



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

Organ Donation within the Black, African and Caribbean Community

On the 18th July 2016, Dela Idowu, GSTTKPA committee member, received a LIFEFFECTS star award for her work on raising awareness of living and deceased organ donation within the black community.



Dela has worked tirelessly to raise awareness of the importance of organ donation in the borough of Brent where there is a high percentage of people from the Black, Asian and Minority Ethnic (BAME) community. Some of her achievements include working with Brent Council to encourage their BAME staff to consider joining the organ donor register; working in schools to raise awareness of the importance of organ donation and she also teamed up with Tesco superstore Brent Park to engage and educate shoppers about organ donation. Many residents of Brent who had not previously considered becoming a donor have signed up to the organ donor register because of her campaigns.

Her biggest passion, though, is to increase the numbers of living kidney donor transplants for black patients with kidney failure. Dela is a member of the Living Donor Kidney Transplant 2020 Strategy Implementation Group and earlier this year approached the group to look into home-based education as a way of increasing living kidney donor transplants among Black and Asian patients. Home-based education is a successful and effective intervention

used in the USA and in the Netherlands. It has increased living donor transplants especially in BAME communities. As a result of the research on home-based education and the peer educator work done by Kidney Research UK; NHS Blood and Transplant (NHSBT) have funded the first UK home-education, peer educator led pilot.

Guy's Hospital kidney team are very enthusiastic about the intervention and its possible outcomes and agreed to become a pilot site for African and Caribbean patients enrolled on the programme alongside Queen Elizabeth Hospital in Birmingham, the pilot site for Asian kidney patients.

The peer educators are volunteers who have been living donors, living donor recipients, deceased donor recipients and those currently on the transplant waiting list. They hope by sharing their personal experiences in a home environment it will encourage family members to consider coming forward as a potential living donor.

The expectation is that the pilot will provide evidence to show that home-education is an effective addition to clinic based education and can be rolled out to other NHS kidney centres.

COME TO OUR ANNUAL GENERAL MEETING & FIND OUT MORE ABOUT YOUR KIDNEY PATIENTS' ASSOCIATION

**The Roben's Suite
29th floor Tower Wing
Guy's Hospital**

**Saturday
19th November 2016
10.00am – 12.00pm
(refreshments provided)**

**All kidney patients,
families and staff are
members of the GSTTKPA
and are welcome**

THE KPA'S EQUINE JOURNEY

The Guy's and St Thomas' Kidney Patients' Association added three equine supporters to its ranks over the last eighteen months.

This has been in the form of racehorses – Allez Encore, King Simba and Magic Money – who have been racing across the country, on behalf of the charity, to raise funds and awareness of kidney disease and the excellent kidney care provided by both hospitals.

This innovative concept was the suggestion of our 'racing fanatic' Vice Chair, Henry Kimbell. It has raised over £12,000 and produced victories at racecourses like Bangor on Dee and Plumpton as well as gaining the GSTTKPA airtime on Channel 4 Racing. Furthermore Committee members Sonia Moorhouse (Chair) and George Brown were invited to a charity lunch hosted by the racing partnership in May where they had the opportunity to meet King Simba and Magic Money as well as have chance to thank the owners in person.



Funds will be directed to support projects including the new £10,000 'innovation grant' the charity announced earlier this year. The grant has been split two ways and is directed at recognising previously unsupported ideas that directly benefit patients. The first successful application for funding is for an illustrated booklet for children living with parents or other family members with kidney disease. The second is spearheaded by the Renal Chaplains and focuses on progressing a service, as part of the Living Well Initiative, to improve the self esteem and confidence of adult dialysis patients.

Henry Kimbell, Vice Chair of the GSTTKPA and orchestrator of the racing partnership, explained, "I am delighted the Charity Racing Partnership idea has been so successful. It is a novel way of raising funds and awareness of kidney disease to a different audience and horse racing as a sport very much backs charitable initiatives like this."

The charity is extremely grateful to Kim Bailey, who trained the horses, and all of his staff and partnership members at Thorndale Farm near Cheltenham for working in partnership with us to launch this successful fundraising activity.

kidneytalk WINTER 2016/17

Double kidney transplantation

By Mr Chris Callaghan,
transplant surgeon, Guy's

Guy's Hospital has recently performed its 50th double kidney transplant. This is an operation where both kidneys from an adult deceased donor are placed into the same recipient. The outcomes after these transplants have been encouraging, and it is likely that more double kidney transplants will be performed in the future.



The number of deceased donors in the UK has increased over the last 10 years, and because of this, the number of patients waiting for a kidney transplant has slowly come down. Although we are transplanting more kidneys, half of deceased donors are aged 55 years or older. Deceased donors are now more likely to have other medical problems such as obesity, high blood pressure, and diabetes than they were ten years ago. We know that kidney transplants from older donors and those from donors with long term medical problems tend not to last as long as those from younger donors.

