

kidneytalk

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



World Kidney Day

The KPA embraced this year's World Kidney Day with a collaborative event alongside the PKD Charity, Diabetes UK and Guy's and St Thomas' Medicinema facility.

Kidney patients and their families were invited to an afternoon of tea and cake followed by a screening of JOY starring George Clooney. Members of the GSTTKPA Committee manned an information stand in order to promote awareness of the charity's activities and organ donation – there was a lot of interest from visitors and many questions were answered.

For those of you who aren't aware the Medicinema facility is available to all patients and carers under the care of Guy's and St Thomas'. Based on the

second floor of the Tower Wing, this state of the art facility provides a hospital cinema and much needed respite and independence for inpatients whilst also being available for individuals who might just be passing through following an outpatient appointment.

As ever we will be out in force again for 2017. If you like working with other people and feel you can spare just two hours a month to assist the charity with their expanding promotional work then please contact us as we are regularly on the hunt for willing volunteers!

Improving experience for kidney patients in London – survey results

At the end of last year dialysis patients across London were invited to take part in a survey to find out more about what works well in their kidney unit and what could be improved. The Guy's and St Thomas' responses were as follows:

WHAT WE DO WELL

- You said you get help from experts such as dieticians, counsellors, physios or pharmacists
- You agreed that you are encouraged to do as much as you can in your treatment
- You agreed that your carers are involved in the way you want
- You agreed that the kidney team treat you with care & compassion
- You agreed that you feel able to discuss your emotions

WHERE WE NEED TO IMPROVE

- We need to ensure you have a written care plan agreed by you and the kidney team
- Action:** we are looking at ways to provide you with a personalised dialysis report which will also include a care plan
- We need to give you more information about patient groups

Action: we are working with the GSTTKPA to raise awareness of patient groups

- We need to give you more information about Peer Support

Action: we have recruited more Peer Supporters and we are raising awareness of this service via written information and via the staff

- We need to involve you more in how services are run

Action: we will be actively seeking to involve patients in all new developments

- We need to show you results from surveys

Action: survey results have been sent to the dialysis units and we will keep you updated via this newsletter.

By Ros Tibbles, Service Improvement Nurse

For further information contact:

E: ros.tibbles@gstt.nhs.uk T: 020 7188 7552

The survey was compiled by the London Strategic Clinical Network and around 93 Guy's and St Thomas' dialysis patients kindly completed the survey for us.

A word from the Chair...

Guy's and St Thomas' Kidney Patients' Association (GSTTKPA) in partnership with the Poly-Cystic Kidney Disease (PKD) Charity and the Trust celebrated World Kidney Day on 10th March 2016. We were also supported by the Trust's Research Team; British Kidney Patient Association; Diabetes UK; Medicinema, GIFT (Living Kidney Donation); National Health Service Blood and Transfusion (NHSBT); Carers UK and Breathe Arts. The purpose of the event was to raise awareness and was designed by Nicki James. PKD also launched their Telephone Befriending and Peer Support Project with funding from the lottery. This service is accessible to all patients with a PKD diagnosis. For more information, please see the link: <http://pkdcharity.org.uk/support/pkd-telephone-befriending-and-peer-support>

In this edition, Peter Bennett, responsible for GSTT transport services, provides an informative update regarding transport services and delivery (see page 4).

The Renal Registry is working with a number of renal units to enable renal staff to encourage more patients to take a more active role in their health management and care to improve patient outcomes and experience of services and to reduce costs. These change processes run in tandem with NHS England's agenda to improve quality and also to reduce costs; more information later this year.

Following a request from the Renal Department, the GSTTKPA has funded a staff 'photo board' for the Outpatients' Clinic. Our current, additional funding projects are to the chaplaincy service to help dialysis patients improve their coping skills and the production of an illustrated book for 4-7 year olds whose parent(s)/carer(s) are suffering from renal disease (see page 5).

Following feedback from World Kidney Day, we are pleased to announce the launch of 'newsletter doses' which will be focusing on issues of interest and concern to patients including diet and general lifestyle advice.

Finally, we will be having our 2nd Fun Day for patients, families and staff at the 'all weather' venue (rain or shine) in Honor Oak SE23 on 26th June 2016. All are welcome.

