

Trevor Cook (1947-2013)

The Renal Unit at Guy's has lost a great friend and supporter but as we mourn Trevor's passing, it is important that we reflect on his many achievements.



Trevor worked tirelessly and enthusiastically as a GSTT KPA volunteer for over ten years and was proud to become a wonderfully effective chair. It was Trevor, more than anyone, who translated the KPA motto of 'patients supporting patients' into tangible and sustainable action. He spent a great deal of his own time talking to fellow patients, as he was determined to be best placed to understand what they really wanted and needed from their supporting charity.

Trevor's own personal values came to permeate the work of the KPA and helped to ensure that it always worked towards the

best interests of patients and their carers. He regularly visited all the dialysis units to promote and encourage KPA funded social activities, such as parties and away-days. He also supported the nursing teams to celebrate important national events such as the 2012 Olympics within clinical areas, allowing patients to feel a keen sense of participation. Trevor progressively increased the reach and influence of the KPA, notably through a regular newsletter and an excellent website.

In addition, Trevor was a trained volunteer within our Peer Support programme. This meant he was able to offer patients with newly diagnosed kidney disease, or with difficult treatment decisions to make, a welcome opportunity to talk to an experienced non-clinical mentor.

Trevor's legacy includes a programme of fundraising and grants that have facilitated research, supported service innovations and, most importantly, improved the quality of life of patients and their carers. He developed productive relationships, always based on mutual respect, with academics, clinicians and managers alike. This ensured that KPA funds were consistently used for the maximum benefit of the greatest possible number of patients. He was an astute patient representative on the Renal Project Board,

vigorously contributing to our research agenda, whilst always reminding us that the patients' perspective should remain at the heart of many of our plans, no matter how ambitious they may be.

Under Trevor's leadership the KPA went from strength to strength and it is now, unequivocally, one of the most vibrant and patient focussed in the UK. It was in recognition of this that he received the Guy's and St Thomas' Volunteer of the Year award in 2012.

He bore his devastating final illness with characteristic fortitude.

Our thoughts are with his family and friends.

Simon Steddon
Consultant Nephrologist



Introducing our new Chair

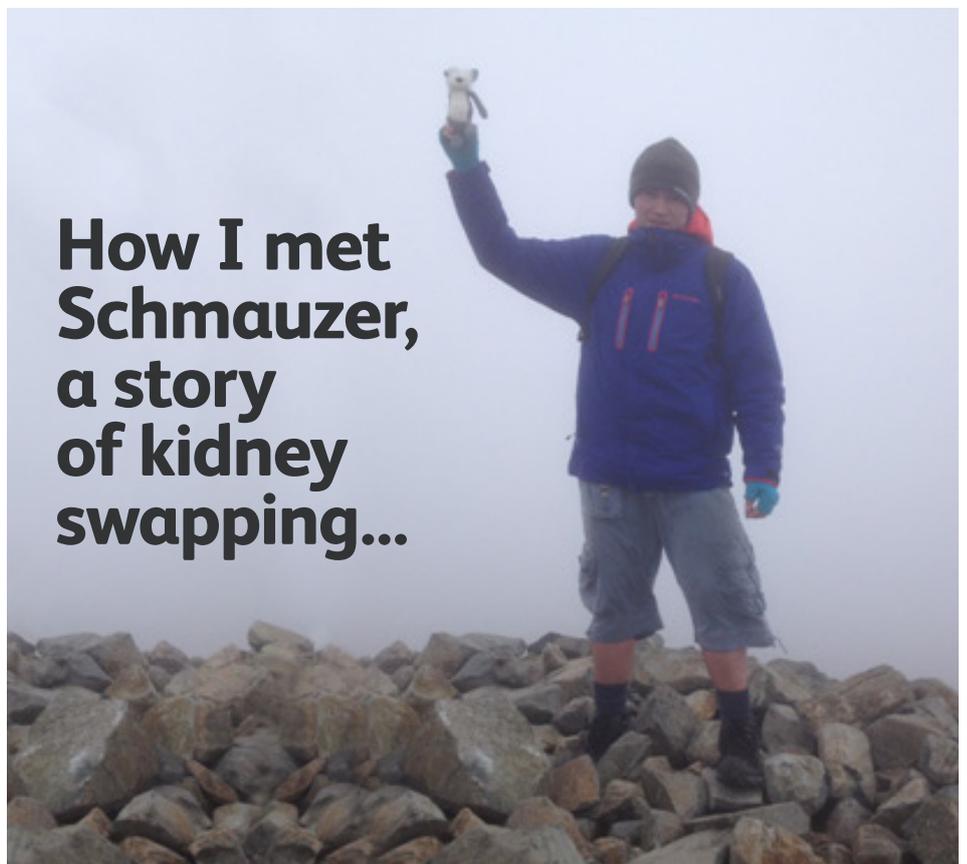
Sonia Moorhouse



When I was a about six years old, I was determined I wanted to become a nurse and as a teenager, I volunteered during Easter and summer holidays at Lewisham and Hither Green Hospitals. However, I had a change of heart and trained as a social worker and one of my first jobs was at St Thomas' Hospital.