In order to improve the outcomes for kidney transplants from older deceased donors, Guy's Hospital started its double kidney transplant programme five years ago. The aim of a double kidney transplant is to provide more kidney function for the recipient than if they had received one kidney from that donor. This would be expected to keep them off dialysis for longer. This approach also enables the transplant team to consider transplanting kidneys from older deceased donors that they might not have considered suitable for transplantation five years ago.

The transplant team would consider a double kidney transplant if the deceased donor was more than 65 or 70 years old.

This decision depends on a lot of other factors such as if the donor had other medical problems and how good their kidney function was before they died.

The results of the double transplants performed so far have been promising. After a double kidney transplant at Guy's, more than nine out of ten recipients are off dialysis at one year after the transplant. Of those recipients that have had their double kidney transplant for three years or more, more than eight out of ten are dialysis-free. At one year after the double transplant, the average transplant function in these recipients is just as good as those patients who received a single kidney transplant from a younger deceased donor.

However, we know that a double kidney transplant is not suitable for all patients on the waiting list. It is a longer operation than a single transplant, and causes more blood loss during surgery. Elderly patients, and those with significant heart or arterial diseases, may not be suitable to receive a double kidney transplant.

If you are waiting for a deceased donor kidney transplant, please discuss whether or not you are suitable for double kidney transplantation with your kidney doctor and transplant surgeon.



“Absolutely brilliant opportunity”

Almost fifty young adult kidney patients got the chance to mix together at the recent residential weekend in Derbyshire. It was open to all 18-30 year olds from different parts of the UK. Seven kidney patients from Guy’s fully embraced the various activities that were on offer including outdoor pursuits, rock scrambling and abseiling. There was also lots of time for socialising, karaoke, bonfires and visits to the local Derbyshire tourist sites and the chance to make new friends. As well as all this, people participated in workshops; got the opportunity to find out about different research projects and the various kidney patient charities.

Kate, a young adult kidney transplant patient from Scotland passionately spoke about her personal journey and how she had lost her first transplanted kidney through not looking after herself. She gave a very inspiring, motivational talk.

The weekend was fully funded by a generous donation from the British Kidney Patients’ Association (BKPA).

Here is a selection of the quotes from some of the young adults who took part during the weekend:

Steve 24

This was a great experience and a lovely time. I have been before and I was quiet and shy in previous years but this year I’ve come out of my shell and have made way more friends.

Kate 22

Being a renal patient for 21 years, from a very young age, it is very easy to feel alone in your situation however having weekends like the one in Derby makes you feel part of a community of other young people who are going through the same things. It is so important to be able to talk about what you are going through and meet other people who you can lean on, support and become friends with. It was an incredible weekend all round and I thank the BKPA hugely for their funding to make the weekend happen.

Jake 18

The food was gorgeous and I loved it, I made new friends. I had the best weekend ever and everyone was so kind and caring.

Michael

Once more this has worn me out and once more I couldn’t be happier. Great event, great people, and lovely to see people from all walks of life getting along.

Sarah 28

Have had an amazing time meeting up with friends I met last year and meeting some amazing new people. This weekend is so inspirational because of the people you get to spend time with. I found myself pushing myself to do things like go on the climbing wall even though I hate heights. I am able to be free and relaxed and simply be myself. I wish we were able to have these weekends more often. I think having representation from the charities is so important to show the range of information and support available to young adults. I love this weekend and cannot wait for next year.

Keve 20

The Ravenstor young adult kidney weekend gave me the opportunity to meet other people like myself, with similar problems which has given me insight into the challenges I could potentially have in the future and how to overcome them. Summarising in just three words would be: inspirational, accommodating, enlightening.

Georgie

I have really loved this weekend and speaking with other young adults. I’ve met and made some new friends as well. I really enjoyed doing the abseiling and the scrambling and I will definitely be coming back next year. Also the food and accommodation has been really top notch, great staff and service too.

Hayden 18

I’ve got more independence and confidence being here. I was put out of my comfort zone but that was good. I’ve learnt how to communicate with others.

Holly 29

This weekend has been an absolutely brilliant opportunity. I feel like it was well organised particularly for me as someone who has recently started PD. I was appreciative of the efforts made to allow me to participate. Also appreciated being presented with opportunities to be involved in stuff like the young adult focus group, SPEAK study etc. It’s good to have information about these things.

For more information please contact Vanda Fairchild, Young Adult Kidney Care Coordinator; Tel: 020 7188 7188 Ext 52722 or Email; vanda.fairchild@gstt.nhs.uk

FROM OUR CHAIR...