Sonia Moorhouse, Chair, GSTTKPA
Email: chair@gsttkpa.org

LONDON MARATHON RUNNERS 2016

The 2016 runners were Mellissa Byrne, John Cook, Ian Jack, Steve Pockett, Daren Snook, Giovanni Tritto and Russ Williamson. Paula Cozens and Johnathan Hubbard were sadly injured in the lead up to the race however both of their places will carry over to next year.

The charity would all like to express our thanks to each of the runners who have put in many miles both training and fundraising for this iconic event! As the time of printing the combined fundraising total was in excess of £10,000 for the GSTTKPA – some achievement indeed!

If anyone would like to make a donation to any of the runner's fundraising pages then please make a contribution directly to the charity, via BACS or online at www.justgiving.com/gsttkpa, stating your recipient's name in the reference box.

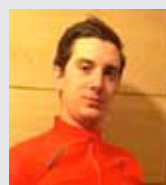
The charity is delighted to have 'the services' of John Cook in this year's Marathon. John is the son of Trevor Cook who was the former chair of the KPA for almost ten years and devoted much time and expertise during his tenure to the benefit of the charity. Sadly Trevor passed away in late 2013.



Mellissa Byrne



Ian Jack



Daren Snook



Steve Pockett



Giovanni Tritto



John Cook

This year I am running the London Marathon in memory of my late father, Trevor Cook, who passed away a little over 2 years ago. I will be running for GSTTKPA, a charity that my father benefitted from as a patient and was later Chair of the charity until shortly prior to his death.

Thank you for supporting a charity that is close to both me and my family.

John Cook – son of former GSTTKPA Chair Trevor Cook.



Dave Stevens

My reason for choosing such a worthy cause is quiet simple, as a child I was helped by Guys hospital and at this moment a friend's grandson is currently receiving treatment at Guy's and St Thomas'. Furthermore my mother and uncle have also received excellent care here as well - so in my eyes my small effort is a small thank-you for everything.

Dave Stevens on his reasons for taking up the London Marathon challenge.



Russ Williamson

After being lucky enough to obtain a ballot place in this year's London Marathon, I wanted to fundraise for a charity that helped people on a local level in the area I live in. Some of my colleagues at work praised the essential services that GSTTKPA provides to kidney patients, and so it was an obvious choice! I'm delighted to be running in support of the organisation. Bring on the start line!

Russ Williamson on why running for the GSTTKPA is motivating for him.

OTHER EVENTS

The KPA has successfully filled two of its three places for the **Prudential Ride 100** cycle ride, which takes place on Sunday 31st July. Our representatives this year are:

Chris Reid Consultant Children's Nephrologist at the Evelina Unit and Paul Palmer.

There are also charity places available for the **British 10K** in London on Sunday 3rd July and in the one mile **Swim Serpentine** event on Saturday 24th September.

To secure your place at either event please contact GSTTKPA Events Co-Coordinator Teresa Durkin using teresa.gsttkpa@outlook.com or by calling 0207 1887552.

2ND FAMILY FUNDAY

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

**SUNDAY
26TH JUNE
1PM-6PM**

**GUY'S & ST THOMAS' KIDNEY PATIENTS' ASSOCIATION
INVITE KIDNEY PATIENTS,
FRIENDS & FAMILY, GUY'S & ST THOMAS' RENAL STAFF.**

WILL INCLUDE:

**BOUNCY CASTLE
5- ASIDE- FOOTBALL**

**FACE PAINTING
FREE BBQ**

**EGG & SPOON RACE
CAKE SALE STALL**



VENUE:

**KINGS COLLEGE SPORTS GROUND
BROCKLEY RISE/ STILLNESS ROAD, LONDON, SE23 1NW,
(Nearest Station Honor Oak Park- Buses P4, 122,185)**

**TO RESERVE YOUR PLACE, PLEASE SIGN UP USING THE
REGISTRATION FORM AT YOUR DIALYSIS UNIT OR REGISTER AT
WWW.EVENTBRITE.CO.UK/E/GSTTKPA-FUN-DAY-TICKETS-24233317505**

**THE VENUE IS WHEELCHAIR ACCESSIBLE. PLEASE
NOTE TRANSPORT WILL BE PROVIDED TO AND FROM
CERTAIN DIALYSIS UNITS, CONTACT US BY EMAIL OR
PHONE FOR MORE INFORMATION.**

PLEASE SIGN UP FOR ANY TRANSPORT ON THE SHEETS THAT ARE IN ALL OF THE DIALYSIS UNITS.

