



Bon Jovi, archery and a fashion show?

An account of the annual young adult activity weekend by Vanda Fairchild, Young Adult Co-ordinator at Guy's:

On Friday 12th September we met outside the Borough Kidney Treatment to start our journey up north. We were going to take part in an activity weekend for young adults with kidney disease at Millers Dale, a small village in Derbyshire. Despite the long drive through London, travelling on a Friday afternoon was bearable, as everyone was in great spirits and looking forward to the weekend ahead. There were nine of us in the minibus, I had the pleasure of driving and Gemma was an excellent co-pilot, particularly when navigating the last few miles of dark, winding country roads!

Our destination was Ravenstor Youth Hostel, a large old manor house located in glorious countryside in the Peak District. Although we didn't know it when we arrived in the dark that night, there were rolling hills and grazing sheep visible from our dormitory windows.

There were just short of 40 young adults who'd travelled from Bristol, Nottingham, London, Newcastle and the South West to be involved. The weekend away was funded by a grant from the British Kidney Patient Association which meant the accommodation, food, drink and activities were provided free of charge. Most participants paid for their own travel expenses.

There was a varied mixture of organised outdoor and indoor activities on offer on the Saturday and Sunday as well as evening social events. During the day small groups took part in archery, canoeing, bush craft, cycling, orienteering, side care safari, baking and a rather unique fashion show. To help everyone get to know each other Friday night's entertainment started off with a quiz and team challenges involving straws and dried spaghetti. Our team nearly won...

None of the activities was compulsory but most people seemed keen to join in. The palpable energy, and enthusiasm of all those involved was infectious. The organisers and helpers were a mixture of youth workers, nurses and doctors. There was definitely something on offer for everyone with plenty of down time to relax and chat.

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Despite the stress involved I enjoyed coordinating the “bake off” session as we made some “exceedingly good cakes” that were enjoyed by all. One of the highlights of my weekend was seeing the Derbyshire countryside fly past whilst sitting in a vintage motorbike side car. I’ll definitely be volunteering again next year!

Here’s what some of the Guy’s participants had to say about the weekend...



Christian: “I really enjoyed meeting other young people like myself and experiencing the sense of normality that came with a weekend break away from dialysis. I am grateful to the BKPA for providing that opportunity”.

Ollie: “Ravenstor weekend was a fantastic experience that was extremely well organised. I had a great time, met some amazing people and will happily go again next year.”

Chris: “This is was my first time going to the Young Adult Weekend in Ravenstor, and I had a fantastic time. This weekend gave me the opportunity to meet other young people with kidney conditions, and also to have a really fun experience. During the weekend there were various activities on offer including archery, canoeing and a fashion show. On the final night we created a bonfire and just relaxed around the fire, singing out of tune to Bon Jovi!”

For more information about young adult kidney care services at Guy’s Hospital please contact us:

Tel: **020 7188 7188, ext 52722**
vanda.fairchild@gstt.nhs.uk



News from the KPA Chair, Sonia Moorhouse

The Guy’s and Thomas’ Kidney Patients’ Association (GSTTKPA) held their annual general meeting (AGM) on 8th November 2014, it was well attended by patients and carers. As well as the business items regarding our annual activities and financial management; the keynote speaker, Jonathan Hope MBE, presented some challenges and benefits from the perspective of being a patient during his thirty-five years’ of kidney care. In addition, we were also informed by patient attendees they want the GSTTKPA to facilitate the Trust to be more mindful of the emotional well-being needs of kidney patients; for the peer support scheme to be more visible and for digital technology to be used in the kidney clinic to provide information and education about kidney care and management. The AGM provided a further opportunity to hear directly from a dialysis patient, Zandria Richards, who gave an account of her fluid management tips and ideas, which was very well received.

The theme of our AGM (patients taking greater control) reflected the National Kidney Federation (NKF) Annual Conference, which was held in Blackpool in October. The Conference commenced with an update regarding proposed national cuts of 15% for the dialysis tariff rates, which was successfully thwarted until 2016/2017 by an organised response from national kidney charities, MPs and kidney patients’ associations (KPA) including GSTT. Currently, kidney services are commissioned by NHS England, however, it is possible this might be devolved to local health commissioners, known as Clinical Commissioning Groups. (CCGs)

The main concern is how this might affect standardised kidney care. We will keep you advised of these important developments in later editions.

