



KIDNEY PATIENTS SUPPORTING KIDNEY PATIENTS

Welcome to the latest issue of Kidney Talk, the newsletter of Guy's & St Thomas' Kidney Patients' Association (GSTTKPA). As the weather gets colder, the leaves fall from the trees and the shops bring out their Christmas displays, it's a good time to reflect on the past few months since the last issue of Kidney Talk.

As far as GSTTKPA is concerned, it's been an eventful summer. We held our Fourth Family Fun Day in July for kidney patients, family carers and staff at GSTT (page 4), and it was our most successful event ever. Our thanks to every one of our supporters who made the Fun Day possible—we're already looking forward to Fun Day 2019.

I am also very pleased to let you know that our fully updated website is now live at www.gsttkpa.org. We will be gradually adding new content, but in the meantime you'll find links to information about kidney disease and its treatment, support services, holidays, kidney-friendly cookbooks, and current kidney and transplantation research at GSTT. You can also sign up to our mailing list to receive regular alerts about your KPA, including a link to read Kidney Talk.

We were very pleased to be able to provide financial support to the GSTT adult and the Evelina London teams at the British Transplant Games, held in Birmingham in August. You can read about the medal-winning success of the teams on pages 6-7. Our congratulations to everyone who took part, including both teams' volunteer supporters without whom many people could not compete in the Games. If these reports inspire you with thoughts of

competing next summer, when the British Transplant Games will be held in Newport, you can find out more at the Transplant Sport UK website at <http://www.transplantsport.org.uk>.

You will see on pages 2-3 that GSTTKPA also helped a group of young adult kidney patients from GSTT to attend a 'Climbing Out' outdoor activity weekend in North Wales. I was personally very pleased that we were able to support this visit. When I 'crashed landed' into kidney failure, I was a young adult aged 25. I was not dependent on my parents, had finished my education and had started my career, so I was more fortunate than other young adults who had lived with their condition since childhood. However, even 40 years later I still recall the loss of self-confidence and fears for my future following my diagnosis.

One of the ways that I coped with my new future was by talking to other patients—people just like me who understood my feelings and worries. This is why the availability of peer support at Guy's kidney clinic is so important. Peer support gives us the opportunity to talk with a fellow patient, who has gone through similar experiences and has been trained to give one-to-one support.

Peer support is available at any time, including when you are first given your diagnosis or when thinking about your options for treatment. You can ask to be put in touch with someone of a similar age or background, or undergoing a specific type of treatment. If you would like to know more about peer support, ask your kidney doctor or nurse or, if you prefer, telephone the consultant nurse for advanced kidney care on 020 7188 7924.

Support for our fellow kidney patients is always a key aim for GSTTKPA, but we know that we could do better. If you have any suggestions or would like to support us, please email me at chair@gsttkpa.org. Better still, share your thoughts at our Annual General Meeting at Guy's on Saturday 1st December from 10.00 to 12.00 (details on page 8).

Until then, my very best wishes for Christmas and the New Year to you all.

Sue Lyon, Chair

KEEP IN TOUCH WITH YOUR KPA



Visit our new website at gsttkpa.org to read the latest issue of Kidney Talk and sign up to receive KPA news direct to your inbox.

Join our Facebook group facebook.com/groups/gsttkpa

Follow us on Twitter
[@GSTTKPA](https://twitter.com/GSTTKPA)



Climbing Out!

Young adult kidney patients take to the hills

In early July a small group of Guy's and St Thomas' young adult kidney patients took part in a Climbing Out outdoor activity programme held in North Wales. They joined other young people from Leeds Renal Unit to stay together in a youth hostel situated on a remote hillside. I was fortunate in being able to attend as a volunteer youth worker to support the whole group and fully participate in the challenges on offer.

Climbing Out (www.climbingout.org.uk) is a charity that runs bespoke five-day outdoor activity programmes aimed at rebuilding confidence and self-esteem in young people aged 16-30 years, who've been through a life-changing injury, illness or trauma. The programme offered a wide range of activities, including climbing, gorge scrambling, coast steering, kayaking, hill walking, abseiling and raft building.

