



kidneytalk

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

Just a thought...

Where would I be if former patients had not given generously?

I have been a kidney patient for about 20 years and things have changed a great deal. Many of the changes have been the result of gifts from former patients. These have supported everything from research which has led to more patients able to have transplants and dialysis to simple things to make life more enjoyable. Probably the television we watch in the dialysis unit was bought by voluntary contributions.*

One way of marking our appreciation for the help you may have received is to leave a gift in our wills. Many people do.

We should all have a will and occasionally review its content. Why not ask a solicitor or will writer how we might leave a legacy to the Guy's and St Thomas Kidney Patient Association.

Our gift will help future generations of people with kidney disease to make the best of their lives.

Thank you

Trevor Cook
Chair GSTTKPA.

*full list of expenditure listed elsewhere

I can do it.

The KPA celebrated World Kidney Day by holding a workshop for people who wanted to learn more about going back to work or volunteering.

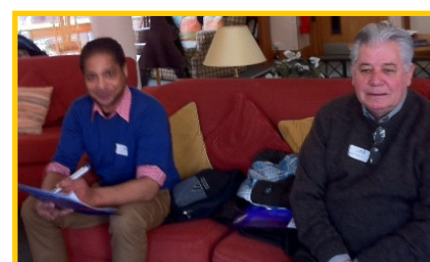
"The Workshop was very good, it gave me ideas how to 'big up myself' which was very useful."

The KPA feel that we are privileged to be patients at one of the worlds greatest teaching hospitals, and we receive outstanding clinical help, but what happens then? Surely the purpose of a transplant or dialysis is to help us back to as near normal life as soon as possible – but we all know how difficult that can be.

"It helped me to develop some confidence."

Spectrum (a specialist employment company) with Maddy Warren, one of our kidney patients, put together an extremely challenging programme which helped patients to identify their strengths, develop coping and confidence skills. Many of the skills required to be an expert patient – reliability, honesty, time keeping, inner strength, toughness are just the skills many employers are looking for.

"Such a good idea to hold a session like this, I have personally felt a good deal of anxiety in regard to going back to work."



We heard about the legal issues concerning employment, benefits and volunteering. None of these should present barriers to employment if managed well. Sainsbury's maintain an open recruitment policy and try to match a "willing employee" with a "willing employer" (Sainsbury's) where these two things come together then success is inevitable. We also heard that the Trust would do all it can do to help to fix dialysis times to work around the needs of a job.

"This course was very interesting, I've enjoyed all new suggestions."

Without exception all those who attended went away with a "skip in their step" and their inner strength and determination boosted for the future. We wish them well.

**Bin Negative Thoughts –
There Is Always A Positive!**

AN INTERVIEW WITH Professor Steve Sacks

Consultant Nephrologist

Attending a large and famous teaching hospital like Guy's and St Thomas' means that many of us kidney patients may be invited to take part in a research project. Where does the research happen? How many scientists are working on solutions to kidney problems? Who pays? To find out a bit more about the work; I interviewed Professor Sacks who heads up the Medical Research Council's Centre for Transplantation located at Guy's Hospital.

I met Professor Sacks in his remarkably modest office and asked a few questions which I hope many patients may find useful.

Why is it necessary to have a Research Centre for Transplantation? The number of people needing transplants is growing constantly. A number of initiatives are being developed to address the need. Here at Guy's research is underway to

help slow down the progression of kidney failure and to help transplanted kidneys last longer.

The research technique is called translational research which is a term used when academic discoveries from the laboratory, are translated into clinical practice. You may hear this referred to as taking research from 'the bench to the bedside'.

How big is the team? At its core there are 37 scientists and doctors, these are funded by the Medical Research Council and from a donation of £500,000.00 from the Guy's and St Thomas' Kidney Patient Association over five years. Because of the quality of the research, Professor Sacks confirmed that grants have been obtained from many other organisations expanding the current team to about 150 people.