The NKF Conference heard informative presentations from Mr Marc Clancy, Kidney Surgeon regarding additional pathways to make more kidney transplants available for patients with significant, pre-existing complications; Heather Davies spoke movingly about the difficulties of giving birth to a baby, who was diagnosed with impaired kidney function and Lorraine Pooley gave a robust account of taking control of her fistula management following poor care from non-kidney staff during a routine surgical procedure. She suggested wearing a fistula wrist band as well, constantly reminding staff not to take blood or blood pressure readings from the same arm with a fistula.

National patient transport was discussed at some length at the conference. There were concerns expressed about the procurement and review processes regarding patient transport contracts. It was reported that some Trusts are considering using more innovative models of patient transport, which are currently being trialled. You can view the entire conference presentations on line; see the following link:

<http://www.kidney.org.uk/about-us/conference/nkf-annual-patients-conference-2014-presentations/>

Finally, the KPA has vacancies for new Committee members: if you have time; you are a team player and have fund-raising skills, please contact me:

Sonia Moorhouse, Chair, GSTTKPA
chair@gsttkpa.org

Another record year for transplantation – but more organs are needed

by Dr Marlies Ostermann and James Van der Walt

2013/14 was a record year for organ donation and transplantation in the UK; more than 4,600 transplants were carried out. Of these 1,146 transplants were made possible by living donors who gave a kidney or part of their liver, while 3,509 patients benefitted from organs donated after death. Guy's and St Thomas' contributed to this by carrying out 263 life-saving or life enhancing organ transplants – 8% of all UK kidney transplants.

Despite this, around three people die each day across the UK due to a shortage of organs. We have seen a 50% increase in organ donation since 2008, but we must continue working to raise awareness about the benefits of organ donation.

The deceased donor transplant rate in the UK is currently 54.9 per million of the population. Last year, the initiative "Taking Organ Transplantation to 2020: a UK strategy" set out to increase the deceased donor transplant rate to 74 per million of the population to match the countries with highest rates by 2020.

This year's National Transplant Week had the simple slogan 'Spell It Out', which urges us all to tell those closest to us whether we want to be an organ donor. At Guy's and St Thomas', it was a very successful week where the organ donation committee worked closely with the KPA to promote organ donation.

Guy's and St Thomas' has an active Organ Donation Committee whose aim is to raise awareness about organ donation within the local community and within the hospitals. The Trust also has three specialist nurses for organ donation, James Van Der Walt, Katrina Kesek and Kelly Martin. They are senior nurses who have previously worked in intensive care. Their role includes:

- Identification of potential organ and tissue donors in collaboration with the clinical teams in critical care environments.
 - Provision of end-of-life care
 - Provision of support and comfort to grieving relatives
 - Teaching and education of medical and nursing staff and lay people
- They can be contacted by email:

James Van der Walt:
james.vanderwalt@nhsbt.nhs.uk
or james.vanderwalt@gstt.nhs.uk

Katrina Kesek:
katrina.kesek@nhsbt.nhs.uk

Kelly Martin:
kelly.martin@nhsbt.nhs.uk

If you would like to have your name added to the NHS Organ Donor Register, please ring 0300 123 23 23 or visit www.organdonation.nhs.uk. Remember - tell your family and friends!

Cycling from London to Surrey (and back) for the KPA



The KPA had three cyclists in the Prudential London to Surrey 100 mile cycle ride on Sunday 10th August; Chris (pictured), Ian and Sam. Despite the adverse weather conditions all three of them completed the course. Chris said: "it was VERY wet and then it got VERY VERY wet!"