HOLIDAY DIALYSIS UPDATE

By Ros Tibbles, Service Improvement Nurse

The holiday season is fast approaching and many of you may be thinking about taking a short break. If you are a dialysis patient you should start planning your holiday at least two months before you wish to travel. The dialysis away from base guidance from NHS England has recently changed, our new information leaflet will be available soon, meanwhile, here is a summary:

Dialysis in the UK

- At an NHS dialysis unit you may have an unlimited number of holiday dialysis sessions per year free of charge, providing the unit can accommodate you.
- In a private (non NHS) unit in the UK you may have an unlimited number of dialysis sessions free of charge as long as the private unit has an agreement with NHS England. You should check this with the private unit before booking treatment with them.

Dialysis outside of the UK

Within the European Economic Area (EEA):

1. Dialysis in a state-provided unit:

The European Health Insurance Card (EHIC) allows you to access state-provided healthcare in all European Economic Area (EEA) countries.

2. Dialysis in a private unit:

In this situation you will need to pay for the dialysis treatment sessions yourself and apply before you go away for a partial or full refund from the Cross Border team of NHS England under a European directive known as Article 56.

Outside of the European Economic Area (EEA):

Check whether or not the country has a reciprocal healthcare agreement with the UK. This information is available on the NHS Choices website. If they do not have a reciprocal healthcare agreement, you will have to pay for the entire cost of your treatment(s) in that country yourself.

Dialysis on a cruise ship:

If the cruise is within the boundaries of, or the majority of the cruise ports of call are to an EEA country or a country with which the UK has a reciprocal agreement, then you can be reimbursed up to the cost of an NHS dialysis treatment. Before you go on your cruise you will need to get approval from your Guy's and St Thomas' kidney team for the reimbursement and we will refund you on your return.

If the cruise is taking place **outside** of the EEA or to a country(s) with which the UK does not have a reciprocal agreement, you will have to pay for the total cost of dialysis yourself.

How can I arrange holiday dialysis?

1. Check with your kidney care team to ensure that you are fit enough to travel.
2. Choose your destination, find out where the nearest dialysis unit is located (nursing staff in your dialysis unit can advise you how to go about this); make contact and see if they can accommodate you for dialysis on your preferred dates.
3. When you have contacted your unit of choice and confirmed that they can accommodate you, inform your nursing staff so that they can forward the holiday unit an infection control checklist.

What are the risks?

Although we will carry out checks on the holiday dialysis unit, it is not possible to give complete assurance regarding the service and level of risk, particularly for units outside of the UK. Blood-borne infections, such as hepatitis B and hepatitis C, are more common in other parts of the world than they are in the UK. As a dialysis patient, you are more vulnerable to these infections, which can be life-threatening.

Will I be suspended from the transplant list if I go on holiday?

Yes, if you travel to a location outside the UK where getting back quickly enough will be a problem. If you have been to a country where blood-borne infections are common you will be suspended from the transplant list for two months as the transplant medications can be dangerous for people with recently acquired infections.

What should I do about medications?

Take enough medications with you to cover your entire holiday period and carry them in your hand luggage.

It may all sound complicated and worrying but many of our dialysis patients do travel so please don't be put off! Ask the nurses in your dialysis unit for assistance in planning your holiday. Look out for the updated patient information leaflet in the leaflet racks and on the trust website (kidney section).

You may also wish to visit www.gsttkpa.org/ kidney-information for more information about holidays for kidney patients.

IMPROVING OUR PATIENT TRANSPORT SERVICE



By Peter Bennett, Head of Hotel Services, Guy's and St Thomas' NHS Foundation Trust

We provide a free transport service for our patients with a medical need. Every month, we carry out approximately 24,000 patient journeys, nearly half of which are for patients travelling to our kidney units. Ensuring you have a comfortable, timely and safe journey to and from our units and hospitals is a priority for us. We are constantly working on ways to improve your experience despite a very busy and challenging service.

Our latest challenge was to transfer the majority of the service to Savoy Ventures to ensure we delivered a consistent service across the board. Savoy Ventures have already been providing the service to Camberwell dialysis unit and shared the service, with our own patient transport team, to Borough Kidney Treatment Centre and Astley Cooper dialysis unit at Guy's. Since December 2015, Savoy Ventures are also providing the service to Tunbridge Wells, Sidcup and Forest Hill dialysis units.

