



kidneytalk

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

Support us to support you

Without the fundraising support of staff, patients and their friends and family, Guy's & St Thomas' Kidney Patients' Association (GSTTKPA) is unable to exist or provide valuable resources and support to kidney patients and their carers. We help patients by funding social events in the dialysis units and activities such as The Transplant Games. We also fund patient amenities, such as TVs in clinics and dialysis units as well as raising funds to support research activities at Guy's.

We have put together some fundraising ideas to help you support us to support you. Fundraising can seem daunting at the first, but with a positive attitude, the support of friends, family, colleagues and some imagination you will be amazed at what can be achieved. Some take a little organising however most are very simple:

- Dress-Down Day - wear casual clothes to school or work for a day, and ask everyone to donate £1 to the KPA, you could theme the day, wear pink, tartan, a hat, no tie or a flower.
- Give Something Up - like a Friday night take-out or a morning latte for a week and donate the money to the KPA. Alternatively, get sponsorship for every day you can go without something e.g. chocolate, if you're a serious chocoholic, or your favourite snack.
- Dance Marathon - get your music on and ask people to sponsor you for every five minutes of boogying you manage, or for every song you shimmy to.
- Ironing - do your entire household's ironing for one week in return for a donation to the KPA
- Sponsored Silence - would your family and friends pay money for a quiet day?
- Swear Box - get your friends or colleagues to put 50p in the box if they swear.
- Afternoon Tea Party - hold a party and ask for donations in return for light refreshments.
- Homemade Cake Sale - everyone loves cake. You will be the most popular person at work or college.
- Come Dine and Donate with Me - instead of going to your local restaurant, create a mouth-watering menu, invite your friends and ask them to make a donation. (If you can't cook, rope someone in to help!).
- Sell your stuff - dig around under the bed and at the back of wardrobes for anything you can sell and organise a jumble sale or car boot sale. Get your friends in on the act, selling their own unwanted items and donate the profits to the KPA.
- E-Bay selling is another great way to raise money by selling unwanted items. The KPA, is registered with E-Bay. You will avoid commission fees on sales by declaring the money raised will be donated to the GSTTKPA. <http://www.ebay.co.uk/egw/ebay-for-charity/charity-profile/Guy-s-and-St-Thomas--Kidney-Patients-Association/41105>
- Run or Cycle for Fun - train for a run or cycle event. The KPA have charity places in The Vitality British 10K Run and The Prudential Ride London cycle race. Contact us for details. You could train with a friend, support each other and get fit together.



Match Funding

Raise more by asking your employer to match the amount you raise. Many companies operate match donation schemes; they can get tax relief on charitable donations too. Ask your employer if they operate this type of scheme.

Set up a Standing Order

Make a regular payment to the KPA. Even a few pounds a month can make a huge difference to our work. The standing order form can be found on our website

<http://www.gsttkpa.org/donate-to-gsttkpa/>

Tips for Success

Look through the list of ideas and decide which one(s) you like and which one(s) you think you can do.

Create a 'JustGiving' page at www.justgiving.com/gsttkpa, it's quick, easy and secure. When someone donates on your page the money comes straight to us, so you don't have to worry about a thing and people can automatically add Gift Aid to their donation meaning we get an extra 25p for every £1 they donate if they are a UK tax payer. It's also a brilliant place to shout about GSTT KPA, so let people know that you have set up an account.

Spread the word about what you are doing, the more people that know, the better your chances of reaching your target. Your personal reasons for fund raising will really help motivate your supporters. Use social media, tell people at your work, your church, clubs or school. Facebook and Twitter are ideal for inviting and updating people. Join our Facebook page and follow us on Twitter. Seeing how you are progressing helps inspire people to give generously and fundraise too. Take lots of photos and send us copies. We can include them in our newsletter or in our social media pages. Tell us about your activities in advance and we can help promote them.

Please take extra time to plan fundraising activities involving children. Any fundraisers under the age of 18 should have their parent or guardian's permission to take part. Make sure children are properly supervised.