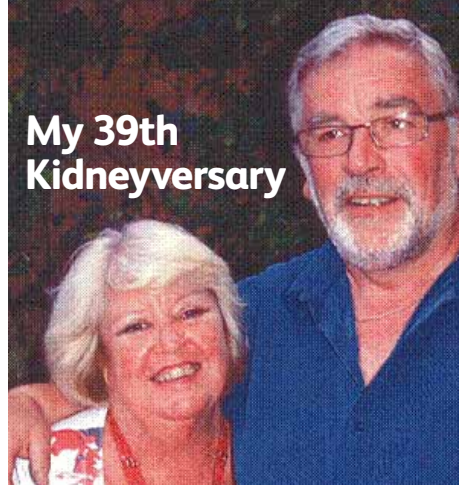
On the day, the total distance of the course was reduced by 14 miles as some of the roads around Box Hill and Leith Hill had been replaced by fast flowing rivers. Chris said the best parts were cycling on roads closed to cars, riding up The Mall towards Buckingham Palace with the sun finally shining and getting home, having a bacon sandwich, two cups of coffee and a chocolate brownie!

Together Chris, Ian and Sam raised over £3,000 for the KPA. Next year, 2015, the KPA have places in three prestigious events:

The Virgin London Marathon
The Prudential Ride London
The British 10k London Run

If you, or someone you know, would like to take part in any these events and raise money for the KPA contact info@gsttkpa.org or phone 020 7188 7552 to find out more.





In 1975 I found out I had kidney failure and was in hospital for a couple of months before starting haemodialysis. My mum (now in her 80s and still going strong), after finding she was compatible, donated a kidney and in November of that year I became one of the first patients at Guy's to have a living donor kidney transplant. After the operation I was on what seemed like hundreds of tablets and I was in hospital for a month. I believe nowadays patients are often home in under a week!

My lovely boyfriend David proposed to me while I was still in hospital and we have now been married for 37 years. We have one son, Rob who is an anaesthetist and intensive care doctor at Queen Elizabeth Hospital Birmingham, possibly inspired by having to follow his mum round lots of hospitals as a child! Two years ago he married Clara, also a doctor. Clara is currently doing a PhD looking into early signs of lung cancer. Our first grandchild is due in January next year.

I've had my ups and downs including a hip replacement, breast cancer, a brain aneurysm and skin cancers but I'm determined to keep going so that I can enjoy life with our grandchild. One of my ambitions is to visit New Zealand. About 22 years ago I was invited with my son to attend a 'celebration of life' event at Claridges in London for mums who had given birth post transplant. It was arranged by Elizabeth Ward the founder of the British Kidney Patients' Association. It really brought home to me what my mum had done for me as without her I would probably never have become a mother myself.

The care I have received at Guy's from the early days right through to the present has been great and I have met many lovely patients, families and staff over the years. I hope my story will inspire any kidney patients who are just starting out on their 'journey' and that's why I have chosen to share it with you today.

By Judy Green

Managing Your Fluid Restriction on Dialysis from a Patients' Perspective

By Zandria Richards (endorsed by Linda Tarm, Principle Renal Dietician, Guy's and St Thomas')

“Small things done consistently,
produce extra ordinary results”

For patients on haemodialysis managing your fluid is the most difficult aspect for many of us. In our diet if a favourite food is restricted we can often find an alternative, However when it comes to fluid, there is ONLY fluid! In dialysis patients, an excessive fluid intake puts a huge amount of strain on the heart causing it to expand in order to pump the extra fluid around our bodies, over time enlargement of the heart can lead to heart failure.

A major contributing factor to drinking too much is salt intake. Eat less salt and you will find that you need to drink less. 75% of our salt intake comes from processed foods so try to avoid tinned soups, processed meats and 'ready meals' etc. To help us dialysis patients manage our fluid restrictions, I decided to put together this hints and tips guide:

- Large pieces of ice have less surface area so it's less fluid than the smaller pieces and lasts longer. Wait for it to melt instead of crunching through it.
- Never finish a drink, leave a couple of inches or throw the remainder away, alternatively share drinks.
- When socialising, go for a spirit and a chaser rather than a pint.
- Reduce your salt and sugar intake and watch you thirst reduce drastically.