Delays in recruiting new drivers and receiving new vehicles have affected the way the service was delivered in its first weeks and a number of you have voiced your concerns. We would like to take this opportunity to apologise for any inconvenience or worry that this has caused. We have been working with Savoy Ventures, patients and staff to resolve these problems. The Guys' and St Thomas' Kidney Patients Association and the nursing teams have put forward some ideas for improvement and one of the new initiatives involves us undertaking regular visits to the dialysis units to get feedback from patients and staff about any specific, local issues or concerns so that we can address them directly.

Dedicated drivers and back-up support for each dialysis unit, along with brand new vehicles, will soon ensure your journeys are completed on time and to a great standard of comfort and care.

For more information, please contact the patient transport team – Tracey Connors, Patient Transport Liaison Manager (020 7188 7188 x 53080, tracey.connors@gstt.nhs.uk)

INNOVATION GRANT

The charity recently announced expressions of interest for a £10,000 innovation grant. We wanted to be able to proactively accelerate the development of a piece of research, service or equipment, through making a significant financial contribution available, that otherwise would remain unfunded

A range of applications were submitted and we are delighted to announce that the joint winners are:

Victoria Hanson – Clinical Nurse Specialist in the Advanced Kidney Care Clinic

Victoria is developing an idea for a children's book aimed at boys and girls up to the age of seven who have a family member living with kidney disease. The book provides animated illustrations to help them better understand kidney disease and kidney care whilst helping to answer important questions about dialysis, transplantation and diet.

Reverend John Watts and Reverend Peter Oguntimehin – Renal Chaplains

This grant will further expand on the Living Well programme which was an outcome from the Modernisation Initiative. This donation will fund a support group made up of kidney patients, kidney chaplains and other members who will provide pastoral support helping dialysis patients deal, and importantly overcome, feelings of low self esteem, planning life goals and managing their pain thresholds.

Calling all 4-7 year olds! Art Competition...

We are asking children who have a relative with kidney disease to draw or paint a picture of what kidney disease means them

The topic can cover anything the child wishes
Example topics might be dialysis, transplantation, medication, or diet

The WINNING entry will be included in our new children's book about kidneys and featured in a future KidneyTalk newsletter!

Please return your child's picture to Victoria Hanson at Guy's Kidney Clinic or email victoria.hanson@gstt.nhs.uk

Competition entries only open to children aged 4-7 who have a relative with kidney disease

Closing date June 30th

(Don't forget to add your child's name and age)

After taking into consideration feedback from our stakeholders, KidneyTalk will now have a new look feature. Each newsletter will have a focussed feature offering patients advice and guidance on how to deal with health, diet and general lifestyle questions when living with kidney disease.

The first in our series entitled 'NEWSLETTER DOSES' tells you all about Hepatitis E.

What is hepatitis E?

by Dr Rachel Hilton, Kidney Consultant

Hepatitis means inflammation of the liver and this can be caused by a number of different viruses, including Hepatitis E Virus (HEV). In most cases HEV infection causes either no or very mild symptoms. But in rare cases, particularly in pregnant women, it may be fatal. The infection usually clears by itself, but in individuals whose immune system is suppressed, following transplantation for example, the virus can persist and cause chronic liver inflammation.

How common is hepatitis E?

Hepatitis E occurs in parts of the world where sanitation may be poor, including Asia, Africa and Central America. However HEV infection may also be caught in the UK and Europe, and the numbers of confirmed cases and infections have increased significantly recently.

How can I tell if I have Hepatitis E?

Most people who get infected with Hepatitis E Virus will never know about it. Fewer than one in a hundred people can get yellowing of the skin and eyes (jaundice), darkening of the urine and pale stools, tiredness, fever, nausea, vomiting, abdominal pain and loss of appetite. These symptoms usually disappear within four weeks. However, in individuals who are taking immunosuppressant medication there may be no symptoms, even if the infection has become persistent. HEV infection can be confirmed by blood tests.

How is Hepatitis E Virus transmitted?

