



kidneytalk

Guy's & St Thomas' Kidney Patients' Association Newsletter

LISTENING & LEARNING...

We recently held our AGM on 21st November 2015; I am pleased to report both of our excellent speakers: Sue Lyon, medical journalist and Dr Amy Carroll, kidney clinical psychologist, spoke to the audience about emotional support. They gave informative and thought-provoking accounts of delivering psychological services, and what 'being treated' feels like from the perspective of a patient.

Sue's kidney care (spanning nearly four decades) was and remains defined by gaining control over her condition through self-care and her trust in her clinicians, which began when she was first diagnosed in her 20's. Hope came from a clinician who took the time to understand the impact of Sue's kidney failure on not only her physical but also her emotional well-being. Acknowledging that patients need hope, amongst other things, to manage the adversity of a chronic disease is an ordinary and, yet, profound form of emotional care and support.

Dr Carroll informed us about psychological services for kidney patients within the Trust and also other forms of emotional support that may be accessed via GP services.

AGM attendees spoke of their appreciation when staff recognised they needed additional support, and other AGM attendees emphasized the fact that kidney clinicians are not mind readers and we, patients, need to tell our treating clinicians when we don't feel well and/or if we are not coping as we would like to.

The Trust has embarked on a programme to train additional peer supporters and to ensure patients are aware that they can access a fellow patient to provide support. Many of you may already have an established network of family, friends or other patients. However, if you want to talk, to an independent patient about a kidney related matter, please contact Ros Tibbles, Service Improvement Nurse on 020 7188 7552.

At this year's AGM, we were asked to clarify the agreed waiting times for patient transport and the actual reality for kidney patients. We will undertake this piece of work in the New Year and will advise in future editions of Kidney Talk, via the GSTTKPA website and notice board in the 4th Floor Kidney Clinic.

Many of you will know we held a Family, Friends and Staff Fun Day on 23rd August 2015. Baroness Doreen Lawrence attended in a private capacity to open the event. There were a range of traditional activities: face painting; bouncy castle; egg and spoon; sack and three-legged races and plenty of picnic and barbecue food. We will be holding another summer event and hope to see you there. Notices will be placed in Kidney Talk and in the Kidney Clinic.

Finally, on behalf of the GSTTKPA Committee, we hope you will find this edition useful. Please let me know, if you have any comments: chair@gsttkpa.org

Merry Christmas and Happy New Year!
Sonia Moorhouse, Chair, GSTTKPA

Fun Day Report

We are pleased to report that our first GSTTKPA Fun Day took place this year at the Kings College Sports Ground in SE London.

Predictably, despite it being the middle of summer, the afternoon started off with a downpour, however thankfully the sun soon re-emerged and everyone was able to make the most of the day. It was an opportunity for patients, staff, families and friends to get together in a relaxed setting. As well as the games described by Sonia above, there was



a home made cake stall, a clothes stand, face painting and an endless supply of food!

Additional activities included some extremely competitive sack races, egg and spoon races and five a side football. For those of you who haven't visited the King's College Sports Ground – it truly is a magnificent venue with excellent facilities for all weathers.

The intention is to hold a Fun Day each year in the summer and to include a range of activities and stands so that everyone has something that interests them!

My thanks to George Brown and Dela Idowu for their support in organising the day.

Henry Kimbell, Vice Chair

Polycystic Kidney Disease and TOLVAPTAN (JINARC®)

Recently, the National Institute of Health and Clinical Excellence (NICE) has approved a new treatment with Tolvaptan (Jinarc) for people with Autosomal Dominant Polycystic Kidney Disease (ADPKD). This is one of the commonest genetic conditions, and one which can lead to kidney failure, dialysis and transplantation. It runs very strongly in families.

Tolvaptan (Jinarc) received European prescribing authorisation in May 2015, based on the findings of the TEMPO 3:4 trial – the largest clinical study conducted in ADPKD to date. In this three-year study, tolvaptan significantly reduced the loss of kidney function over time, by limiting the rate at which kidney cysts expanded and reducing the likelihood of new cysts forming. It also led to reduction in kidney pain and cyst or urine infections.