Donating funds to the KPA

For sponsored events, setting up a 'JustGiving' online account is an easy way for you and your friends and family to get the money to us, and the site also provides additional promotional material which you are able to download to promote your event.

JustGiving™

<https://www.justgiving.com/gsttkpa/>

Another simple way to donate is via our JustTextGiving number: Type the code WGXJ22 insert the amount you wish to give and this will be added to your next mobile phone bill.

We are also able to accept cheques and postal orders made payable to Guy's & St Thomas' Kidney Patients' Association.

Send by post with our donation form (which can be found on our website) or a short note saying how you have raised the money to:

GSTTKPA c/o Renal Offices, 6th Floor, Borough Wing, Guy's Hospital, Great Maze Pond, London SE1 9RT.

Please note that we are unable to accept cash.

After the event

Contact those who donated, send thank you notes, text or facebook messages, emails. It's a small thing to do but appreciated by donors. Let us know if you come up with a new idea to share with others!

Be Innovative, Inspired, Have Fun and Help Make A Difference!

Zandria Richards, KPA committee member

PIVOTAL

Proactive IV iron Therapy in haemodialysis patients

Dr Paramit Chowdhury

ANAEMIA IN DIALYSIS

People with kidney failure do not make enough erythropoietin (EPO), a hormone that triggers the bone marrow to produce red blood cells. Haemodialysis patients are also deficient in iron as it is lost during dialysis and patients are unable to absorb enough in their diet. Iron makes up the haemoglobin in the red blood cells which transports oxygen around the body.

Therefore, one of the complications for haemodialysis patients is that they develop anaemia. This leaves people feeling exhausted, lethargic and can reduce their quality of life.

Patients already have EPO injections and intravenous iron to treat the condition, but there is no consistency across the NHS as to how much is given due to a lack of research evidence.

PIVOTAL TRIAL

This is the largest clinical trial that has been conducted in renal units in the UK. It is funded through Kidney Research UK and Vifor Fresenius Medical Care Renal Pharma Ltd. Kidney Research UK co-ordinates the whole trial.

AIM OF THE TRIAL

To provide evidence about how much intravenous iron can be given to patients on dialysis to treat anaemia effectively and safely.

THE FACTS

The PIVOTAL trial will test two different approaches. Some patients will be given high doses of iron to increase the levels of iron in their body, but not so much as to be considered unsafe whilst another group will receive lower doses of iron only as per normal routine treatment when their iron levels start getting too low. The trial will gather evidence as to the safety and potential benefits of giving more iron.

Patients will be treated for at least two years once they are in the trial. It will be overseen by a safety committee of experts who will check that no patient is placed at risk.

The outcome of the trial will be evidence to identify the best method so that we can continue to treat all patients safely and improve their quality of life on dialysis. This new evidence can then be used to influence decision makers in the NHS to change the approach across the UK and may also influence healthcare globally.

WHO'S INVOLVED?

Around 2,080 patients from more than 50 renal units across the UK, who are in their first 12 months of receiving dialysis, will be recruited. The chief investigator is Professor Iain Macdougall of King's College Hospital, London, who is a world-renowned clinical expert on renal anaemia care. The trial manager is Claire White, also based at King's. The local investigator for Guy's patients is Dr Paramit Chowdhury and the study nurse is Emmanuel Mangahis.

The Robertson Centre for Biostatistics and Glasgow Clinical Trials Unit, University of Glasgow, collect all the data. There is a steering committee of experts, as well as an Advisory Board with representation from all of the major stakeholders in the kidney community.

For more information in the PIVOTAL trial, please contact Claire White, Clinical Trial Manager at clairewhite4@nhs.net

PATIENT AND CARER SUPPORT GROUP

Patients have played a key role in the development of PIVOTAL and a Patient and Carer Support Group has been established to raise awareness of research in their local areas. Members of the group also provide support and understanding for patients and research nurses as well as gathering feedback, to help inform the research, improve practice and care, and potentially help boost recruitment to the trial. If you are interested in being part of the Patient and carer support group, contact patients@kidneyresearchuk.org

We're off to the races!



