

Farewell to Bernie



Bernadette Lynch started working for the KPA in October 2011 and quickly became “the face of the KPA”. She managed the administration of the KPA with efficiency and friendliness and soon became well known in the dialysis units and kidney clinic. Some of you may even remember her from way back when she was a nurse on the children’s kidney ward; her association with and support of the KPA has spanned many years.

Bernie is leaving Guy’s to spend more time in Majorca (a difficult choice I hear you say!). However you will still see her around and about as she has offered to continue supporting the KPA as a volunteer and will be assisting our Treasurer, Janice, with the finances. The KPA would like to extend their sincere thanks to Bernie for all her hard work and dedication during her time with us.

Contact Us:
Contact the KPA Chair at: chair@gsttkpa.org or for general enquiries: info@gsttkpa.org or Tel: Ros Tibbles on 020 7188 7552

Postal address: GSTT KPA, Renal Offices, 6th floor Borough Wing, Guy’s Hospital, Great Maze Pond, London SE1 9RT



KIDNEY TRANSPLANT ANNIVERSARIES

How do you celebrate yours?

There have been a number of posts on Facebook and Twitter about your kidney transplant anniversaries (Kidneyversary). People have said that each milestone is a cause to celebrate, think of the donors and remember the fantastic staff at the hospital that cared for us. Also we remember our fellow patients who still are waiting for ‘the call’.

The KPA are launching a new campaign in Transplant Week, 7 – 13 July, called “Celebrate your Kidneyversary”. We would really like to hear about how you celebrate each year. Perhaps you have make a special cake or host a celebration meal for friends and family or do something to raise awareness of organ donation, whatever you do please let us know!

Our “Celebrate your Kidneyversary” campaign will enable all your family and fellow KPA supporters to celebrate with you and maybe raise a few pennies for the KPA in the process. Our Treasurer Janice said “I always like to mark my kidneyversary in some way - from a party to thank everyone who supported me, to a holiday in Las Vegas with my mum, to a few cakes at work.”

Vice Chair Henry Kimbell added: “I have actually undergone two transplants so I have double the number of kidneyversaries to remember and celebrate!

For me it’s usually something quite casual like having drinks and a meal with close friends and family as well as raising a glass to my donor. I will probably do something a bit more adventurous for my fifth kidneyversary which is only 18 months away.”

We would especially like to hear from anyone who will be celebrating their kidneyversary in the summer and would be willing to help promote this campaign. Please contact us on info@gsttkpa.org or Tel 020 7188 7552 if you would like to know more.

Janice Stephens

RUNNING IN THE LONDON MARATHON FOR THE KPA

The KPA had four runners in this year’s Virgin London Marathon which took place on Sunday 13th April 2014. Between them so far they have raised over five and half thousands pounds for us.

Representatives from the KPA were there on the day to support our runners and cheer them on. Jane (pictured) said “This is the first time that I have taken part in the London Marathon; it was a fantastic day and a truly wonderful experience. The atmosphere was brilliant and the crowd support certainly helped to get me over the finishing line”.

There is still time to make a donation, just go to www.virginmoneygiving.com and donate to one of our runners: Jane Branch, Matt Varrier, Avanish Kumar and Ugo Boggi

Alternatively you can send a donation to: Guy’s & St Thomas Kidney Patients Association, Guy’s Hospital, Renal Offices, 6th Floor Borough Wing, Great Maze Pond, London SE1 9RT. Cheques to be made payable to: Guy’s & St Thomas’ Kidney Patients’ Association.

The KPA would like to thank all our runners and everyone who donated in support of them for our charity.

If you are interested in running in the 2015 Virgin London Marathon for the KPA please email your interest to: info@gsttkpa.org



A MESSAGE FROM OUR TREASURER

Help us to turn £1 into £1.25!

It has been a busy few months since I took over as KPA Treasurer and I already feel a great commitment to the Charity and supporting the next stage of its development. We have now finished paying a number of research and other grant commitments, this has left our reserves fairly low and we need to rebuild them. To help us to continue to support our patients we need to make every penny count and I would like to ask your support with this by ensuring that get all the gift aid we can. Gift aid is a scheme which allows charities to reclaim tax from the government, for example:

You donate	+ Gift Aid	Total donation to the KPA
£1	25p	£1.25
£10	£2.50	£12.50
£100	£25	£125

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To pay for the activities we support we rely on the generosity of our donors who give us money in a number of ways. We are fortunate that a number of people donate monthly to the charity; this helps us to plan our finances. Others may give as a one-off after a transplant or in memory of a loved one who has sadly passed away.