I later worked as guardian ad item reporting and advocating in private and public legal proceedings. I qualified as an adult analytical psychotherapist and have MSc and MBA degrees. I currently work as a general manager and clinician within the NHS.

It is a tremendous honour being Chair of the GSTTKPA. I looked forward to 'learning the ropes' from the out-going Chair but as many of you will know, Trevor Cook passed away earlier this month. I don't think I will be able to emulate Trevor but I will maintain the centrality of kidney patients being at the heart of what the KPA strives to do.



How I met Schmauzer, a story of kidney swapping...

Schmauzer and I were introduced in March I was in Guys Hospital, having just donated my left kidney and Schmauzer was a gift from my wife and mother-in-law.

I am part of a 'Paired Donation Scheme'. The way that it works is that people with two healthy kidneys can quite happily donate one without any long-term ill effects. At the same time, someone else donates a healthy kidney and they are effectively 'swapped', meaning that both your loved one and their loved one gets a healthy, working kidney. Not many people know about kidney swaps or altruistic organ donating, but it's an incredibly important procedure that can drastically improve the quality of life for the ones you care about the most.

Of course, I was scared. I knew that the recovery would take a while, but the hospital was excellent. They talked me through everything that I would need to do to make sure I was well prepared physically, mentally and emotionally. My anxiety though was completely outweighed by the results. Not only did my loved one have a working kidney, but my donation had saved someone else from dialysis (which can take up many hours each week) and made things easier for them and the people they care about.

I feel fully recovered now, so much so that I want to continue to raise awareness and funds for kidney research whilst challenging myself in the process. It's fair to say that my next challenge will be a big one!

Schmauzer, myself and my friend, Anthony, are completing a physical challenge to prove that you can lead an active healthy life after kidney donation.

We completed the '24 Peak Challenge' on October 11th and 12th by ascending 24 Lake District Peaks in a 24 hour period. Each peak is over 2,400 feet high and we did this over 2 gruelling days!

How you can help

Sponsorship is always welcome! You can donate some money by texting PKTK73 and an amount £1 - £10 to 70070 or visit my Just Giving page:

www.justgiving.com/kidneytrek

Give blood and join the organ donation register - Both of these things drastically improve the quality of lives of others. If you join the organ donation register, please let your family know of your wishes

Find out more about kidney swapping and altruistic kidney donation - Visit www.giveakidney.org

We can all make a difference!



BLACK HISTORY MONTH

We arrived at the rather splendid Club Langley Banqueting Hall where both I and Sonia Clarke-Swaby, Guys & St Thomas' kidney / pancreas transplant Coordinator, had been invited to give a presentation at a Black History Month dinner and dance. The event was to raise money for the KPA in honour of Sharon Brown, a Camberwell dialysis unit patient, who sadly passed away in October 2012; also to commemorate the 65th Anniversary of the Empire Windrush.

The evening was an opportunity for Sonia and I to raise the awareness of the fact that as black people we are 3-5 times more like to suffer kidney failure, and also for the need for more of us to sign the organ donor register and consider living organ donation.

The evening was both a wonderful celebration of Sharon's life, a fund raiser and also an opportunity for us all to reminisce, with the help of Sam King MBE, on the Windrush years.

The Empire Windrush, a ship that arrived at Tilbury dock on the 22nd June 1948, brought Jamaican born Sam King, who soon settled in Southwark. A tireless campaigner for the community he went on to help set up the first Notting Hill Carnival, and was also a driving force behind the first black newspaper, the West Indian Gazette.

I gave a presentation on my life as a kidney patient, currently on dialysis, and what that entails. My wish was to make those present understand that they could quite easily be

in my situation just because they were black and that the need for them to consider organ donation was one they should seriously think about, as only 2% registered are black, yet 80% of people would accept a donation.

Sonia Clarke-Swaby the winner of the Mary Seacole prestigious nursing award 2009, also gave an impassioned speech on the facts from the perspective of a transplant coordinator.