In the developing world the virus may be transmitted in contaminated food or water. In the developed world infection is through eating undercooked meat or shellfish. Person to person transmission is very rare, although someone with Hepatitis E should always wash their hands after using the toilet. There have been cases of the virus being transmitted through blood transfusion and organ transplantation.

How is hepatitis E treated?

In most cases, Hepatitis E infection clears by itself, with no need for any treatment. However, in immunosuppressed patients the HEV infection may become persistent and either a reduction in medication or a course of antiviral treatment may be needed to clear the virus.

How can I avoid Hepatitis E Virus infection?

Wherever you are in the world you should avoid eating raw or undercooked meat, particularly from pigs, wild boar, deer or rabbits and also shellfish. In the UK and Europe, it is important to make sure that processed food containing pork is well cooked, especially sausages. When travelling to countries with poor sanitation, it is advisable to boil all drinking water, including water used for brushing teeth. Currently, there is no vaccine for hepatitis E.

Where can I get further help?

Further information and advice is available from: NHS Direct (Tel: 0845 46 47 or www.nhsdirect.nhs.uk/), your own GP or The British Liver Trust Tel: 0800 652 7330 or www.britishlivertrust.org.uk/home.aspx

A strike, a double or a turkey!

A small group of Guy's young adult kidney patients met up with other young people from St George's and the Royal Free kidney units last month for an afternoon of bowling, food and fun.



The Hollywood Bowling Alley at Queensway was chosen as a good central location to make it easy for travel. Most of the young people had not met before but taking part in bowling, no matter what your skill level is, proved to be a great way to break the ice. Some people were definite naturals whilst others showed that you don't have to be an expert to still have fun and enjoy yourself.

We had time for more than one game of bowling so the people who scored the highest from the first game got the chance to compete for top scorer of the day. There was no golden trophy, just the glory and fame to play for.

After the bowling while we waited for our food we had the chance to try out the slot machines, arcade games and play a few air hockey matches. The dance machines proved very popular and kept us all entertained.

The afternoon was organised by myself and the kidney youth workers at St George's and the Royal Free kidney units and was open to all young adults with kidney disease. It proved to be a great success and everyone involved is looking forward to the next chance to meet up again. The British Kidney Patients' Association (BKPA) generously funded the afternoon so as many people as possible could attend.

A "Picnic in the Park" is being planned at a central London location in mid June. If you are aged 15 – 25 and you'd like to be involved in this, or if you have other ideas that could help bring young adult kidney patients together outside the hospital setting, then please get in touch. Social events and activities can provide the opportunity for vital peer support and the chance to mix and talk with other people of a similar age.

Please contact: Vanda Fairchild – Young Adult Kidney Nurse on 07581 621 930 or email vanda.fairchild@gstt.nhs.uk

Social Media Volunteer

The KPA is on the hunt for an energetic, enthusiastic and committed individual who can assist in their online management and campaign planning as well as helping expand the charity's social media profile.

Are you a student who is studying media at College or University?

Have you previously worked in the media agency world and would like to offer something back to support a charity?

If this is YOU please contact us for further information about the role.

BKPA young adult

ACTIVITY WEEKEND

RAVENSTOR 2016

16TH · 17TH · 18TH SEPTEMBER

If you're 18–30 and have a Chronic Kidney Disease, had a transplant or are on dialysis, you can come and enjoy an action packed free weekend at Ravenstor Youth Hostel, an impressive country house in the heart of the Peak District.

- Meet other young adults from across the UK.
- Enjoy a wide range of activities including archery, canoeing, walking, cycling and lots of fun socialising.

"Awesome weekend away, met some great people and now have some epic memories. Can't wait for the next one."

How do I book my place?

To book or for more information email the British Kidney Patient Association at info@britishkidney-pa.co.uk, write on the [young@NKF](https://www.facebook.com/young@NKF) Facebook page or contact the Young Adult Worker at your unit:

Vanda Fairchild, Young Adult Kidney Nurse
Mbl: 07581 621 930
Email: vanda.fairchild@gstt.nhs.uk

The weekend may not be suitable for people with mobility issues. If you have any concerns please check with the Young Adult Worker at your unit.

BRITISH KIDNEY
Patient ASSOCIATION
improving life for kidney patients

How to contact the GSTTKPA

E chair@gsttkpa.org or info@gsttkpa.org
W www.gsttkpa.org **T** 0207 188 7552