- Larger supermarkets sell small 150mls cans of fizzy drinks - get the fizz without the volume!
- Measure out your total allowance for the day in the morning and keep a record of your entire fluid intake including the hidden fluid in foods.
- Don't leave drinks in arms reach, "out of sight out of mind"
- Buy the smallest cups you can find
- Urges last seven minutes; try waiting and you may forget you wanted a drink.
- For a special event try and restrict your fluid intake the day before.
- Eat a few grapes or cut up a piece of fruit, bearing in mind your potassium levels or eat sugar-free sweets.
- Avoid foods with hidden fluid such as rice, custards, jellies and soups.
- Eat soup or cereal with a fork instead of a spoon.
- If your mouth is dry, brush your teeth, rather than have a drink.
- Weigh yourself regularly to keep an eye on your fluid gain.
- Create a fluid schedule i.e. a drink after a meal or when taking medication.
- Get physical and keep busy.
Ask yourself, "am I really thirsty?"
"No one gets it right all of the time, but the ones who get it right a lot of the time, are the ones who try most of the time"

You may also wish to ask your dialysis nurses for a copy of the GSTT patient information leaflet: Eating Less Salt or download it from www.gstt.nhs.uk



LATEST RESEARCH INTO ADULT POLYCYSTIC KIDNEY DISEASE (ADPKD)

This comes in all sizes, shapes and flavours. Sometimes it is about how genes contribute to diseases, sometimes it is about how certain drugs work, and sometimes it is a direct question “will this treatment help prevent or cure this disease”?

All of these types of research are important – without the basic understanding of how faults in the genetic code are translated into diseases, we would not be clear about the potential “targets” for new treatments.

In ADPKD there has been a fair amount of research into all of these questions but no overwhelming answers as yet. However, I am optimistic that within a few years we will know a lot more, and the beginnings of a “fight-back” will have started.

It's important to remember that it can take up to fifteen years from a having a “good idea” to arriving at a “widely prescribed treatment”. This will include time spent on pre clinical research (in the labs) to clinical research trials involving patients, to approval. There are many such trials in progress; some are for liver cyst patients, some for kidney cyst patients, and some for both.

Recent published research about new drugs have focussed on why the cysts in ADPKD start to form, and then to enlarge. Tolvaptan, Octreotide, and Everolimus have all been tried out in the last five years in patients with ADPKD and full medical reports have appeared which have detailed progress and set-backs. It's fair to say that the beneficial effects of these drugs, which seemed quite promising when used in animals, have been somewhat disappointing when used in real patients.

The impact on the progression of the disease (cyst enlargement) has been modest at best, and sometimes nil.

All of these treatments (which, incidentally are “old” ones, previously



used for other medical conditions e.g. cancer) have potential and real side-effects.

Two important studies which should be reporting fairly soon are known as “HALT-PKD”. These trials will examine the benefit of reducing blood pressure in ADPKD, and whether using medicines known as ACE inhibitors or angiotensin receptor blockers will also prove beneficial in ADPKD. These types of medicines are already in use and are commonly prescribed for diabetic patients to prevent kidney disease developing or progressing. Prescribing these medicines is something that we could easily do for all patients if the “HALT-PKD” trials give us a clear indication to do so. For more information visit:

<http://cjasn.asnjournals.org/content/5/1/102.full>.

This website lists all of the current research projects in ADPKD:

<http://www.pkdcure.org/research/drug-development>

Currently most of the trials are not taking place within the UK but you may wish to ask your doctors to let you know if they become aware of any new trials happening in the UK, so that if you were interested and eligible, you could be considered for participation in a trial.

One of the goals of the Polycystic Kidney Disease Foundation is to raise the profile and awareness of research trials. You can find out more by visiting their website: <http://www.pkdcure.org/research/clinical-trials/awareness>

**By Professor David Goldsmith,
Consultant Kidney Doctor**

Success for the children at the British Transplant Games

Thanks to generous funding from the KPA, twenty young kidney patients from Guy's and St Thomas' Evelina London Children's Hospital attended the British Transplant Games held in Bolton in July. They successfully competed in sports including running, swimming, squash, and archery and came home with 28 medals.

Transplant nurse, Grainne Walsh, play specialist Cathy Gill and dispensary manager Pat Hayes, accompanied the group – known as the ‘Evelina VIPs’.

Grainne said: “These children have been through a difficult time so the games are a celebration of their lives. They also get to spend time with other children who've been through the same thing and make friends for life. I'm very proud of them all.”