In 2013/14 we received over £13,000 without Gift Aid forms which means we ‘lost’ over £3,000 of gift aid! If you are a UK tax payer please complete a gift aid declaration so that we can claim 25% gift aid on your donation. If you have donated in the last four years and did not complete a gift aid form it would be great if you could complete one. Please contact info@gsttkpa.org and we can send you a form

We are also in the process of updating our website donation page to include new ways to donate to the charity so keep an eye on www.gsttkpa.org

Janice Stephens, KPA Treasurer



World Kidney Day

World Kidney day took place on 13th March and this year’s theme was “Kidney Health Matters – Help Reduce the Risk to Your Kidneys”.

To mark the day, Guy’s & St Thomas’ Kidney Patients’ Association, in conjunction with the National Kidney Federation and the NHS Blood and Transplant team set up a stand in the foyer of Guy’s Hospital.

Throughout the day we gave out information and advice suggesting ways in which people can help reduce the risk to their kidneys. We also took the opportunity to raise awareness of kidney disease and the importance of organ donation.

The day was a great success with a number of people signing up to the Organ Donor Register and many more taking away information sheets about Kidney Health.

You can still help to support World Kidney Day by encouraging friends and family to join the organ donor register either online at: www.organdonation.nhs.uk or by calling the NHS Donor Line on **0300 123 23 23** or by texting **SAVE** to **62323**.

KPA Upcoming Events

National Transplant Week:
7 – 13 July 2014

Look out for us at Guy’s raising awareness of transplantation and organ donation.
www.transplantweek.co.uk

British Transplant Games:
7 – 10 August in Bolton

Both the adult and children’s transplant games teams have a track record of success at the games.
www.britishtransplantgames.co.uk

Prudential RideLondon:
10th August

The KPA have three riders in this 100 mile cycle challenge:
■ Sam Turner
■ Chris Reid
■ Ian Ogilvie

To sponsor Sam or Chris please visit <https://uk.virginmoneygiving.com> and enter their name.

To sponsor Ian please visit www.justgiving.com/cyrus-homes

First in man Tolerance Study launches at Guy's!

The main problem for transplant patients and their doctors is that the immune system can reject and destroy the transplanted kidney, even after many years.



To prevent this happening we use immune suppressing drugs to damp down the immune response, but these drugs have side-effects, such as making transplant patients more vulnerable to infection and to certain types of cancer, particularly skin cancer. Many patients still experience transplant rejection and may lose their kidney even when using the newest and most powerful immune suppressing drugs.

Doctors and scientists at Guy's have been looking at different ways of controlling the immune system without immune suppressing drugs, a situation called Tolerance. The ONE Study is a new and

ground-breaking research study into a more natural way of suppressing the immune system in kidney transplant patients.

During the study we will take blood from patients who are scheduled to receive a kidney transplant from a living donor. We will separate the white blood cells from the red blood cells and among the white blood cells we can identify and purify a particular type of immune suppressing cell called a regulatory T cell. We will grow these cells in the laboratory and 5 days after the kidney transplant, we will give them back to the patient using a 'drip'. We want to see whether the cells will

survive in the patient and whether they can alter the immune system so that it is less likely to reject the new kidney. If this more natural way of suppressing the immune response is successful this would allow us to use lower doses and fewer immune suppressing drugs so that patients would experience fewer side-effects.

Please contact Dr Rachel Hilton or Dr David Game for more information about the project.
Contact: rachel.hilton@gstt.nhs.uk or david.game@gstt.nhs.uk

Rachel Hilton

CARAVAN HOLIDAYS FOR KIDNEY PATIENTS



The Dudley Kidney Patients' Association own three large caravan holiday homes that they let to patients and their families / friends to enable them to have holidays at a very reasonable cost. They are now kindly offering this facility to Guy's and St Thomas' kidney patients.

Up to six people can stay for a week or for short breaks depending on availability. They are all on lovely sites with excellent facilities including swimming pools, bars and entertainment, restaurants, play and sports facilities.

Two of the caravans are close to the seaside and the other is within an area of water parks. They are open from April to the end of October. The caravans can be found at:

- Hoburne Cotswold site near Cirencester in Gloucester
- Hoburne Devon Bay site at Goodrington, Devon
- Haven Holiday site at Burnham-on-sea, Somerset

Haemodialysis is available at local hospitals but must be booked well in advance. Peritoneal dialysis patients can have their fluids delivered to the caravans. Transplant patients and pre-dialysis patients are also welcome to use the caravans.

Enquiries should be made via the Dudley Kidney Patients Association website:
www.dudleykidneypa.org
(follow the link to the caravan page)

Raising awareness

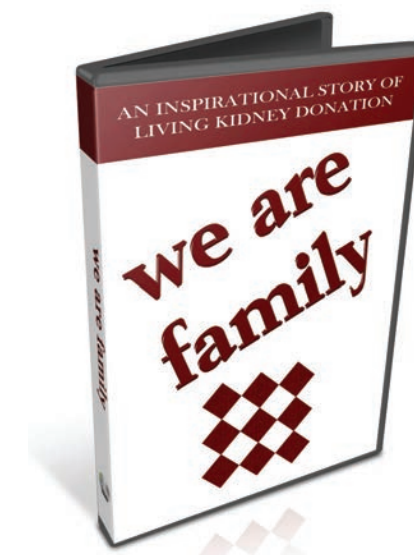
Living kidney donation in the African Caribbean Community

I walked through the revolving doors at Guy's Hospital in January 2011 for first day of my living kidney donor assessment. Nothing could have prepared me for the journey ahead; I was nervous and excited about donating one of my kidneys to help my brother Tayo.

