



# kidneytalk

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

## Giving and spending

**The Kidney Patients' Association is a charity devoted to fund raising and supporting projects to enhance quality of life for kidney patients and their families.**

Over the years quite large sums of money have been raised and spent on life saving research, pieces of equipment and even extra staff without most patients actually knowing about it.

The KPA would like to acknowledge and thank all of those people who have given or helped to raise funds over the years. This newsletter tells you more about how we are currently spending KPA monies and highlights some of the more recent fund raising activities.

If you are able to help the KPA by contributing time or resources please contact us or visit our website for more information: [www.gsttkpa.org](http://www.gsttkpa.org)

**Trevor Cook**  
Chair GSTTKPA.

## What do you know about The Transplant Games?



**The British Transplant games have been staged annually since 1978 and take place in a different UK city over four days during the summer.**

Anyone who has received a transplant can enter.

Participants can compete in a variety of sports from athletics, swimming, badminton and tennis to bowling, snooker, darts and possibly (as in one previous year) bobsleigh! The list continues.

The aim of the games is to celebrate the success of transplantation. Some people go to The Games to win medals, having trained well in advance, while others go just to take part and enjoy themselves.

Those competitors who do exceptionally well in The British Transplant Games form a team to

represent Great Britain and Northern Ireland at the World Games which are held every two years.

Guy's and St Thomas' have a very successful adult team winning seven gold medals at the 2010 Games in Bath and five members of the team have been selected to represent Great Britain at the 2011 World Transplant Games in Sweden.

The KPA provide financial support to both the children's and the adult Guy's and St Thomas' teams.

To find out more about The Transplant Games (adult), contact **George Newman**: [Georgenewman1@hotmail.co.uk](mailto:Georgenewman1@hotmail.co.uk)

# The Charity's work



**The Charity receives a considerable amount of money donated by patients, relatives and others. There are also amazing gifts from people who run marathons, climb mountains, manage collections in railway stations, hold coffee mornings or simply have a whip round in the pub.**

This money is used to benefit the kidney patient community. We aim to fund projects that benefit groups of patients rather than individuals. (BKPA are often able to help with more individual needs).

So, what have we funded over the last few years? Our major and most important area of expenditure is research into kidney disease how it might be prevented or at least better managed. About £500,000 has been committed to supporting the Medical Research Council (MRC) Centre for Transplantation here at Guy's which is doing ground breaking work from which patients have already benefited or may do so in the future.

On a smaller scale we support the Ronald McDonald House which is a facility for families with young patients who have to stay over in London while treatment is carried out at The Evelina Children's Hospital at St Thomas'. Each of the Dialysis Units receive an annual allowance of £500 to spend on social events – such as celebrating the Royal Wedding, BBQs, trips out etc.

We encourage and support the Transplant Games – and generally win most of the medals!

We are working in partnership with Blind Aid to offer support to blind and partially sighted kidney patients. Blind Aid offer a home visiting service; help with equipment and advice about living with visual impairment.

Next year we aim to look at how we can offer kidney patients help and advice about managing some of the everyday issues that affect us all. We are planning to hold a patients' conference on World

Kidney Day focussing on the non-medical aspects of living with kidney disease such as going back to work, continuing with education, volunteering or starting a new hobby. Foster Brown Associates, experts in supporting people back into work following illness, will be on hand to help with legal advice, interviewing skills and CV writing. They will also offer tips on how to negotiate part-time hours with employers, manage hospital appointments etc. This should be a really exciting event.

If you or your family / friends wish to help the KPA please visit our website [www.gsttkpa.org](http://www.gsttkpa.org) to find out how to give.

**By Trevor Cook**  
Chair



To all at KPA,

I would like to thank you for your kind donation to help fund my trip to the World Transplant Games in Sweden. I am very excited to be representing the UK and I hope to bring back some medals.

I am very grateful for your support.

From  
Rebekah



Sharon Frame,  
Clinical Nurse Specialist in Transplantation

# NEW ANNUAL REVIEW CLINIC FOR KIDNEY TRANSPLANT PATIENTS.

There is a major drive nationally to improve the care of patients with long-term conditions and with this in mind; we have started annual review appointments for patients that have had a kidney transplant for more than ten years. These annual check-ups have been successful in other kidney units in the UK, looking at the overall health issues rather than just concentrating on kidney function.

The aim is to offer patients a longer consultation once per year to discuss how to prevent some of the long-term complications that can arise as a result of the immunosuppressant medication. This will include maintaining healthy bones, skin care and how to keep your heart healthy. In addition to this we can offer advice and support on living a healthy lifestyle including diet, exercise, giving up smoking, reducing alcohol intake and managing stress.