I hope you had an enjoyable summer; the weather was glorious throughout August. I am pleased to report the 2nd GSTTKPA Fun Day was a great success attracting more patients than in the previous year.

As ever, GSTTKPA was supported by a number of runners for the London Marathon and cyclists for Ride London, which is fast becoming a prestigious, fund-raising event. Staff, relatives, carers and friends of kidney patients gave their time, effort and support to run and cycle to enable the GSTTKPA to help kidney patients. Thank you! The GSTTKPA is also grateful to all those who give funds 'In Memory' of a relative and we are mindful of their kindness during bereavement.

We have a recurrent budget to assist patients on dialysis to participate in social activities and to enable adults and children to compete in the British Transplant Games. In addition, we are funding two specific projects: to provide an accessible book for younger children, who have a parent/carers/sibling affected by kidney disease and via the chaplaincy to help patients who are finding it both distressing and challenging adapting to dialysis treatment.

In partnership with the Trust, we are trying to work up other spending plans, these include providing additional services for patients, who are reaching the end of their lives; emotional support for patients with a failing transplant and refurbishing Richard Bright's Patient Day Room. The GSTTKPA seeks to be prudent regarding planned spend and endeavours to work in partnership to accomplish projects.

During the summer, the GSTTKPA has continued to work with the Trust and Savoy, the contracted provider for Patient Transport. On the one hand, Savoy provided free transport to enable patients to attend the GSTTKPA's Fun Day, which was much appreciated, but on the other hand, there are still desperate on-going delays in transporting some patients, to and from the hospital or dialysis units, which is a significant cause for concern. The GSTTKPA



summer events



understands there is, now, a Transport Improvement Plan in place, and we are waiting to receive assurance that renal patients will be transported within the contracted waiting times. Please contact me, if you are affected by transport delays or other difficulties.

Finally, please note our Annual General Meeting will be held on 19th November 2016; 10-12 noon, in the Robens Suite. Hearing your voices helps us to prioritise your needs, so please attend. This year we will be hearing from two speakers talking about their experiences of live donation.

Sonia Moorhouse, Chair, GSTTKPA,
email chair@gsttkpa.org

NEW KIDNEY TREATMENT CENTRE OPENING AT SIDCUP IN 2017

Guy's and St Thomas' have had a temporary dialysis unit at Sidcup for some time situated in the grounds of Queen Mary's Hospital. We are pleased to be able to inform you that internal building work to convert an existing building into a kidney treatment centre has started. There will be 20 dialysis stations in the new centre which means that more patients will be able to dialyse closer to home.

The new centre is located at the east end of the main building in Queen Mary's Hospital, not far from the new Guy's and St Thomas' Cancer Centre which will be opening later this year. Car parking will be available nearby, free of charge. When this facility opens the temporary Sidcup dialysis unit will close.

The new centre will be managed by our commercial partner Diaverum UK and so it is likely that the current nursing team will not change. Kidney care will continue to be managed by the Guy's clinical team, as at present. The new centre will include an outpatient clinic so that more patients can be seen locally for their clinic appointments rather than having to travel into London.

We anticipate that the new centre will be open for patients next spring. It will be a vast improvement on our existing facilities and we hope patients will find it pleasant and comfortable.

For more information please contact Ros Tibbles, Service Improvement Nurse on 020 7188 7552 or via email: ros.tibbles@gstt.nhs.uk





Reviewing kidney care services across London – a patient’s perspective.

Staff and patients from Guy’s recently took part in an initiative designed to improve kidney care services across London.

The approach used is called “Peer Review”. It was first applied by a team of health specialists in the West Midlands. Experts from the West Midlands assisted with the London project and their input was invaluable.

The hospitals involved were The London (Barts Health), King’s, St George’s, St Helier, the Royal Free, Imperial and of course Guy’s. In each case, teams of staff from different disciplines looked at the service in the renal unit and reported back to a London-wide steering group. Each team included at least one patient to make sure that the perspective of service users was reflected.

I was involved in the reviews of the Royal Free and St Helier. The experience was very intensive. Each visit lasted two days and work began early in the morning and finished at about 6pm. I travelled to units far from where I live in Sydenham. Tottenham Hale and Crawley were on the list, though thankfully not on the same day.

The West Midlands work had developed quality standards based on national guidelines relating to renal services. The teams were there not just to rubber-stamp these services but to look critically at them to make sure patients were getting the best care possible and to suggest improvements where necessary.

The review teams got a warm welcome and tremendous support from staff at the various locations. Patients were a bit puzzled by all these strangers

turning up but some took an interest and made suggestions.

I was part of a team including doctors, nurses, pharmacists, technicians, counsellors and probably others I’ve forgotten. A senior doctor led each team, but everybody worked together, whatever their background.