The group was made up of young people with different kidney conditions (dialysis, transplant, chronic kidney disease and nephrotic syndrome). All the activities were tailored to the needs and capabilities of the individual participants, so that it didn't matter about their fitness or physical limitations and everyone was kept fully involved throughout the week

The instructors were specifically trained in personal development coaching as well as outdoor activities, and ran fun and light-hearted sessions each morning and evening, so the young people could review and reflect on their learnings from the day's activities. These sessions provided

the young adult kidney patients with the skills to then transfer those lessons to life after completing the programme.

On arrival, only a handful of the participants knew each other, having only met on their long journey to Wales. But by the end of the week, there was an overwhelming feeling of camaraderie and team spirit due to the shared learning and positive experiences they had gained together.

Different social events were held each evening, including an inspirational talk by a young person who had experienced challenges and trauma in their life, a Quiz night and a BBQ and there were plenty of opportunities for the young people to socialise with their peers.

Although the activity week was fully funded by Climbing Out, these young people were only able to travel from London to participate due to the generous grant made available from GSTTKPA. I would like to say a personal thank you to the current Chair and KPA Committee for their continued support of young adult kidney patients and for all those people who tirelessly help to raise precious funding for the KPA. The statements here are from just a few of the young people who attended the week.

Vanda Fairchild
Young Adult Kidney Co-ordinator, Guy's and St Thomas' NHS Foundation Trust



Georgie (age 21 years)

I would just like to say a massive thank you to the KPA for funding the car and the diesel, which made it possible for us to go to North Wales and to participate in the Climbing Out programme. The days I enjoyed most were when we did the abseiling and the coast steering. I would have loved to have done the abseiling again but we ran out of time. :) The challenges I faced were being scared to try the activities out on show, for example the coast steering and the abseiling. I was very worried at first, but with all of the support from the staff I was able to conquer my fears and do the activities. I have learnt a hell of a lot while away in North Wales—stuff that I will take away and use in day-to-day life.

Steve (age 26 years)

My time in Wales was inspirational, filled with new experiences and challenges to overcome. This was an adventure and I would recommend everyone to attend this programme. I'm greatly appreciative to all those involved; you have given me a memory that I won't forget.

Lia (age 19 years)

I would like to begin this message with a massive thank you for GSTTKPA. Participating in the Climbing Out programme has inspired me to feel fearless, despite the general lack of self-confidence partially caused as a result of my illness. Climbing Out has reignited my passion for the interests I used to have, but have had to stop due to my health. For the first time in my life I felt able to freely open up about my condition. I no longer felt like I had to hide behind a curtain to fit in with society's perception of 'normal.' I was able to feel accepted for who I was. Climbing Out has broadened my horizons. It has offered opportunities to experience some outdoor activities that are rarely experienced—for example, kayaking, abseiling and coast steering—all of which have had a substantially positive impact on my self-confidence. Through this experience I have learnt that I can make positive choices and that I am my own teacher.

Opening soon

TWO NEW DIALYSIS UNITS FOR GUY'S & ST THOMAS'

St Thomas' dialysis unit

Work is progressing on a four-bedded dialysis unit on the 12th floor of the North Wing at St Thomas' Hospital. This purpose-built unit will provide haemodialysis for inpatients only. This means that inpatients at St Thomas' who require haemodialysis will no longer need to be transported to Astley Cooper at Guy's. This will significantly improve the patient experience.

The unit will be staffed by the Guy's kidney team and is due to open before the end of the year. Initially, the unit will be open from 7.00 am to 8.00 pm Monday to Saturday and will treat two shifts of four patients.

Lewisham dialysis unit

Construction has started on a new dialysis centre at University Hospital Lewisham, which is expected to open next spring/summer. The unit will be run in partnership between Guy's and St Thomas' and dialysis specialist providers Diaverum UK. The purpose-built unit will have five more dialysis stations than the existing dialysis unit in Forest Hill, which it will replace.

The new unit will also include two side rooms dedicated to caring for inpatients at University Hospital Lewisham who need haemodialysis. Currently these patients are often transferred to Astley Cooper dialysis unit at Guy's, three times a week, for their haemodialysis treatment.

The new unit will be modern, spacious and more comfortable for patients and will bring vast improvements of comfort and privacy. It will be staffed by the same team and operate the same opening hours as the Forest Hill unit.

Would you like to help plan kidney services in South London?