Allez Encore (L) and King Simba (R) with some of their owners

The Guy's and St Thomas' Kidney Patients' Association (GSTTKPA) is keen to embrace new and innovative activities as part of our fundraising strategy. To this end, we are delighted to announce the charity is the chosen beneficiary of a charity horse racing partnership run by Henry Kimbell – our Vice Chair.

The 'GSTT KPA Charity Partnership' launched in January this year and already we have had beginners luck by having two winners from our first two runners!

Henry, who has run other partnerships before, has been a keen race-goer from a young age. He has joined forces with Grand National winning trainer, Kim Bailey, and together purchased two exciting horses who will run in the GSTT KPA's colours over the next year.

The first horse is a six year old called Allez Encore who will be running in mares' novices' hurdles. She has already won twice for us during

February – at Bangor and Plumpton – and we are very excited about her future. The second horse is King Simba, aged four, who will make his racing debut during the Spring. He is progressing well and everyone at the yard is impressed by his potential.

A percentage of each share price is donated to the charity along with 20% of any prize money earned by both horses. The charity also has its logo and name displayed on the jockey's silks whenever the horses run in order to raise our profile as much as possible.

£10,000 is the anticipated target from this venture and already we have reached £4,000 Racehorse ownership is often wrongly seen as only available for the wealthy however with the increase of partnerships and syndicates in order to spread the cost of keeping a horse in training, more and more people are turning to it as an exciting interest.

As an owner you will receive:

- Badges when the horses race
- A share of the prize money
- Behind the scenes visits to Kim Bailey's yard near Cheltenham
- The chance to meet the trainer and jockey
- Invitations to social events – such as pub lunches and the trainer's annual Open Day
- The chance to support kidney patients of Guy's and St Thomas'

Unfortunately my first transplant only lasted four years and I underwent a second one four years ago. During that time the expert care and attention I received was superb, especially given the rare disease that caused my kidney problems in the first place. I am so grateful to the kidney team at Guy's Hospital for helping me back onto my feet again. Today I feel as fit and healthy as I have ever done in my whole life.

This partnership is very important to me as I want to use it as a way to raise funds for the charity but also of equal importance is to raise awareness of kidney disease and the wonderful work that both Guy's and St Thomas' hospitals perform on a daily basis for patients like me.

There are just four shares remaining in our partnership so please contact me to discover more about this exciting venture.

Mobile: 07979 522744 or email henrykimbell@hotmail.com

If you want to follow the exploits of Allez Encore and King Simba please keep in touch via our Facebook (GSTTKPA) and Twitter pages (@gsttkpa)

Henry Kimbell, Vice Chair

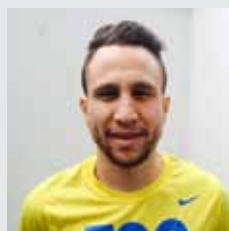
LONDON MARATHON RUNNERS 2015



Sarah Wilding

<http://uk.virginmoneygiving.com/SarahWilding>

I am the Head of Nursing and Joint Clinical Director at present for the kidney service at Guy's so a large part of my role is to improve services for kidney patients. I am part of a women's running club, have ran 10km for charity previously and am fully committed to building up running experience.



Oliver Ogilvie

<http://uk.virginmoneygiving.com/OliverOgilvie>

I would like to run for the GSTT KPA as it is very close to my heart. Guy's have been really good with my dad and are always nice and pleasant when I drop by the dialysis centre. I have ran a half marathon previously last year and am excited to be involved in a full marathon supporting them again this year.



James Hodges

<http://uk.virginmoneygiving.com/JamesEHodges>

I am delighted to be running for Guy's and St Thomas' Kidney Patients' Association. My mum is a volunteer with a kidney dialysis unit in Norfolk and I am friends with a sister at Guy's and St Thomas'. Having seen their passion every day in looking after people, I am keen to try and match that passion on the roads.