This year was Cathy's 22nd Games with the children: “We're so proud of them all. It's quite a feat to come back with 28 medals. When our youngest patient Beau, aged just two, won a bronze medal, there was barely a dry eye in the house!”

Sonia Moorhouse, KPA Chair attended The Games and the KPA also provided funding for the Guy's and St Thomas' adult transplant games team.



Transport for All Campaign Update

As you may be aware the National Kidney Federation (NKF) has acted as a partner with Transport for All (TfA) in their patient transport campaign 'Sick of Waiting'. The report, from the campaign survey released in October 2014, can be read through the link below: <http://www.transportforall.org.uk/news/just-out-report-into-patient-transport-in-london>

It has become increasingly noticeable that many haemodialysis patients have a huge dependence on transport through the 312 individual journeys they have to make to dialysis sessions, let alone outpatient appointments.

All sections of the patient community are now becoming more committed to improve 'the transport concern'. This has been strongly demonstrated through the creation of the TfA Patient Transport Charter, which has endorsement from Guy's and St Thomas' NHS Foundation Trust, The Independence Ambulance Association and The NHS London Procurement Partnership. TfA call upon every Health Trust to endorse

the following five key demands, which make up this Charter:

- 1.** Minimum standards in-patient transport contracts, regularly and closely monitored, with proportionate service credits (i.e. financial penalties) if standards are breached.
- 2.** No more endless waiting - no more missed appointments. Deliver us to hospital a minimum of fifteen minutes before the appointment, and maximum one hour wait from arriving in the dispatch lounge to being picked up for the outward journey. Maximum three-minute wait on the phone to book transport.
- 3.** Keep us informed - Information, in a variety of formats, on what we can expect from patient transport and how to give feedback; and on the Healthcare Travel Costs Scheme; text messages or calls to confirm that patient transport is booked and on its way.
- 4.** Fair and transparent eligibility assessment based on medical need: whether you are able to use a taxi or whether you go to the shops yourself is irrelevant.

5. Nothing about us without us - Patient involvement through surveys and a patient transport user group, including clinicians, that holds real power and is involved in the contract management process

Naturally these are early steps and TfA will be sustaining the drive on this highly important issue across London, while the NKF are developing their own national working group specific for kidney patients. It is clear that further engagement with all Patient Transport Stakeholders will be pivotal, especially as innovative practices to be adopted in one London Trust may well show a way forward and hopefully be complimented by the awareness generated from this campaign.

To read more about the Transport for All campaign, please visit: <http://www.transportforall.org.uk/> or all them directly **020 7737 2339**. Nick Palmer, GSTTKPA Committee Member, Head of Advocacy, National Kidney Federation
nicholaspalmer.nkf@btinternet.com

Meet the social workers and clinical psychologists

The kidney service at Guy's employs two experienced Social Workers, Kamal Charan-Gilles and Pauline Edwards. They offer support and advice to kidney patients and their families. They work closely with the clinical staff to support and prepare patients going home after a long or complex stay in hospital. Often these are vulnerable patients with multiple social care needs. The social workers liaise with community services to ensure that the patient and their family are supported at home and feel safe. The social workers can also offer advice on:

- Claiming benefits
- Managing finances
- Accessing your local Social Services
- Managing work
- Legal issues

You can contact the social workers directly: **020 7188 4023** or **020 7188 5684** (Monday to Friday, 9am to 5pm).

The kidney care team also includes two Clinical Psychologists, Therese Andre and Amy Carroll. They work with your medical teams and social workers to provide overall care for kidney patients on hospital wards, in the out patient clinic and in all of our dialysis units. They help patients cope with and adjust to the changes that inevitably result from having a long term condition like kidney disease.

Kidney patients can experience a whole range of emotions including anger, frustration, anxiety and hopelessness.

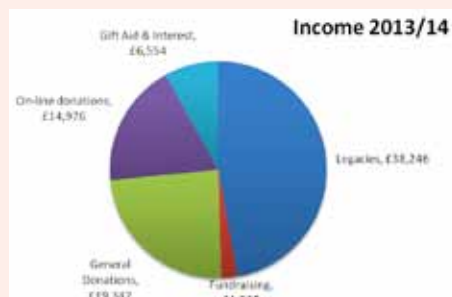


These emotions, and others, may occur at various stages of the kidney care journey. This is all quite normal but at times it might become overwhelming, asking for help from a clinical psychologist is a step towards managing these emotions and feeling more in control.