The South London Renal Operational Delivery Network (ODN) was set up in 2017 by NHS England to work with the four hospital trusts (including GSTT) that provide kidney care for people in South London, North Kent, East Sussex and East Surrey.

The ODN is now setting up a Public and Patient Scrutiny Group, and wants to involve as many patient and carer representatives as possible to help with

improvement, planning and service delivery.

If you are interested in joining the Public and Patient Scrutiny Group, please contact Sharon McDonald on england.southlondonrenalodn@nhs.net or 020 8296 2250.

- Meetings will be held four to six times a year in the early evening or weekends at accessible venues.
- Approved travel expenses will be reimbursed based on the policy of the hospital

You can find out more about this improvement programme at <https://bit.ly/2DeSg9F>

GSTTKPA FAMILY FUN DAY

Fun Day 2018 was held on 15th July, which proved to be one of the hottest days of a very hot summer. However, the heat and a competing event (the World Cup Final in Russia) did not prevent over 120 patients, family members and kidney unit staff from enjoying the entertainment, raffle, sports competitions and free barbecue.



The KPA is very grateful to everyone who made the event such a success, especially to actor Peter Quince, who formally opened the event; everyone who kindly donated the prizes; George Brown and Teresa Durkin, the event organisers; the staff at King's College Sports Ground; and the GSTT patient transport team.

This year was our fourth family Fun Day and the most successful ever. We are starting to plan next year's event, and will share the date as soon as we can. In the meantime we welcome your thoughts on how we can make Fun Day 2019 a day to remember. Email us at info@gsttkpa.org

Transplant at Evelina London?

Did you or a family member have a transplant at Evelina London? If so, the team would like to hear from you.

This November sees the milestone of the 50th anniversary of the first Evelina children's kidney transplant. To mark the occasion, the Evelina team are planning an event on Friday 23rd November from 1.30 pm to 6.00 pm in the Evelina Atrium and Governors' Hall at St Thomas' Hospital.

The theme of this very special anniversary meeting is: *'Remember the past, live the present and shape the future'*. The event will feature former and current patients and staff, and it is going to be a real celebration.

If you would like further information or would like to join the celebrations, get in touch with Grainne, Transplant Advanced Nurse Practitioner at Grainne.Walsh@gstt.nhs.uk or 07342 060347



Introducing PITHIA

New research study aims to boost transplants from older deceased donors

Many potential kidney transplants are from deceased donors aged 60 years or older, but many of these kidneys are not used due to worries about how they may work. But age alone does not predict good kidney health and so many good organs may currently be discarded. PITHIA is a UK study that aims to increase the number and quality of kidney transplants from older donors.

PITHIA began on 1st October 2018 and will last for two years. All the kidney transplant centres in the UK are taking part in the trial, which will introduce a national biopsy service to assess kidneys, before transplantation, from deceased donors aged 60 years or older.

A small sample of the donor kidney's tissue will be taken (a biopsy) so that it can be examined under a microscope. This biopsy will happen at the donor's hospital and before the kidney is transplanted. This will allow doctors to look at each kidney in more detail and hopefully identify more good kidneys for transplantation.

Every four months, a randomly chosen group of UK kidney transplant centres will be given access to the national biopsy service. By the end of the trial, all centres will have the biopsy service, and the researchers will be able to see if it has made any difference to the number of transplants from older deceased donors.

Mr Chris Callaghan is leading PITHIA at GSTT. Chris says: "This is an important study that will address whether or not the availability of a national donor kidney histopathology service in the UK will help increase the number and quality of

deceased donor kidneys transplanted from older donors. The Guy's team support this study and will consider whether or not a kidney biopsy should be taken on an individual basis."

For more information about PITHIA, go to: <http://www.pithia.org.uk>

WHAT YOU SHOULD KNOW IF YOU ARE WAITING FOR A KIDNEY TRANSPLANT

- Not all kidneys from older donors will be biopsied; it will only be done when the transplant surgeon thinks it is needed.
- If a kidney biopsy is asked for by the transplant surgeon, it will usually be done before you are called into hospital.
- If a biopsy has been performed on a kidney, doctors will inform you before you agree to the transplant operation.
- The trial does not affect your right to refuse a kidney if you feel it is not right for you.



Caring for your PD catheter exit site

Look after your PD catheter and it will look after you.