Natalie Larnder

<http://uk.virginmoneygiving.com/NatalieLarnder>

I came to hear about the KPA through a colleague whose son underwent a transplant at a very young age. I really admired the fundraising efforts of their family so I was very excited to have the opportunity to run the London Marathon in support of the charity. My training is going well and I'm really looking forward to the race.

Teenagers in Brent put their creative talents to the test to raise awareness of organ donation

Dela Idowu a member of the GSTTKPA and director of Gift of Living Donation (GOLD), is working in partnership with The Crest Academies in Neasden, North West, London where pupils aged 11-17 will be putting their creative talents to the test over the coming months to take part in a poster competition. The aim is to raise awareness of organ donation in young people as well as people from Black or Asian communities, who make up around 80% of Brent's residents.

The posters will spell out the benefits of being an organ donor, which will then hopefully inspire residents to join the organ donor register. The winning posters will be displayed in Wembley library and local medical centres.



Dela said "We came up with the idea to work with students after GOLD carried out a survey which found young people said they knew little or nothing about organ donation. They are very keen to express their views on organ donation through art. The poster competition is based on the tag line "1 donor = 9 lives saved".

Hopefully we will be able to print the winning poster in the next issue of Kidney Talk.

Dates for your diary

Charity Race Night

Saturday 25th April, Princes Park Stadium
Dartford, 7pm.

In aid of the MPGN/DDD
(Membranoproliferative Glomerulonephritis /
Dense Deposit Disease) Charity.

Contact Kim for details: T: 07956 377516
E: kpjessup@hotmail.co.uk

Virgin London Marathon

Saturday 26th April – support the KPA runners

National Transplant Week

6th – 12th July

Vitality British 10K Run

Sunday 12th July – support the KPA runners



Celebrate your Kidneyversary with the KPA

We would really like to hear about how you celebrate your kidney transplant anniversary each year. Maybe this year you, your family and friends would like to make a donation to the KPA to help us help other kidney patients. You can use the text number or set up your own Just Giving page and JustGiving text number.



www.justgiving.com/gsttkpa/



www.facebook.com/groups/gsttkpa



@gsttkpa



Kidney News - In Summary

Following the GSTTKPA AGM and subsequent discussions, Sue Cox, Consultant Nurse, has agreed to re-start the peer support programme. See the GSTTKPA notice board in the Kidney Clinic.

Nationally, there are on-going tensions regarding the provision of social work for kidney patients. The National Kidney Federation (NKF) has decided to collect data to evidence what social workers are actually doing. The NKF is also challenging the utility costs for home haemodialysis patients (water and electricity). The national tariff has not been reviewed since 1974!

World Kidney Day was on 12th March 2015. We had a stall in the Guy's Foyer. We promoted awareness about kidney disease. Look out for us during Transplant Week (7th-13th July 2015).

The Government will be announcing (30th March 2015) additional funds to drive down transport waiting times. Nationally, the majority of complaints from kidney patients relate to transport.

Dr John Scoble, Consultant Nephrologist, will be retiring in April 2015. Dr Scoble leaves a legacy of care for his patients. Thank you, Dr Scoble.

Many of you will also know, Dr Scoble, is also a kidney patient, when he donated to his cousin, in 2010. The experience, he acknowledged, increased his awareness about what patients actually think and feel.

Please see Dr Scoble's story in the link below:

<http://ind.pn/1Mn9qjQ>

Finally, this edition has a strong emphasis on fund-raising: we need funds to support patients. However, this is only part of the picture. The GSTTKPA strives to be patient-led by your voices and so if you have any comments or suggestions as to which areas of your patient experience so be given due consideration by the charity then please get in contact!

**Please contact me, Sonia Moorhouse,
Chair, GSTTKPA**

Email: chair@gsttkpa.org

T: 0207 188 7552

**Post: GSTT Kidney Patients' Association,
Renal Offices, 6th Floor Borough Wing,
Guy's Hospital, Great Maze Pond,
London SE1 9RT**