You can contact the clinical psychologists directly: **020 7188 9770** or **0207 188 7845** (Monday to Friday, 9am to 5pm).

Financial Update from the KPA Treasurer, Janice Stephens

At the AGM our Treasurer, Janice Stephens, presented a summary of the financial accounts for the year ended 5th April 2014, as well as an update on the projections and forecasts for the year to 5th April 2015. Here are the highlights.



2013/14 Accounts

Income for the year was £81,083 and the pie chart shows how this was made up. Income was lower than in the previous financial year, primarily because legacy income was lower.

Expenditure for the year was £202,602. The pie chart shows how the monies were spent: we completed the final payments of its £500,000 grant to the Research Centre for Transplantation at Guy's - a grant commitment over five years. We also completed the final payments for a grant of £34,717 for Prof Dorling for immunosuppression optimization.

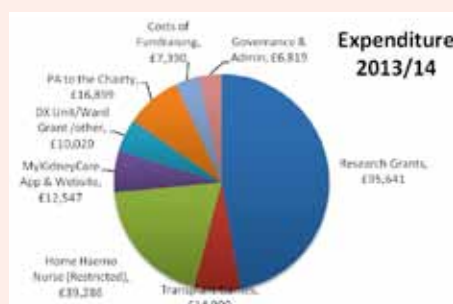
Grants were made to support participation in The Transplant Games for adults and children, Dialysis Unit patient activities, and to pay for the printing of "More than a Match" book by Dela Idowu to increase the understanding of living donation in the BAME community.

We developed a version of the MyKidneyCare app for iPhones/iPads. We also funded a nurse to support patients on home haemodialysis from a restricted legacy.

Fundraising costs include the costs of raffle prizes, on-line giving fees, this newsletter and other promotional material. In common with all charities the KPA incurred some governance costs including audit fees, legal costs and insurance premiums.

The KPA spent £121,519 more than its income, this was funded from its 'brought forward' reserves. It ended the year with net assets of £528,999, of which £489,353 was restricted in its use by the donors, £39,646 was general unrestricted funds.

We have agreed a reserves policy which sets an amount of unrestricted reserves we expect to hold at any point in time; this is £38,500 which is based on key grants we expect to be able to give each year and governance and administrative costs. The KPA ended the year only slightly ahead of this at £39,646.



2014/15 projections

General donations are forecast to be lower than in previous years, but new initiatives such as the Racing Partnership (read about this in the next newsletter) and Kidneyversary campaign have generated new income sources.

Our expenditure plan was £19,078 and we are expecting to spend £4,861 more than this, predominantly driven by extra grants made for adult patients to attend The Transplant Games. However, the KPA expects to have a surplus of £8,313 general unrestricted reserves and the committee is considering how to spend this in line with our objectives.

The KPA has a restricted fund of £489,143 following a generous legacy and is working with the Trust to see how this can be utilized in line with the donor's wishes.

How can you help?

Like many charities the KPA has experienced a reduction in donations over the last few years, combined with lower interest returns on its cash

deposits. We need to continue to generate new ways of raising money. We have charity places in three large events: the Ride London cycle ride; the London Marathon and from 2015, the London 10k run. These will generate sponsorship money for the charity but will not be sufficient for the KPA to continue to make grants to support patients to the extent that has been possible in the past. If you can help us to fundraise by doing a sponsored swim, run, bungee jump, cake bake, or in any other innovative way please let us know. Here are some other ideas on how you can help:

- Regular giving e.g. a monthly or annual standing order to the KPA – visit our donation page on our website to download a standing order form
 - Give As You Earn (GAYE) – Donations set up this way enable you to benefit from tax relief at source.
 - Charities Aid Foundation – the KPA is able to accept donations using CAF cheques.
 - Do you like to sell on eBay? Did you know you can donate between 10% and 100% of sale proceeds to the KPA. eBay have a short video showing how to do this: http://pages.ebay.co.uk/ebayforcharity/Support_charity_when_you_list.html
 - Support our "Celebrate your Kidneyversary" campaign – ask friends and family to make a donation to the KPA to help you celebrate. Set up your own fundraising page and text giving number on Just Giving and promote with friends and family using Facebook, Twitter, email or by good old word of mouth.
- And finally, if you are a UK taxpayer, please ensure we have a gift aid form for any donations you make or collect on behalf of the KPA.

