



# kidneytalk

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



## Bonjour!

**On the May 4th 2013, my boyfriend Tim and I completed a London to Paris cycle ride to raise money for the Guy's and St Thomas' charity, we asked for the money to be utilised by the kidney unit at Guy's hospital and also the Kidney Patients' Association.**

We set off at around 7.30am from outside Guy's Hospital, where I had very gratefully received my donated kidney from my mother six months previously. The weather was

amazingly sunny and we seemed to get out of London in no time arriving at Portsmouth by about 6pm where we boarded the overnight ferry to Le Havre.

We were graced with fine, sunny weather in France and we set off again at around 8.30am. It was a slow morning trying to figure out our best route out of the port towards Paris; however it did enable us to ride through some beautiful villages. This seemed to help distract from the enormity of the hills we were climbing! After another nine hours of cycling, we settled down that evening to a nice hot bath and some supper to recharge our batteries for our final day of cycling (fingers crossed)!

Day three came; we set off early, making great progress as the roads were definitely flatter on this last leg. We finally arrived in Paris at around 5pm, making our finish line the famous Eiffel Tower! We really enjoyed the challenge and were so fortunate to be blessed with wonderful weather and stunning scenery in both the UK and France.

I feel very lucky to have been able to do this challenge, and it would not have been possible without the care and skills of the staff at the Kidney Clinic at Guy's Hospital. My Mother and I are truly thankful for the successful transplant that was performed on 30th October 2012. As a token of thanks we have managed to raise just over £1700 for the Guy's and St Thomas' Charity via donations from friends, family and work colleagues.

**Kay Tomlinson**

Kidney Patient, Guy's Hospital



To celebrate National Transplant Week the KPA joined forces with representatives from the Organ Donation Team to raise organ donation awareness and encourage people to sign up to the Organ Donor Register.

We had a stand at Guy's Hospital Foyer on Monday 8th July and also at St Thomas' Hospital on the 11th July. There was quite a lot of engagement with patients, staff and members of the public. It was a very successful and encouraging two days with many people signing up to the register there and then and many more who left with the required information to help them make their decision.

If you or a member of your family would like to sign up to the Donor register or find out further information you can do so online at [www.transplantweek.co.uk](http://www.transplantweek.co.uk)



## Specialist Nurses for Organ Donation (SNODs)

### Who are they and what do they do?

You'll find us working in the critical care areas of the hospital, most often in the Intensive Care Unit and Accident & Emergency Department as it is in these areas that organ donation may be an option, when nothing else can be done to save that person's life. In this sad situation, when recovery is not possible, the focus of care is to provide comfort at the end of life and to fulfil the patient's wishes.

Families who go through this difficult experience sometimes describe it as 'an emotional rollercoaster'. This is because as well as their grief for the person lost, they may also experience a range of other emotions such as anger and guilt, which can be confusing and upsetting.

When someone we love is dying there can suddenly be many decisions to make. The decision about whether or not to help others through organ donation and transplantation is just one example. Our role is to support families and staff through this decision making process. We do this by listening and providing information in response to families' needs.

More than half of the families who are approached say "yes" to organ or tissue donation. The experience can often give some sense of meaning to their loss. However, although 90% of the UK population say they support organ donation, only 28% are registered on the organ donor register. The decision for a family to agree to organ donation can often be made easier if the wishes of their loved one are known. That's why it is important that everybody discusses their wishes with their families and friends.

If you'd like to help others after death by donating your organs please discuss your wishes with your family and register online [www.organdonation.nhs.uk](http://www.organdonation.nhs.uk)

Every hospital in the UK has a SNOD attached to it and so every bereaved family in critical care has access to this highly trained and experienced specialist support. We are also available for information, teaching and to help raise awareness of organ donation:  
[cara.murdoch@gstt.nhs.uk](mailto:cara.murdoch@gstt.nhs.uk)  
[katrina.kesek@gstt.nhs.uk](mailto:katrina.kesek@gstt.nhs.uk)

# GAMBIT Study

Clinical research is crucial to the advancement of medicine. As an example of one of our many research studies in kidney transplantation, we would like to introduce you to the GAMBIT study which is being carried out at Guy's hospital. This study received support from the KPA last year as well as long standing support from the Medical Research Council and from Guy's and St Thomas' Charity.



Kidney transplantation is an important treatment for children and adults with kidney failure. Although most patients need to take immunosuppressive drugs for life to prevent transplant rejection, some patients may become "tolerant" to their transplants. This is a state where, even without immunosuppressive drugs, the immune system does not recognise the transplanted kidney as "foreign". If we can identify patients who are "tolerant", we may be able to reduce or even completely

stop immunosuppressive treatment and this would avoid unnecessary side effects.

We have collected and analysed samples from around 400 patients who have received a kidney transplant. We have identified specific "markers" in a small number of patients who have been able to stop their treatment but still maintain good kidney function. We could potentially use these markers as a screening tool to find other tolerant

patients and decide whether these patients might be able to reduce or stop their immunosuppressive treatment.

