - other than needing to be home each night.

My fitness returned. I'm 54 and rarely get serious PKD pain. Cycling alleviated the pain and helped with other symptoms. I felt better, had more energy and reduced bouts of restless legs (heck, they really make life miserable). But mainly, it's the sheer fun and emotional wellbeing that kept me on my bike. It gave me new purpose and new friends - I set up a cycling group catering for those of 'a certain age'. I set myself the target of 100km in a day, which I achieved on a charity ride in Cumbria.

Fast forward...

The above was written last year. Just before Christmas I got 'THE CALL' leading to a quick drive to the Freeman Hospital for a kidney transplant. It went well and I was out of bed the day after. Unfortunately, 4 days post transplant, I had a massive cardiac arrest, leading to me being in a coma for a few days, along with the fitting of an internal defibrillator in my shoulder and wires in my heart. The medical team couldn't find the cause of my heart trouble, it was just 'one of those things'. However, the physios



got me on my feet the day after being released from intensive care and soon I was back cycling. They put a stationary exercise bike at the bottom of my bed so I could hop on and gently pedal for 10 minutes at a time.

I am now home and it's tremendous to no longer be on dialysis, to eat and drink what I want, and feel so unbelievably grateful for each day. I've been back on the bike for relatively sedate rides. I have to return to fitness at a steady pace, largely because of the heart issue but each day I get a bit stronger. I know I am extremely lucky to survive a cardiac arrest. I am very, very lucky that a generous donor family gave me a kidney and I am very lucky the kidney survived my time in ICU - in summary I am the luckiest person I know! I also know the surgeons and countless others who helped me through the transplant didn't put that effort in so that I sit on my behalf for the rest of my life. The Freeman specialists said that one reason for my good recovery from transplant and cardiac arrest was my initial level of general fitness. Cycling and being fit when on PD may well have saved my life (in the UK the survival rate for cardiac arrests is only about 8% - and the hospital crash team worked on me for 40 minutes before my heart was properly going again). For me to survive, and to keep the kidney working and not to suffer brain damage...well...let's just say I had medics visiting me in hospital as my speedy recovery was indeed a rarity for them.

Yes I have a heart issue, yes I have PKD, yes I have a transplanted organ - but I will regain my fitness and yes I will enjoy the future.

Latest Tweets

RT @kaylout35: Charlie's school letter sent out yesterday. Hopefully people will get behind it & help me raise more awareness #pkd #BumpPK...



PKD Charity UK
about 3 hours ago

Read our PKD Charity News | #ADPKD Info Day, St George's London, 1 July 2017 | #ARPKD Family Day, Birmingham, 22...

<https://t.co/4sXH7kXQn>



PKD Charity UK
about 17 hours ago

PKD Charity News | 2017 #ADPKD Info Day #ARPKD Family Day - <https://t.co/34gkSvpVPj>



PKD Charity UK
about 17 hours ago

RT @kaylout35: Events I'm doing for @PKDCharity are :- 21st may 5k inflatable obstacle run. 26th may school fun day. 4th June ramathon hal...



PKD Charity UK
3 days ago