NICE expects the NHS in England and Wales to make tolvaptan available to patients within three months of publication of its final guidance (scheduled for October), so this is by January 2016.

This treatment is expensive and it is only being authorised for use in selected patients. Those patients are people in whom the polycystic kidney disease has already started to cause mild to moderate kidney failure. So we can only use the new treatment for patients with CKD stages 2, 3a and 3b (this is kidney function of eGFR 30–90 mls/min which means your kidneys are working between 30% and 90%). It is not recommended for those patients who are close to, or on, dialysis, nor is it suitable for patients with a working kidney transplant.

The treatment has a number of side-effects. These include excessive thirst, excessive urination, low blood sodium and abnormal liver function tests. It will be necessary for all doctors who prescribe and monitor this therapy to receive specific guidance and training. It will also be necessary for patients to undergo regular blood monitoring to ensure that continued treatment is of benefit, and not causing medical side-effects and problems which should lead to its discontinuation. The long-term effects of taking this medicine are not yet known.



If you have ADPKD, and are attending one of our chronic kidney disease clinics, please do discuss this new development with your doctor, and ask him/her about whether you are both eligible and suitable for the treatment.

Professor David Goldsmith,
Consultant kidney doctor Guy's and St Thomas' NHS Foundation Trust

USEFUL LINKS

<https://www.nice.org.uk/>

<https://www.nice.org.uk/guidance/indevelopment/GID-TAG447>

<http://pkdcharity.org.uk/news-events/latest-news/217-nice-recommends-first-ever-drug-tolvaptan-jinarc-to-treat-adpkd>



As described in an earlier edition of KidneyTalk – the KPA is the beneficiary of a charity horse racing syndicate. The GSTTKPA Charity Partnership is a horse racing venture where two racehorses – trained by Grand National winning trainer Kim Bailey near Cheltenham – have been racing to raise funds and awareness for the charity over the last year.

17 shareholders have made a contribution to the charity when joining the partnership and 20% of any prize money won by either horse is also donated to the KPA.

Allez Encore - the first horse - has only been out of the first four

places in six runs for the charity - including winning twice earlier this year. Furthermore two of her six races have featured the charity on Channel 4 through our logo being displayed on the jockey's silks.

Whilst King Simba has raced four times for the partnership running with great promise but sadly not filling one of the top four places...yet!

The Partnership has raised £6500 to date and the objective is to hit £10,000 by the end of the season in May.

Both horses will be racing regularly between now and May so please keep a look out through the usual channels.

Henry Kimbell, Vice Chair

Grateful family call for more BME organ donors

The family of a man whose life was saved by a kidney transplant at Guy's Hospital are campaigning for more people from black and minority ethnic (BME) backgrounds to sign up as organ donors.

Their timely plea coincided with Transplant Week, which took place from 7th to 13th September. Tayo Idowu, 58 and from Dulwich in south London, had a transplant in 2014 after his kidneys failed. The operation was a success, reversing the decline in Tayo's health and ending his reliance on daily dialysis treatment.

A serious shortage of organ donors from BME communities means it can take far longer for suitable organs to be found for patients from BME backgrounds. Sadly, these delays mean that some patients die from organ failure before a transplant can take place.

Tayo and his family are sharing his story so that they can help others understand the importance of organ donation.

Tayo says: "The kidney transplant was truly life changing for me. After my kidneys failed I faced a very bleak future, but the transplant has given me back my health. I'm hugely grateful and I know I'm really lucky."

Following the transplant Tayo and his sister Dela set up the 'Gift of Living Donation'

organisation, which raises awareness of organ donation in BME communities. Dela is also a GSTTKPA Committee Member

Dela Idowu says: "The transplant gave Tayo a new lease of life and inspired us as a family to share our experience with others. We want to help promote organ donation and particularly to highlight the need for more donors from ethnic minority communities.

"We know that many people in these communities simply lack information about organ donation and how it can save lives. There's an urgent need for more donors from all backgrounds but particularly from ethnic minorities. We're determined to raise awareness and we believe that sharing our story helps other people understand why organ donation is so crucial."