The annual review appointment takes place over 30-40 minutes to ensure a good quality consultation and it can reduce the need for more frequent clinic visits during the rest of the year. There are

two models for these appointments so you are either seen by a specialist nurse, or a specialist nurse and a doctor.

The feedback we have received so far has been really good nevertheless these clinics are relatively new so we are assessing them continually and changing things as necessary.

So if you have had a kidney transplant for more than ten years book your Annual Review appointment by contacting:

**Diane Wright** for appointments on 02071885714

**Sharon Frame** for any further queries on 02071885676.

**By Sharon Frame**

Clinical Nurse Specialist in Transplantation

## These are some of the comments from patients following an annual review appointment;

‘Nice to know there is such a service as the one you have set up. I think it is very reassuring indeed.’

‘I was able to discuss issues which I have not been able to talk about in the usual clinic.’

‘Thank you for sending a copy of the medical report ..... from our side we are trying to maintain a healthy diet for the transplant and getting more exercise by cycling, swimming and gym sessions.’

## NOTICE OF THE ANNUAL GENERAL MEETING OF THE GUY’S AND ST THOMAS’ KIDNEY PATIENTS ASSOCIATION.



The law requires the Association to give notice to Members (all GSTT Kidney Patients, relatives and staff are Members) of the Annual Meeting of the Charity.

This year the meeting will be held in The Roben’s Suite at Guy’s Hospital on Saturday 12 November 2011 at 10.00 a.m.

The formal part of the meeting is an opportunity for the Membership to elect the following officers:

Chair  
Vice-Chair  
Treasurer  
Secretary

to appoint auditors for the forthcoming financial year, and agree any changes to the Constitution.

It is also an invaluable opportunity to show support for the work which the retiring Committee has undertaken on your behalf, to make suggestions for the future direction of the Charity, or to be nominated to the Committee.



# Golfing in the sun at Stoke Park

Friday 8th April saw the Guy's and St Thomas' Kidney Patients Association's own version of the Ryder Cup take place at Stoke Park Golf Club in Buckinghamshire.

Instead of the Americans as their opponents, a team from the Eyeless Trust charity lined up in the inaugural Lillian Ramsay Memorial Trophy with twenty one golfers per side, all of varying standards, going head to head over eighteen holes in a mixture of four ball and foursomes.

Lillian was the late grandmother of Rupert Ramsay, co-organiser, who founded The Eyeless Trust in 1993. The charity's objectives are to provide respite and social care to children born with debilitating eye conditions. Lillian regularly used Stoke Park as a venue for her various fundraising ventures and Rupert was therefore keen to return to Stoke Park and use the essence of competitive sport to benefit these two charities.

On the day itself the weather was superb with temperatures reaching 20 degrees and upwards! The match, somewhat irritatingly, ended up in a tie! After the golf, the golfers and thirty

non-playing guests, were treated to a magnificent three course lunch along with the inevitable fundraisers – a raffle and a live auction.

The auction proved to be a tremendous success with top lot, a week's holiday for four in a Cornish cottage, reaching an impressive £820! The KPA would like to take this opportunity to thank all the people who worked so hard in order to make the day the success it was with special thanks going to Rupert for all of his hard work.

Finally at the latest count I am pleased to report £8000 was raised for both charities, which is a superb sum. A second event in 2012 is being planned and I hope that KPA members will show their support by joining up with some friends and entering a team of four or, at the very least, joining us for lunch.

By Henry Kimbell

Vice Chairman and Captain of Team GSTTKPA



## Transplantation Laboratories

A rare opportunity to visit the Transplantation Laboratories was recently offered to GSTTKPA Members. The event was celebrated by unveiling a plaque by Professor Steve Sacks and Trevor Cook (KPA Chair) which recorded the KPAs support for research.

Everyone who attended; patients, guests and scientists enjoyed the visit and felt that they had learned a great deal.

Keep in touch at [www.gsttkpa.org](http://www.gsttkpa.org) and follow us on [facebook.com/groups/gsttkpa](https://www.facebook.com/groups/gsttkpa)

## Standing Order Request

If you wish to set up a standing order to benefit the KPA, please fill in the form below and send it to your bank.

### To the Manager

Bank.....

Branch.....

Address.....

.....

.....

.....

**Please Pay:** NatWest Bank Plc, Dartford Branch

**To the benefit of:** Guy's & St Thomas' Kidney Patients Association

**Account number:** 71122605

**Sort Code:** 60-06-33

Quoting reference

(your name in full).....

The amount of £.....

commencing on the .....day of.....

with further payments to be made

on that day every .....until.....

### Account to be debited:

Name in which account is held.....

Account Number.....

Sort Code.....

Signature..... Date.....