For more information about any of the above please contact us on info@gsttkpa.org

PATRICK'S KIDNEY VAN - DIALYSIS ON WHEELS



About fifteen years ago I started looking at the possibilities for mobile haemodialysis to give me and my family the freedom to visit friends and go on holiday without having to book into a local dialysis unit. I self care on nocturnal (overnight) dialysis at home anyway so I was keen to explore how I could take a machine away.

We were informed that portable machines were being developed but as the years passed and no portable machine capable of providing eight hours dialysis through the night appeared to be on the horizon, we decided to look at putting a machine in a caravan.

Some friends came to dinner one evening and we talked about the idea, they gave us £10 there and then as 'seed' money towards realizing the dream. We started looking into which caravan would be suitable but we discovered that none of the mass produced vans would cope with the weight of the

machine apart from one costing in excess of £40K that was over 8m long!

A builder friend then suggested using a crew cab builder's van so that we could build what we needed in the rear section; the idea was born. Those same friends who came to dinner and another friend proceeded to arrange a fundraising event to raise £50K to make this idea a reality. A sponsored cycle ride from London to Sussex was planned.

We found a company called 'Blackburn Trailers' who would do the conversion, but after our initial conversation with them it became clear that a van was going to be too narrow to accommodate all that we would need, but Mark Blackburn, suggested he build us a purpose built 'exhibition style' trailer, which on the inside would be like a caravan, but would be able to cope with the weight of the dialysis equipment – perfect!

Our friends were now raising money to buy the trailer and a car to tow it.

The bike ride took place in April 2013 with 55 riders; the money raised through that and other activities came to £58,100 - staggering!! This enabled us to build a trailer that sleeps 4 people; a car and a generator as emergency electricity back up.

Today we have a mobile dialysis trailer that enables me to do day-time or nocturnal dialysis. We have enjoyed a number of trips and it's truly amazing, delivering a new level of freedom we have not known since before 1993!

When we go away I no longer need to disappear off to a dialysis unit very other day and because I do nocturnal dialysis at home, this schedule continues when using the trailer, so those precious days away are spent ON HOLIDAY and not in a dialysis unit. Fantastic!

By Patrick Pearson-Miles

New Cross Gate Summer BBQ



Patients, families and staff from New Cross Gate Dialysis Unit got together on Sunday 3rd August for their annual summer BBQ. The sun shone, the drinks flowed and the sausages sizzled. There was even a karaoke machine to sing along to.

The event took place in the garden behind the unit in Goodwood Road. The BBQ was once again funded by the GSTT KPA and members of the committee were there to join in the fun. Many thanks to unit manager, Phil and all her team for working so hard to prepare, cook and serve all the lovely food.

Getting Involved

With research:

The KPA often get requests from doctors asking for patients to get involved in research. This is different from taking part in a research trial. This is about working with researchers as expert patients and may involve:

- helping to prioritise research
- joining a project steering group
- helping to develop research materials such as questionnaires

By doing this you can help to ensure that research addresses the needs of patients. You don't need any special skills other than basic literacy skills. If you think you could help to support research at Guy's please contact: Ros Tibbles on **020 7188 7552** or email **Ros.tibbles@gstt.nhs.uk**

With the KPA newsletter:

Do you have a story to tell? By this we mean have you been able to hold down or return to a successful and satisfying job, go abroad to an exciting, unusual destination or take up a new hobby whilst dialysing or even after your transplant?

The KPA are looking for a range of inspiring stories to promote via social media, our website and in the next newsletter in order to encourage positive thinking, share uplifting experiences with other patients and carers as well as proving that one can carry on leading an active and fulfilled life despite coping with a chronic illness.

If you are willing to share your experiences please email: **info@gsttkpa.org** with a brief outline by **20th February 2015**.