I never considered that it might not happen, but sadly after months of tests and tearful moments I was told I couldn't be a donor due to health reasons. I was absolutely heartbroken as by now Tayo had started home dialysis and as I watched him prepare for his overnight sessions I noticed the changes to his once bubbly and outgoing personality and the struggles he was facing. It was during this time I knew I needed to use my experience to promote living kidney donation in the African Caribbean community so people like my brother would have a better chance of having a kidney transplant.

I wrote a book called "More Than a Match"; which narrates a moving account of my family's experience as potential living kidney donors. The book gives people an understanding of the living kidney donor assessment process in a simple and informal style. Due to the tremendous efforts and endorsement of the book by Trevor Cook, the late chair of Guy's & St. Thomas' Kidney Patients' Association, it has been distributed to clinics and dialysis units at Guy's; the Evelina London and Great Ormond Street children's hospitals.

People from my community would often ask me why I would even consider being a living donor! I simply explained my brother needed a kidney and since I could live a normal healthy life with only one kidney it was a 'no-brainer' to give him the other one so he could have a better quality of life. This was a unique opportunity for me to raise awareness on living kidney donation. I chose to use film as its visual form can give people a different perspective and it is a great way to engage people. I co-wrote, self-funded and produced a short independent film called We Are Family.



We Are Family is an inspirational and thought-provoking story about the



Williams, an African Caribbean family struggling to come to terms with one of their own recently diagnosed with kidney failure and who needs a transplant. The film captures their challenges and fears as they embark on an emotional roller coaster to overcome this real life situation affecting many black families today. However the most powerful element of the film is not a portrait of a family in crisis but a wonderful message of love and a genuine solution.

Although the film illustrates black family life it is relevant to people from all backgrounds. I believe it's a powerful resource that can encourage more kidney patients to ask their family and friends for support and more importantly it can succeed in encouraging relatives and close friends to talk about a subject that is unfamiliar.

There is clear evidence that quality of life improves following a transplant in comparison to dialysis. I hope by using my experience it will change the way people think about organ donation in the African Caribbean community leading to an increase in the number of transplants for black kidney patients.

Dela Idowu is Director of Gift of Living Donation, a community interest company; author of More Than a Match; committee member of the Guy's & St. Thomas' KPA and a member of the Clinical Reference Group for Adult Kidney Transplant services.

To purchase a copy of the film email:
info@giftoflivingdonation.co.uk

Walking from the capital to the coast to raise funds for the KPA

The London to Brighton Challenge is a 100km or 62 mile walk and takes place over the bank holiday weekend, 24th / 25th May. I am choosing to do this walk for the KPA as I have been a patient at Guy's and St Thomas' since December 2003 when I was diagnosed with kidney failure soon after the birth of my third child.



In October 2012 I had my first kidney transplant and have responded well.

I have fundraised several times for kidney research over the last 10 years but I decided this time I would give back to the KPA.

The preparation for this has included building up my walking tolerance from a couple of miles to currently being able to walk 15-18 miles in each session. I have also included some Zumba for cardio and toning.

I have set up a Facebook page to keep people updated with my training and my fundraising and a just giving page for my fundraising
https://www.facebook.com/hickmanwalk2014
http://www.justgiving.com/Ellie-HickmanWalk2014
or you can text **CLOP53** £(your amount) to **70070** to donate

To find out more about the London 2 Brighton Challenge visit:
www.london2brightonchallenge.com

Maybe YOU can do it next year!

Ellie Hickman

British Kidney Patient Association



We are often mistaken for the BKPA – in fact they are a quite different charity from the GSTT KPA and have a national remit.

The BKPA is the leading grant-giving charity for kidney patients in the UK. They work to improve quality of life for kidney patients and their families in a number of ways:

- By providing grants to those on low income, helping with welfare and domestic costs
- By supporting projects in renal units to help improve patient care and facilities
- By supporting national research
- By offering patient information, support and counselling
- By funding short breaks and holidays for children, adults and families

Each year, BKPA supply up to £2.5 million in grants. BKPA fund five of the eight NKF / BKPA Advocacy Officers and often support local Kidney Patient Association activities and members.

To contact BKPA:
www.britishkidney-pa.co.uk
www.facebook.com/groups/TheBKPA
www.twitter.com/The_BKPA

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