A peritoneal dialysis (PD) catheter (sometimes called a Tenckhoff catheter) is a special tube that is inserted into your abdominal cavity (space around the organs within your abdomen). Special cuffs help to keep the catheter inside your body (you won't be able to feel them) and reduce the risk of infection. Some of the catheter will be on the outside of your body, and the exit site is where the catheter leaves the body.

Dressing your exit site

The exit site is a potential source of infection and should be thoroughly cleaned on alternate days or following a daily shower. You are taught how to dress your exit site during your training. Here is a reminder:

1. Collect supplies:
 - Disinfection wipes
 - Disinfection hand rub
 - Pack of sterile gauze
 - Mupirocin 2% ointment
 - Self-adhesive dressing
 - Tape to secure tube (if used)
 - Clean scissors.
2. Tuck away loose clothing and ensure that the dressing site is accessible.
3. Wash and dry your hands thoroughly.
4. Discard the first wipe, as it may not be clean.
5. Clean the work surface with wipes. Wipe in one direction only.
6. Open the dressing pack and place on to your newly cleaned work surface.
7. Open gauze packet and place on cleaned surface, squeeze some Mupirocin ointment (pea sized) on to the gauze
8. Remove the old exit site dressing and check the dressing for signs of pus or wetness. The exit site should be clean and dry.
9. Apply hand rub solution to your hands.
10. Removing wipe from its canister, carefully fold it in half without touching the middle. Using the middle section of the wipe, clean the skin close to the tube. Once this has been done, repeat four times using a new wipe each time. Only clean in one direction and only use each wipe for one sweep before discarding it. Take one last wipe and clean along the catheter in an outward movement, taking care not to snag or pull the catheter too hard.
11. Using the sterile gauze put the Mupirocin ointment on to the exit site.
12. Apply a new dressing to the exit site, making sure that you do not touch the underside of the dressing. Make sure the catheter is lying comfortably before securing the dressing—this will avoid having to try and adjust it after you have finished.
13. Using either a second dressing or tape, secure the catheter firmly to your skin.

When to contact your PD team immediately

If you notice any of the following, contact the PD team immediately. You may have an infection and need treatment with antibiotics:

- Redness, pain or itching round the exit site
- Bleeding, moisture or pus oozing from the exit site
- A discharge on the dressing when you remove it
- Any unusual lumps or swelling under the skin near the tube.

A bath or a shower?

It is not advisable to have a bath. A shower with clean running water is best. If you do not have a shower in your bathroom, please use a hand shower attachment. Leave the exit site dressing on while you shower.

Can I go swimming?

Swimming is a good form of exercise, but it is best to swim in a chlorinated pool as the sea and rivers can be contaminated. There is a special pouch that you can put over the catheter to prevent the exit site from getting wet. Please ask the PD team for more information.

Any questions?

If you have any questions or concerns about PD, please contact the PD team on 020 7188 5133 (9.00am-5.00pm weekdays only). If your query is urgent, please telephone Guy's Hospital on 020 7188 7188 (ask for the PD nurse to be bleeped: bleep number 1053).

At all other times please telephone Patience Ward on 020 7188 8838.

Caroline Willis, PD Sister
Guy's & St Thomas' NHS Trust

British Transplant Games 2018



The 2018 British Transplant Games took place in August in Birmingham. The Games are a four-day multi-sports event whose aim is to promote fitness after transplantation and highlight the continued need for organ donation. Teams from Evelina London Children's Hospital and GSTT adult kidney unit attended the event with financial support from GSTTKPA.



The Evelina London VIPs

Grainne Walsh, Transplant Advanced Nurse Practitioner, writes: Our team is known as the Evelina London VIPs; we know our competitors are very important people/patients—hence VIPs—however, our transplant clinic is the Penguin Zone of our Hospital. So our competitors are actually Very Important Penguins!!

Uncertainty, lifelong medicines and hospital appointments are integral to life after transplant. The Games allow our young people to compete in sport alongside their peers who have been through similar experiences. The Transplant Games are the only competition we know where a negative drugs screen would mean disqualification!

This year's opening ceremony was emotional with both the Donor Family Network and Living Donors given a standing ovation. It was wonderful to see so many of our living donors share this ovation on stage.