We are currently developing a clinical trial to properly test these markers in the clinic. This could help some patients to reduce the unwanted side effects of medication including the increased risk of infection and cancer. For more information, please contact Dr Maria Hernandez-Fuentes [maria.hernandez@kcl.ac.uk](mailto:maria.hernandez@kcl.ac.uk)

## FREE internet access for patients, visitors and staff

Free WiFi is now available across Guy's and St Thomas' including the Evelina London Children's Hospital; Camberwell, New Cross Gate, Tunbridge Wells and Borough Kidney Treatment Centres.

By connecting to the WiFi SPARK network through a laptop, smart phone or tablet, you can:

- Access personal emails
- Browse the internet:
  - Visit the KPA website: [www.gsttkpa.org](http://www.gsttkpa.org)
  - Keep in touch with the KPA via Facebook and Twitter
  - Check out GSTT kidney information for patients on: [www.guysandstthomas.nhs.uk/our-services/kidney/patients/patients.aspx](http://www.guysandstthomas.nhs.uk/our-services/kidney/patients/patients.aspx)

WiFiSPARK

### TO CONNECT:

- Look for the **WiFi SPARK** hotspot wireless network in the settings on your smart phone, tablet or laptop
- Connect
- Enter your name and an email address
- Accept the terms and conditions

You are then automatically redirected to the internet which can be used in the normal way.

At Sidcup and Forest Hill dialysis units free WiFi is available but on a different network, please ask staff for details.





**The KPA have endorsed this very moving book which has been written by Dela Idowu about her experiences as she tries to become a Kidney Donor for her brother. This is a very interesting and thought provoking book and if you would like to receive a free copy please contact:**

**Email:** Bernadette.lynch@gstt.nhs.uk

**Telephone:** 0207 188 5667

## **Hugh Lyon** 1949 – 2013

It is with sadness that the KPA announce the death of Hugh Lyon in Worcester where he had been living for a number of years. Hugh was a past committee member and founding chair of the KPA.

Hugh was the carer for his wife during her nine years of home haemodialysis while living in Charlton, SE London. He was involved in setting up the Guy's Hospital Kidney Patient Association and was a committee member for a number of years. Indeed, until his premature and sudden death, Hugh was one of the very few surviving original founder members of the old Guy's KPA.

Hugh was a prime mover in establishing the first Guy's holiday caravan at Sandy Bay near Exeter which was used by home dialysis patients who otherwise would not have been able to have a holiday.

It is thanks to his leadership in the early days that the GSTTKPA has been able to flourish and develop into the successful charity we see today. We owe Hugh a debt of gratitude for his founding work and his continuing support since that time. Our thoughts and sympathies go out to his family and friends.

# **UP AND COMING EVENTS FOR YOUR CALENDAR**

## **London Marathon 2014**

Next year's London Marathon will be on Sunday April 13th 2014. The KPA have five gold bonds and if anyone is interested in running for the KPA and would like an application form or just more information then please contact:

**Bernadette Lynch**

**Email:** bernadette.lynch@gstt.nhs.uk

**Telephone:** 0207 188 5667.

The closing date for applications to be considered will be Monday 16th September.

## **KPA Raise Awareness Week Monday 16th Sept – Fri 20th Sept**

In an attempt to promote the KPA and raise its profile the KPA will be launching a week long raise awareness event. We will be visiting all our satellite dialysis units, Kidney Clinic, Renal Wards as well as having a stand in Guy's Foyer and

St Thomas Hospital. Committee members will be on hand to give out promotional merchandise, information and also answer any questions that patients, staff, relatives and friends have regarding the work of the KPA.

## **KPA Annual raffle 2013**

Tickets are now on sale for the KPA's annual raffle. Last years raffle was a great success and we are hoping to sell even more tickets this year. The prizes are:

**1st Prize** – £500.00

**2nd Prize** – iPad mini

**3rd Prize** – Kindle

More prizes will be announced depending on donations that we receive.

If you would like to purchase tickets please contact:

**Bernadette Lynch**

**Email:** bernadette.lynch@gstt.nhs.uk

**Telephone:** 0207 188 5667

Last date for purchasing your tickets will be Tuesday 1st October 2013 and the draw takes place on Thursday 17th October 2013.

## **Transplant Games Sheffield Thurs 15th – Sunday 18th August 2013**

Guy's & St Thomas adult transplant service and the Evelina Children's' service will be sending teams to compete in this four day event. This annual event is very popular with patients, families, friends and staff and we wish them the best of luck in this year's competition.

New Cross Dialysis Unit are holding their annual BBQ on Sunday 27th July 2013. We hope this event will again be successful and that the sun shines for them on the day.

Camberwell Dialysis Unit will be taking patients on a trip to Brighton on the 18th August 2013. This is the second year running that they have organised this trip as it proved to be so successful last year.

Tunbridge Wells Dialysis Unit are hoping to take their patients on a coach trip to Eastbourne on the 18th August and this will coincide with the Eastbourne air show.

All the above events are supported by the Guy's & St Thomas Kidney Patients Association.