Gift of Living Donation organises information events and produces resources aimed at combating myths and promoting organ donation to BME communities. The organisation also fundraises to improve the quality of life for dialysis patients in Nigeria.

Tayo's operation was performed by Mr Nikolaos Karydis, transplant surgeon at Guy's and St Thomas' NHS Foundation Trust.

Mr Karydis says: "It's fantastic that the transplant has been such a success for Tayo



and that his family have gone on to launch this campaign.

"Three people die each day in the UK while waiting for a transplant. For those from ethnic minorities the situation can be even worse because there aren't enough people from similar backgrounds on the organ donor register.

"Organs from the same ethnic group are more likely to be a suitable match for transplantation. This is why Gift of Living Donation's work is so important and why we're so keen to get more people from BME backgrounds on the organ donor register."

British Transplant Games - success for The Evelina VIPs



A group of 30 children from Guy's and St Thomas' attended the British Transplant Games held in Gateshead in July. All of the young people have had kidney transplants at The Evelina London Children's Hospital.

They successfully competed in a range of sports and came home with a grand total of 59 medals and a trophy for the 'Best Kids Kidney Team'.

The children's team is known as The Evelina VIPs (Very Important Penguins) as the transplant clinic is situated within the Penguin Zone of The Evelina Children's Hospital. All children who are well enough are actively encourage to compete in the transplant games and the team motto is "simply the best".

The British Transplant Games have been held every year since 1978. The event aims to demonstrate the benefits of transplantation whilst increasing public awareness of the need for more people to join the NHS Organ Donation Register and discuss their wishes with their families.

In early September a small group of Guy's young adult kidney patients made the journey to scenic Derbyshire to take part in an activity weekend which was fully funded by the British Kidney Patient Association (BKPA).

“Great weekend, what’s next?”

Steve (23)

The funding meant that more young people throughout the UK could take part and have the chance to enjoy the great variety of activities on offer as well as spend time with people of a similar age group.

Lots of the participants were first timers, as were some of the volunteers but despite feeling nervous they soon settled into the relaxed and welcoming atmosphere at Ravenstor Youth Hostel. I was really pleased to be able to take part again this year as there has been so much positive feedback from everyone that was involved.

“What a weekend, didn’t know what to expect, made some new friends and I now know why I’ve never been kayaking before. Thanks for driving us all there”. Dionne (23)

Next year’s BKPA Young Adult Residential weekend dates are already confirmed. It’s on the 17th/18th Sept 2016. If you’d more like information about this or the forthcoming Young Adult Ten Pin Bowling social event that’s planned for January then please contact me: vanda.fairchild@gstt.nhs.uk mobile : 07581 621 930 or call in to see me at the Kidney Clinic at Guy’s – just ask the receptionist to contact me on Ext 52722, or bleep 1965.

By Vanda Fairchild, Young Adult Kidney Nurse.

“So glad I didn’t miss this. Amazing to be with other people just like me and to not have to explain everything. When is next year’s booked for as I want to go?” Ben (19)



“I was pretty shattered after getting back on Monday afternoon and having to go straight to dialysis, but thank you for everything. The weekend has definitely helped me see things in a new light” Jack (20)



A TIME TO REMEMBER

Each year the kidney care unit at Guy’s and St Thomas’ holds a memorial service for those kidney patients who have died. On the 21st October 2015 the Guy’s Chapel was packed with over 70 attendees in honour of the remembrance service. These included relatives and friends of those who have died, patients, staff members of the kidney department and our wider team such as physiotherapists, dieticians, occupational therapist as well as the chaplaincy team and the representatives from the GSTT Kidney Patients’ Association.

We welcome all, though specifically, relatives and friends of patients who have died in the last

two years are invited. Indeed some have kept attending the memorial service over many years and feedback from them tells us that it brings them comfort and aids coping with their own bereavement.

The service consisted of religious and non religious content - readings from the bible and poems. For the first time the presence of a choir gave a magnificent addition to the musical content. Also a memory tree allowed individuals to write thoughts / memories of their loved ones and hang them on a lit tree - this will remain in the kidney clinic for the next few weeks. The theme of the address by the chaplain was fear

of death and loss - this provided an opportunity for timely reflection on our own lives in the context of our world today.