Professor Sacks and his colleagues keep in touch with patients and clinical practice by doing regular clinics.

Professor Sack's enthusiasm for the work is infectious and he paints a very positive picture for the future of research and the impact on the lives of patients. The development of gene therapy and other new techniques promise really exciting outcomes for patients.

Giving and Spending

Throughout the past year the Kidney Patients Association has been funding events, equipment and research which have helped to improve the patient experience for all of our kidney patients.

Below is a list of grant applications which were approved and subsequently funded by the Kidney patients Association.

The Kidney Patients Association has no regular income from any source. Grants are made as a result of fund raising activities undertaken by volunteers, collecting at railway stations, running Marathons, making personal gifts or arranging legacies (see article 'Just a thought'). If you have benefited in any way from the work of the KPA (and most patients have) you may wish to consider contributing in a small way by setting up a direct debit, making a donation occasionally or arranging a legacy.

GRANT	FUNDING
TVs in patient waiting areas at Astley Cooper and Camberwell dialysis units	£10,000.00
Transonic device to monitor and assess vascular access (fistula) for dialysis patients	£17,000.00
Grants to Kidney Dialysis Units and Wards for patient/staff events	£7,000.00
New nursing post to promote home dialysis and self care	£100,000.00 over two years
A smart phone application (app) for young kidney patients to use as a place to keep their own health records and to act as a reminder for appointments, medications etc	£22,000.00
Transplant games (providing assistance for patients and families to attend games)	£28,000.00
Research (£75,00 as part of a grant of £500,000 over 5 years)	£28,000.00
Ronald McDonald House (for use by families of young kidney patients)	£20,000.00
Maria Hernandez Research biomarkers	£12,750.00
Claudia Kemper Research in renal transplantation	£8,333.00

Spotlight on...



Debbie Mundle

Community Haemodialysis Matron

Q. What's your role in the unit?

A I am responsible for all the satellite dialysis units which I aim to visit on a weekly basis, deal with any queries and ensure we deliver a high quality service. I am responsible for seeing patients attending the dialysis unit that best meets their needs. I also manage the home dialysis service for patients doing haemodialysis and peritoneal dialysis at home and ensure they are looked after and their carers supported.

Q How long have you worked in the kidney service here at Guys & St Thomas'.

A A long time! I trained as a nurse in 1985 and in 1992 I worked on Astley Cooper – a kidney ward at that time. After completing a renal dialysis course I worked on Bostock, then the only dialysis unit for Guy's Hospital. I was promoted to Sister (nurse in charge) in 1996 and I became Matron for the satellite dialysis units about five years ago.

Q What do you like most about your job?

A I like meeting the patients and the staff. I get a lot of pleasure working with the teams to look at various ways of improving the experience for kidney patients and staff.

Q Have you seen many changes within the kidney service over the years

A Well yes, there have been great advances in kidney treatments and care. I have also seen new units opening closer to where patients live. Like most people I can find organisational change difficult but I am always ready to try out new ideas.

Q Is there anything that you would have liked to have done?

A As a young girl I thought about being a beautician and later contemplated training as a physiotherapist.

Q City girl or country girl?

A Most definitely a city girl, I was born and brought up in London and I still live within two miles of where I was born.

Q Work-life balance

A Very good, I work nine days a fortnight so this allows me to have a Monday off every other week which helps with home and family commitments.

Q What are you listening to on your ipod?

A As I am always ferrying my children around most of the music I listen to in the car is theirs – so it's up-to-date.

Q You lead a very busy life, do you have time for any hobbies?

A Yes I meet up with some of my friends once a month at a book club. It is a great excuse to meet and catch up and have a glass of wine or two!

Q What's your favourite holiday destination?

A Definitely Cuba, we went 4 years ago – it was amazing. I would love to go back.

Q If you could have a dinner date with anyone who would it be?

A George Clooney or maybe Denzel Washington – they are both gorgeous! Graham Norton would have to come as well to make us all laugh after all I couldn't just look at George and Denzel could I?!