The event was one that Sharon would have been very proud of, as it was enlightening, inspirational and encouraging. Following both Sonia's and my speech, a number of people handed in completed organ donation registration forms, and a few also informed us that they wanted to discuss the issue with their families before registering. It was without doubt a huge success and I would like to thank 'Just Be' for organising the night and the KPA for purchasing our tickets.

Zandria Richards

Meet the committee...



Following the KPA's annual AGM we would like to introduce our new committee, pictured above, who have been elected to stand and serve on the KPA for the coming year.

Top row: George Brown, Nick Palmer, Dela Idowu, Ros Tibbles, Zandria Richards, Pernille Rasmussen, John Ogilvie.

Bottom row: Teresa Durkin, Henry Kimbell, Sonia Moorhouse, Janice Stephens, Bernadette Lynch.

Introducing the KPA Treasurer Janice Stephens



Janice Stephens has now been elected as the KPA's new treasurer. Janice has been a patient at Guy's for seven years and had a living related transplant from her mum five years ago having just avoided dialysis. She is a Chartered Accountant and worked in finance at Guy's for seventeen years. She is now the Associate Director of Finance at the Royal Marsden Hospital with responsibility for both the hospital and the Royal Marsden Cancer Charity accounts. We welcome Janice to our committee and thank her for volunteering to be our treasurer.

National Kidney Federation Annual Conference 11th – 13th October 2013



The National Kidney Federation (NKF) The Hinkley Island Hotel, Leicestershire.

The memorable presentations included a witty and articulate speaker who advised about the many advantages of home dialysis: he emphasized the additional independence, more free time and waiting for hospital transport being confined to his past. In addition, a carer spoke of her husband's 28 years' as a dialysis patient and while this was both a hopeful testimony for patients who do not have the prospect of a transplant, her candour about dialysis management in the home was honest and realistic.

In the exhibition hall the Guy's and St Thomas' KPA stand generated a huge amount of interest focussed particularly on our mykidneycare smartphone app. There was also considerable interest in our KPA pens, notepads, mobile phone 'armchairs' and stress balls all of which assisted in promoting the GSST KPA.

South-west delegates informed us that the sheer geography of their area presents a number of challenges for transporting many patients requiring dialysis - who elect, because of the logistical problems - to be conservatively managed.

This highlighted some of the regional differences that still exist in the provision of renal care.

The NKF reported its long odyssey with the Government regarding standardising renal care, which had made some progress before the commissioning changes within the NHS. The NKF received a mandate from the delegates to escalate matters further if NHS England does not respond.

The 'Gala Dinner' followed in the evening and the band the 'Zippers' were very good and entertained us until midnight.

The next day there was a lengthy debate about travel, life and home insurance. The latter was of note because a member reported being refused home insurance because of his home dialysis machine. Finally, the benefits workshop was particularly illuminating and reminded us of the importance of keeping ourselves up to date with benefit changes. Please visit our kidney information page and follow the link to www.gov.uk for information on benefits.

THE BIG FUN RUN AT CRYSTAL PALACE



WE DID IT! On 13th October 2013, myself and a team of members from the justBe group walked/jogged 5K in the pouring rain to raise money for the KPA in memory of our dear friend Sharon Brown who sadly passed away due to complications associated with kidney failure. Sharon pictured above on the right was justBe's Treasurer and one of the founding Trustees of our group and is sorely missed by all of us.



We were soaked to our skins and had aching knees but we accomplished what we set out to do and have so far managed to raise £1840.00 for the Guy's & St Thomas Kidney Patients' Association who do fantastic work for kidney patients. Thanks to all who supported us!

Yvette McDonald

NICOLE MACKENZIE WORLD TRANSPLANT GAMES

The 19th World Transplant Games in South Africa is now over and I couldn't have been happier with my results.



I got a total of 7 gold medals in the swimming which took place on 31st July and the 1st August at the Kings Park 50m pool, Durban. I then went on to break all the world transplant games records in the 50m fly, backstroke, breaststroke, freestyle and the 100m freestyle.

I also set world records as part of two swimming relays which were the 4X50m freestyle and the 4X50m individual medley which I did the breast stroke.

I set personal bests in all my events as well. This was all a great achievement and I felt that all the hard work and hours I put into my training had really paid off.

My main highlight was when I was awarded by the World Transplant Games Federation for outstanding female junior athlete award for my efforts in the pool and helping out with the younger members of the junior team.

The whole experience of the games was brilliant. I met up with old friends and made new ones and had plenty of opportunities to socialise with other athletes from different countries.