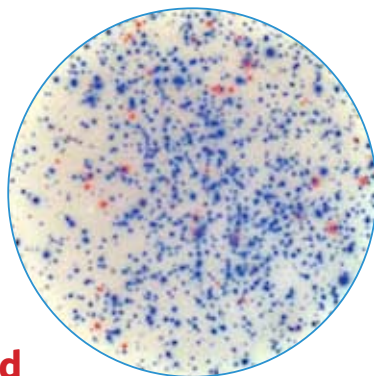
The candle lighting and multi faith prayers depicted serenity and solemnity. A retiring collection was made. Following the service all attendees were invited to stay for refreshments and conversation. We would like to thank the Renal Unit, the chaplaincy team, individuals and organisations who give their time and resources to support this important event.

For further information about the memorial service please do contact the renal supportive care team at Guy’s on bleep 0331.

By Winifred Yeboah and Sarah Watson, Renal Supportive Care Nurses.

THE PROTECT STUDY

Counting white blood cells to predict the risk of infection and rejection in kidney transplant patients



The PROTECT study is designed for patients who have recently (within the last 3 months) received a kidney transplant. The aim of the study is to assess the usefulness of two new blood tests that can measure the strength of the immune system, firstly in fighting an important viral infection called cytomegalovirus (CMV), and secondly in causing acute transplant rejection.

The first blood test is called the T-SPOT. CMV test and this measures the strength of a patient's immune response against the CMV virus. This may help predict how likely a patient is to develop CMV infection following kidney transplantation. CMV infection is both common and serious for solid organ and bone marrow transplant patients.

The new blood test is designed to help doctors more accurately assess and monitor patients who are at risk of developing CMV infection after transplantation and as a result help doctors know which patients are most likely to need protection with anti-viral drugs.

The second blood test is called the T-SPOT.PRT test. PRT stands for Panel of Reactive T cells and this test measures a patient's immune response to foreign tissue and so may help assess that patient's risk of acute rejection. Reducing acute rejection rates is critically important for transplant patients because rejection episodes can often irreversibly damage the transplanted kidney as well as being expensive to treat.

By using tests that have the potential to predict these complications it is hoped that the best treatment can be tailored to each individual.



The doctor in charge of The PROTECT Study is Dr Rachel Hilton and if you have recently received a kidney transplant she may contact you to invite you to take part. This is an observational study so there is no change to your routine clinical care. For further details contact: rachel.hilton@gstt.nhs.uk



Happy 40th Kidneyversary Judy!

You may remember that we featured Judy in our 2014 newsletter; she received her kidney transplant in 1975 from her mum and was one of the first patients at Guy's to have a living kidney transplant.

Judy has a son, Rob who is an anaesthetist and intensive care doctor at Queen Elizabeth Hospital Birmingham, married to Clara, also a doctor. Judy has just become a grandmother to Eric, her first grandchild.

Judy will be celebrating her 40th kidneyversary with her mum and husband, David.

Let us know how you celebrate your kidneyversary each year, just send us a short account of your story" together with a photo of your celebratory event for inclusion in Kidneytalk.



2016 DIARY DATES

World Kidney Day

Thursday 10th March – the theme is: "Kidney Disease & Children: Act early to prevent it!"

Virgin London Marathon

Sunday 24th April – The GSSTKPA have successfully filled seven charity bond places. Each runner will be supporting the charity through fundraising.

Vitality British 10K Run

Sunday 10th July – GSSTKPA have six charity bond places.

Ride London 100 cycle ride

Sunday 31st July 2016 - GSSTKPA have three charity bond places.

National Transplant Week

Date to be announced

National Kidney Federation conference speakers

This year the National Kidney Federation (NKF) held its annual patients' conference in Reading. It was a well-attended event with a focus on living life to the full.

Please access the link below to listen to the conference speakers:

<http://www.kidney.org.uk/about-us/conference/nkf-annual-patients-conference-2015-presentations/>



Martin Huber, a kidney donor at Guy's five years ago, generously decided to climb Mont Aiguille to raise funds for our charity. At just shy of 7000 feet – this was some achievement.