RUNNING FOR THE KPA

Virgin London Marathon 2012

This year the Guy's and St Thomas' Kidney Patients Association are delighted to announce that we have six runners competing in the Virgin London Marathon on Sunday April 22nd 2012.

Our six runners, Carolyn Price, Michelle Le Mercier, Chris Bruce, Rachel Hilton, Ciara Rooney and Zoe Strang are all committed to raising funds for the Kidney Patients Association.

The main aim of the KPA is to support all Guy's and St Thomas' Kidney patients. We do this by raising funds to support activities and buy equipment which we feel benefits the lives of all our kidney patients. This

includes pledging money to help with medical research. We would be unable to do this without the time, effort and sheer energy that people like all of our six runners put in to support us and raise the much needed funds to be able continue with these good works.

We would like to say a big thank you to our marathon runners for choosing our charity to run for and raise money. We wish them the very best of luck

and of course we will be cheering them on and supporting them on the day.

If you would like to sponsor one of our runners then please visit the www.justgiving website or send a cheque to Bernadette Lynch, P A to the Guy's and St Thomas Kidney Patients Association, Renal Offices, 6th Floor Borough Wing, Guy's Hospital, London, SE1 9RT.

Nabeels' story...

My name is Nabeel and I am a 9 year old boy. I have been waiting for a kidney transplant for the last 2 years and in March 2011 I was able to have a kidney from my Mum even though I am of blood group O whilst my mum is of group A. I was the first child to have this kind of transplant at Evelina Children's Hospital at St Thomas'.

Before the transplant, I had to have plasma exchange so that the antibodies could be removed to stop me from rejecting my mum's kidney. Plasma exchange is a process similar to dialysis.

The night before the transplant my family came to see me, my mum kissed me goodbye and went to Guy's Hospital to be admitted so that her kidney could be removed the next morning, my dad stayed with me.

On the big day, my uncle, aunt, nan, cousin and my sister come to see me; my sister started to cry and so did I, it was so emotional! My dad and nan went to the operating theatre with me and I met the surgeon and the anaesthetist, in 30 seconds I fell asleep.

After the transplant when I was on the ward I was half asleep as if I were under a spell. While I slept the nurses, doctors and my dad looked after me. I wasn't allowed to eat or drink, it was hard but I managed to do that. On the third day, I started walking slowly and was eating again. On the Sunday, I was over the moon when my mum made a surprise visit.

Two weeks later I got ulcers in my mouth as a side-effect of the medication. These two weeks were the worst time because they were very painful. It was hard to eat so I only ate things that you don't have to bite. Taking lots of tablets isn't as easy as I thought it would be. I'll be taking tablets to stop the kidney from rejecting every day of my life.

I now find blood tests are easy: all it is, is putting a needle in and blood flows out. Cathy the play specialist and Grainne the transplant sister did a very good job to make blood tests easier for me. I am thankful to all the nurses, doctors and everyone else who looked after me and my family during the transplant.

I missed lots of school during my hospital stay; so I went to the Evelina School. It was really fun because there are lots of activities, we get to do cooking and play on the Wii! After six weeks in hospital, I went to a special sort of hotel near Guy's as I had to go to the transplant clinic every day. It was called the Ronald McDonald House and it's where parents of sick children stay. Because I couldn't travel, I stayed there for a whole month with my Dad who took time off work to look after me. A week later, we left London for home. It was awesome being at home and spending time with my family.

Having a transplant is extraordinary because you feel well and have lots of energy after. I am now doing lots of activities such as swimming, table tennis etc. I am also looking forward to take part in the transplant games next year and going on holidays abroad. I will always treasure this special time of my life because the kidney donated by mum is the most important gift I could receive.

Nabeel



For more information about incompatible transplants please contact:
Grainne Walsh at Evelina kidney services (children)
Or Lisa Silas at Guy's kidney services (adult)