Thirty-five children competed for the Evelina London this year in events such as cycling, track & field, racquet sports and swimming. Our VIPs shone, bringing home 61 medals, and were awarded the Best Kidney Team Trophy. What's more, seven VIPs have been selected to compete for Team GB at the World Transplant Games 2019.

Our team is managed by Pat Hayes, Dispensary Manager, Cathy Gill Senior Health Play Specialist and Grainne Walsh, Transplant Advanced Nurse Practitioner, but is made special by our volunteers who keep the show on the road. Huge thanks go to Janet and Safiya (Beach Floor), Carol, Mandy and Will (Evelina Pharmacy), Judy, Nick, Helen and Felicity (Consultants both retired and current!) and partners Cliff and Mo.

Facilitating such a big team is expensive. We are committed to ensuring financial issues never prevent a child from attending the Games and strive to ensure as many children who want to compete can benefit

from the peer support and friendship that comes from being part of the Transplant Games Family. We are very grateful for the ongoing support of our KPA.

Thank you from all of us!

News from the adult team

Simon Bessant, Guy's Adults Team Manager, writes: A team from Guy's Hospital, made up of 13 kidney transplant recipients and four living donors, along with 16 supporters, made their way to the annual British Transplant Games in Birmingham at the beginning of August. It was to become a record-breaking year, with over 1,000 athletes taking part in the various competitions.

With a relatively small team, Guy's won an astonishing 26 medals (eight Gold, 10 Silver and eight Bronze). The whole team performed really well in what is a true celebration of organ donation, with standout

performances from Henrietta Butcher, who won Golds in 800m, 1500m and 5km runs. Alan Avon, Simon Bessant and Jamie Jessup, as always, cleaned up in their respective badminton competitions.

For those of you wondering what it is like at the games and who are thinking of joining, here's a great insight from one of our newest team members, Mark Mears:

"People often ask me how I got involved with the British Transplant Games and if I was involved with sports beforehand? Well the truthful answer is, I've never really been the sporty type. I took up running about four years ago after I was asked to join some colleagues in a 5km charity fun run, I wasn't a runner but was certainly up for the challenge. During dialysis clinics I heard about the British Transplant Games: I was told about a previous patient who used to enter and win medals[!], and this immediately sparked my interest. After all, what runner doesn't like a bit of bling?"

"I was transplanted in February 2016 and that summer I got in touch with Transplant Sport, who in turn put me in touch with the Guy's Adult Transplant Team Manager. As I hadn't long had my transplant I couldn't take part in 2016, but my wife and I were invited along as spectators.

"We watched a variety of sports over the weekend. Some competitors were very talented in their disciplines and some were just there to enjoy themselves, which was great to see. One competitor, a young girl, will always stand out in my mind as being a true inspiration. She entered a 100m sprint, and she was the only one on oxygen and with a frame. She stood at the start line, put her frame behind her and when the pistol went she gave it her all with a smile on her face all the way down the track—crowds where going wild.

"I have now competed in Scotland and Birmingham where I have (to my surprise) medalled twice in a 5km speed walk and once in a 200m sprint—the sprint medal I should add was by fluke in Scotland! I have found a coach, and with his help I hope to one day be able to fulfil a new dream: speed walking at the World Transplant Games!

"I would strongly urge anyone reading this, with any interest in sports of any kind, to visit the British Transplant Games website at www.britishtransplantgames.co.uk. Taking part in the Games really is a truly life-changing experience."

COULD THE KIDNEY CARE UK NATIONAL ADVOCACY SERVICE HELP YOU?

The Kidney Care UK National Advocacy Service provides in-depth information, personal support and representation to patients, their families or carers. Kidney Care UK Head of Advocacy Nick Palmer explains.



WHO ARE WE?

Our National Advocacy Service is an 11-strong team who have direct patient, carer, or healthcare-giving experience. In fact six of the team are patients with experience of treatment for kidney failure and the challenges that brings. Collectively, we've lived with dialysis, the diet and fluid restriction; and faced the struggles of transport, organising a holiday or gaining work and holding on to a job.

We've experienced the challenging wait for a transplant from either the deceased-donor waiting list or through living kidney donation. We understand the joy it brings but equally, the impact of losing a transplant both individually and to a family. Collectively we understand end of life and can offer support for this and the other emotional challenges, if needed and not available locally, via referral to our Counselling Service.