Until this year I had never got to the top of a mountain using my own power, other than when I walked up Snowdon in 1969. But at 5am on 11th July, I was on my way towards Mont Aiguille (6,841 feet). I would have preferred not to have been up at sun rise but I was happy to see a group of twelve wild boar racing along, in a field next to the road.

The climb would not have been possible without Christian, our guide. He was calm, supportive, professional, good-humoured and determined to make me realise I should go at a pace I was comfortable with (and that pace meant we didn't have time for a drink afterwards in the local bar!). I also benefitted greatly from the encouragement that Jean Marc (another of our group) offered me – whether up or down, my progress was 'superbe'. During the climb, both Christian and Jean Marc helped by pulling and/or pushing me!

We set off for Mont Aiguille at 6am, and the two hour walk took us along a trail through pleasant countryside but also up some 450 metres (approx. 1,500 feet). Then we got prepared, roped up, helmets on (against falls, loose rocks) and off we went. The ascent took approx. 4.5 hours. Through the day I faded from being happy and confident in the morning to weary in the evening, but the climb and descent was a wonderful experience. Christian led the way on the ascent, with me in the middle and Jean Marc at the rear. I could get some sense of where to find handholds and footholds from watching Christian and Jean Marc gave advice from Behind..

On the way, Christian said there would be a surprise at the top. I hoped it would be a plane to take me down, however, just as good, it was a bottle of the 'biere du vercors' to share. We



spent an hour over lunch by ourselves on the top, our only notable companion being a vulture.

I found the descent more difficult – perhaps because of tiredness, but more likely technique, as I was less confident in where to place my feet than when going up. For much of the descent, Jean Marc led, and could then advise me with footholds and handholds.

After the descent, the walk back to the car was excruciating! By now I was very tired and Christian and Jean Marc found me a walking stick and water from a stream to drink (we'd drunk all the water we'd brought with us)! Eventually, 14 hours after setting off we got back to the car. My body ached; my legs were covered in cuts and grazes and my knees were a livid red after being knocked against the limestone but it was all worth it. We later had a wonderful meal where we all celebrated our success.

By Martin Huber

So far Martin has raised £2,500 in sponsorship money for the GSTTKPA. You can make a donation at <https://www.justgiving.com/MartinClimbs>

To view a photograph journey of Martin's heroic feat visit YouTube and type in 'Mont Aiguille fundraising climb for GSTTKPA'.

How to contact the GSTTKPA

T 0207 188 7552

E chair@gsttkpa.org or info@gsttkpa.org

W www.gsttkpa.org



On the 22nd July last year I came into Richard Bright Ward at Guy's Hospital, and became a living kidney donor. Whilst this was a mammoth decision, it came with great reward and was life changing for the recipient. I was the 51st person to donate a kidney out of 78 adult living donor kidney transplants carried out at Guy's from January to December 2014. It's worth remembering that there are over 7,000 people on the UK national organ donor waiting list.

The process to become a living donor took about ten months; at Guy's only one in every two people who put themselves forward is fit enough or suitable to proceed.

The care and consideration I received was overwhelming and I have nothing but admiration for the amazing wonderful work the kidney team is able to do in helping to save lives and improve the quality of lives for patients with a kidney disorder. As a way to help me get back to my pre-op fitness and to show my appreciation to all the doctors, nurses and everyone else involved I decided to take part in the Prudential Ride London Surrey 100 mile cycle event. I had previously done the London to Brighton cycle ride but the London Surrey was a significantly different challenge, especially as I was still not 100% fit.

It was a great day with emotions ranging from inspiring, exciting, funny, scenic, hot and most definitely enduring. Collectively with a total of 114 sponsors; nine hours of pushing those pedals secured an amazing total including gift aid of **£5,203.20**. Thank you to everyone for showing their support.

Guy's and St Thomas' KPA help patients at all levels of their illness, as well as supporting research to help find cures for the various kidney diseases. Life on dialysis can be very limiting; holidays and travel require careful planning, you can't just take off for the weekend. The money I raised will go towards making life just a bit more bearable for kidney patients being treated at Guy's and St Thomas' dialysis centres.

By Sarah Marshall