The review teams found areas where things could be improved in all of the trusts. But they also found a very high standard of service carried out by dedicated professional staff across London.

All the units under review were willing to take on feedback and to make improvements where necessary. The review of Guy’s found “a very good service with strong outward-looking medical and nursing leadership”. There were positive mentions for our patient information and feedback and for our live donor transplant team, among other aspects.

The review process will clearly be adapted in the future. I think changes could be made to identify a clearer role for patients and local KPAs in the review process but peer review is a positive step towards improving patient care which we should support.



John Connor

John has been a kidney patient at Guy’s for over six years. He is a registered volunteer at the trust and a kidney Peer Supporter.

Reviewing kidney care services across London – the Guy’s experience

As John has explained, during the summer the seven London renal centres undertook a peer review process. A team of kidney care staff and patients visited Guy’s renal services in June. The visit included The Borough Kidney Treatment Centre and Forest Hill satellite dialysis unit. As John has mentioned, the review of Guy’s services was very favourable. We would like to share the high (and low) lights with you and give you some idea of our next steps.

The following areas were recognized as ‘good practice’:

- Patient information and patient feedback
- Transition of young kidney patients from children’s to adult services
- The living kidney donor service
- The SCALE weight reduction clinic
- The home haemodialysis service

Areas for improvement were identified as:

- The numbers of patients choosing to undertake peritoneal dialysis (PD) are low compared to the other London centre
- Some patients experience delays in interventional radiology procedures
- The Forest Hill dialysis unit was thought to be ‘cramped’ and short of space
- Updating of procedures could be more timely in some instances

We attended a ‘share the learning’ event at the end of October; our next steps include looking at ways to ensure patients are aware of the benefits of PD; improving access to interventional radiology and swifter updating of procedures. There are plans in place to open a satellite dialysis unit in Lewisham Hospital in 2017 at which point Forest Hill would close.

We all found the peer review process to be a positive and rewarding experience and we are particularly grateful to our patient participants.

By Ros Tibbles
Service Improvement Nurse

The British Transplant Games – Liverpool 2016

By Simon Bessant,
Guy's adult transplant games team manager.

The Guy's Adult Transplant Games team was made up of 15 competitors this year with ages ranging from 18 to people in their fifties. The team consisted of people with many years of experience as well as people at their first games. We also had 18 supporters that attended to cheer on the team. The games were held in Liverpool between the 28th and 31st July.



Thursday

We had four people competing on the Thursday and we made a good start by winning two medals (a gold and a bronze). More competitors arrived during the day so that everyone was ready for the opening parade and ceremony in the evening. After the opening ceremony the Guy's team headed into Liverpool for a team meal and then an early night ready for the first full day of competing.

Friday

The Guy's team had nine athletes taking part in 15 events. These events included golf, badminton, 10 pin bowling and darts. The team did really well and picked up nine medals (two gold, two silver and five bronze). The team was competing at different venues throughout the day but we all ended up at the social event where everyone enjoyed themselves and caught up with friends old and new.

Saturday

It was a very mixed day of sport on the Saturday with volleyball and table tennis in the morning and football and swimming in the afternoon. This was the first time we had entered a volleyball team for a few years and as expected we didn't do very well but we all had a good time and we are looking to enter the volleyball tournament in November. In the afternoon our secret weapon was released with Nicole and Gill taking part in ten swimming events and coming away with seven golds and three silvers! A great effort from our two swimmers! On Saturday evening, we went out for a round of Crazy Golf with everyone having a good time and enjoying each other's company.

Sunday

Sunday was track and field day; we had three competitors and they did not fail to impress winning four silvers and a bronze. In the 4x100m relay, the team came away with a bronze which was a fantastic effort as we were up against some of the best sprinters at the games. After that excitement all that was left to do was get dressed up and head to the gala dinner to finish off a great weekend. There was one final surprise left to come with Nicole (first time at the adult games) winning the Best Adult Female medal! We finished the evening off with a few drinks and danced the night away wishing the day would never end.

This was one of the best years for the Guy's team with ten Golds, ten Silvers and 11 Bronze medals as well as the Best Adult Female! I believe that if we can keep this team together, with the addition of a couple of extra athletes, we could have a chance of winning the Best Team medal.

I didn't think that this year could get any better but in the last couple of weeks the Great Britain and Northern Ireland team has been announced and out of the 15 competitors from Guy's, eight have been selected to represent their country! The Guy's adult team is now raring to go for the 2017 British Transplant Games in Scotland!

The only thing left for me to do is to say "thank you" to the GSTTKPA for funding us, the team would not have been the size it was, or done as well as we did without your support. I hope that you will be able to continue to support us in the years to come.

If anyone is interested in joining the Guy's adult transplant games team, please email: info@gsttkpa.org and we will put you in touch with the team.