When my events were over it was great being able to support other team members in their chosen sports and the team spirit was amazing.

The Opening Ceremony was great and included lots of African culture, and so was all the other entertainment which was laid on for us, and the Gala at the end of the games was brilliant too.

Without the kind donation I received from the Guy's & St Thomas' Kidney Patients Association I would not have had this great experience and I am very grateful for the support of the Kidney Patients Association. I was able to enjoy the sport I love doing whilst promoting the importance of organ donation and showing that you can lead a full and happy life after transplantation.

Nicole Mackenzie

CYCLETTA CYCLE RIDE FOR CHARITY



What a day! I did it!

The Cycletta 50mile cycle ride in the New Forest would have been so much better without the persistent rain. The photo, that's me on the right, doesn't really show how exhausted and soaking wet we were at the end.

It was well worth it though and I managed to raise £650 for the KPA. Thank you to everybody who sponsored me with all proceeds going to the KPA which is such a worthy charity and works so hard to benefit the lives of all kidney patients.

**Victoria Hanson
Clinical Nurse Specialist**

RIVER DART 10K 2013

I've Got The Mug And The Swimming Cap!

Well, what a beautiful swim! We headed down to Devon on Friday evening in the pouring rain, feeling slightly apprehensive and a bit on edge. On Saturday morning there was no rain and even a patch of clear blue sky. After a big bowl of porridge we headed off to Totnes rowing club and the registration tent.

Mr Blue Sky just kept on coming. The weather could not have been better and the water was sparkling in the sunshine. Wet suit and swimming cap on it was time to listen to the safety briefing. As soon as that had finished I, along with 100 or so other swimmers, was escorted down to the water's edge.

We set off from Totnes rowing club where the brackish water was a beautiful temperature. It felt pure, rippling and soul soothing. It was a bit chaotic to begin with but no sooner had we started than I got into my rhythm and was enjoying looking at the oak trees and rolling countryside either side of the river from the water. A couple of twists and turns and then I reached Sharpham boat house and the first feeding station at 3.5Km. By this point I had been swimming for 1 hour and 10 minutes. I felt fine. Quick handful of jelly babies and a bottle of lucozade and I was off again. The scenery was gorgeous. The sun was shining and it all felt magical.

I reached Bow Creek which is where the estuary becomes wider and the water gets more salty and choppy. Swimming across Bow Creek was tough and I was beginning

to feel a bit cold and had a niggling bit of cramp in my right foot but the second feeding station was in sight.

By now I only had 2.5Km left to do. 'Hooray!' I thought. From this point on there were lots of yachts and riverboats passing by and the water was very salty. I thought the final bend into Dittisham would never end, but I could hear others talking about the boat shed and knew this must mean the end was in sight. And it was! I'd made it! It had taken me 3 hours and 51 minutes! So on average I swam at 23 minutes per Km pace. That's a personal triumph!

I have managed to raise £2,710 so far, to be divided between the KPA and another charity.

Antonia Cronin

KPA EVENTS AND ACTIVITIES 2013

The KPA have been very busy over the summer and autumn with lots of activities taking place. Here are just some of the events, some of which were funded by the KPA; some of which raised funds for the KPA.

Awareness Week

In an attempt to promote the KPA and raise our profile we launched a week long raise awareness event. We had stands in Guy's and St Thomas' Hospitals, as well as the Kidney Clinic. KPA representatives visited our seven dialysis satellite units to give out promotional merchandise, information and also answer any questions that patients, staff, relatives and friends had regarding the work of the KPA. This is an annual event and was again a great success.

New Cross Summer BBQ

New Cross Dialysis unit held a BBQ in the summer for patients and staff. It was a lovely day and everyone who attended had a really good time. Funded by the KPA, this has become an annual event because it is so popular with both staff and patients.



KPA Annual Raffle

The KPA held its annual raffle in the autumn with the draw taking place on the 17th October 2013 at The Borough Kidney Treatment Centre. I am pleased to announce the winners were:

1st Prize - £500.00
#02206 – Kamal Charan-Giles

2nd Prize – Ipad Mini
#03112 – Mr John Barnes

3rd Prize – Kindle Paperwhite
#00459 – Mr Patel

Congratulations to all our lucky winners and thanks to everyone who supported the KPA by selling and buying raffle tickets.



Sidcup Funny Hats Day

Sidcup dialysis unit put on a funny hats day to raise money for the KPA. Staff and patients wore funny hats and had a lot of fun as well as raising over £130.00.