Naturally we feel this collective experience equips the service with unique insight and genuine understanding of the whole patient pathway and assistance needed. The team are passionate and provide assistance and support grounded in person-centred philosophy. We feel this complements the care and support provided by NHS professionals. Importantly we are an independent service. We are unbiased, providing a sensitive, confidential and professional service.

WHAT DO WE DO?

There is a London Advocacy Officer and a South East Advocacy Officer for those outside London. We listen and then we listen some more. We understand that often, for many individuals, taking the first step of contacting us can be a challenge, and by listening carefully we can often unravel and decipher exactly how we can best assist you. Then we take action on your behalf.

Every week we receive enquiries about benefits, housing, transport, treatment choices, work and simply managing day-to-day life. We are keenly aware that a diagnosis of chronic kidney disease and treatment of kidney failure can leave individuals and indeed families struggling—physically, emotionally and financially—looking for answers and a helping hand to overcome challenging and deeply frustrating situations.

We help individuals to gain access to the right people, services and support and, where necessary, ensure that every individual is properly represented so that their views and wishes are known.

Advocates are trained not only to listen and support, but also to fight their corner to the best effect. This means being persistent, resilient and challenging when the need arises. We often act as a bridge between the patient and the kidney units, local authorities, the Department for Work and Pensions, and sometimes local MPs.

We don't have magic wands but we are well placed. We write, phone, email and facilitate meetings to support individuals with specific problems. This may mean helping to understand treatment options, supporting an application for benefits, assisting a better understanding of diet, signposting to other support agencies (i.e. housing or employment), or simply listening. Furthermore, we can assist in grant applications for those who meet the criteria.

Essentially as a service we are here for all kidney patients and their families wherever they are in the patient pathway.

MORE INFORMATION

The Head of Advocacy and Lead for London is Nicholas Palmer:
nicholas.palmer@kidneycareuk.org

Caroline Young is South East Advocacy Officer
caroline.young@kidneycareruk.org

Organ Donation Week 2018

Organ Donation Week 2018 (3rd-9th September) continued to raise awareness of the important need for families to talk about organ donation.

Let's talk about it

According to NHS Blood and Transplant, family refusals are the biggest barrier to organ donation. Surveys show around 80% of people support organ donation. However only 33% of people have told their family that they want to donate. If a family does not know their loved one's wishes, they are far more likely to refuse to give their consent to organ donation.

During the Week, there were stands in the Guy's foyer, the St Thomas' birdsong corridor and outside Guy's opposite the Shard. KPA members joined GSTT staff on the stands to explain the importance of ensuring that family members are aware of a decision to join the Organ Donor Register.

Thanks to everyone who helped to share this important message.

Prudential Ride London

Many congratulations and thanks to Michael Blackburne, who rode on behalf of GSTTPA in this year's Prudential Ride London. This is not only the first time that Michael has undertaken any challenge of this kind, but he has also single handedly raised an amazing £4,560.00 inclusive of Gift Aid for GSTTKPA.

If you are a cyclist and would like to take part in Ride London, we have places available for next year's event (we ask people to raise £600 for us). For more information, contact info@gsttkpa.org

Would you like to know about the latest research in kidney transplantation?

Then come to Guy's & St Thomas' Kidney Patients' Association

ANNUAL GENERAL MEETING

Saturday 1st December, 10.00-12.00
Robens Suite, Guy's Tower Wing

Hear from Dr Benedict Phillips of Guy's & St Thomas' about how research could help more people have a successful kidney transplant

Meet your KPA committee and let us know what matters to you



We look forward to seeing you!

SAVE THE DATE

Evelina celebration

Friday 23rd November
1.30 pm to 6.00 pm

Evelina Atrium and Governor's Hall, St Thomas' Hospital

Celebration of 50th anniversary of first children's kidney transplant at Guy's.

For more information, see page 4.

GSTTKPA Annual General Meeting

Saturday, 1st December
10.00 am to 12.00 midday
Robens Suite, Guy's Hospital

Your chance to support your KPA and hear about the latest kidney research from Dr Benedict Phillips of Guy's & St Thomas'.

World Kidney Day 2019 Thursday, 14th March 2019

The 2019 campaign will focus on the burden of kidney disease, disparities and access to healthcare with the theme: Kidney Health for Everyone Everywhere.

For more information:
www.worldkidneyday.co.uk