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NKF would like to thank the following for their continued sponsorship of Kidney Life:

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Welcome to your spring edition of Kidney Life and I hope you all had a great time over Christmas and New Year.

This spring, we bring you our fascinating cover story by Dr Mike Stephens on page 6. He is a surgeon and was involved in the six kidney transplants that took place in 30 hours at Cardiff’s University Hospital, Wales.

As always, I have been inundated with personal inspirational stories and in this issue, I have a heart-warming story about how a community and fundraisers came together to raise £300,000 to create a dialysis unit on the Isle of Bute in Scotland, article on page 21.

Innovative technology is making leaps and bounds across all industries and on page 18, read how surgeons at one of the largest Trusts in the UK have pioneered the use of 3D printing to support successful kidney transplantation.

This edition also includes some useful facts about NKF and highlights the immense work that the organisation has achieved and is continuing to achieve.

With growing uncertainty regarding political events around Brexit and how this will impact kidney patients, this year the NKF will closely monitor events as they unfold and will work more closely with Kidney Patient Associations to ensure that any proposed changes are highlighted and necessary action taken. As always, we at the NKF value your opinions and will ensure your voice is heard.

Sumaya Masood
Editor

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NKF Officers and Executive members do usually belong to a KPA, but offer their services to NKF as individuals. As such NKF recognises that views expressed by its Officers and Executive members are expressed as individuals and do not necessarily represent the views of their KPA.
The **NKF** invites you to the next **KPA day and AGM**

which will be held on **6th April 2019** at the Bentley Suite, Glebe Hotel, Warwick from 10am to 4pm.

This annual event has proved to be extremely rewarding and productive. It will help you understand and influence renal services and treatments provided to kidney patients across the UK. You will have the opportunity to explore current issues and have your say.

The day will run along similar lines to last year’s event. After a series of short presentations discussing issues and successes experienced by KPAs and NKF there will be an open discussion during which the NKF Executive Committee will be voted in. The event is free to attend which will include lunch and refreshments, provided that you register in advance. KPAs will have received the NKF Executive Committee nomination papers and for those interested in becoming a member of the NKF Executive, a completed form needs to be with NKF HQ by no later than 22nd February 2019.

For more details on becoming a member of the **NKF Executive** or if you wish to register for the KPA day this year then please contact the **NKF head office:**

**The Point, Coach Road, Shireoaks, Worksop, Notts, S81 8BW**

Telephone: 01909 544999.

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Your opinions and vote really matter to the NKF so come along and make a difference!

Kidney Charities Together (Kidney Care UK, Kidney Research UK, The National Kidney Federation and The Polycystic Kidney Disease Charity) are once again leading the UK initiative around World Kidney Day in 2019. Help us bring together millions of people across the world and unite with one powerful voice for kidney health awareness. Following the 2019 global theme of Kidney Health for Everyone Everywhere, the aim is to draw public attention to the importance of maintaining a healthy lifestyle to help look after your kidneys, the risks for developing kidney disease and the impact it has on patients.

**KIDNEY HEALTH FOR EVERYONE EVERYWHERE**

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**World Kidney Day in the UK is led by the Kidney Charities Together Group**

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Our Helpline is free of charge to call on 0800 169 09 36

The NKF runs the only UK Helpline dedicated to kidney patients, with over 200 unique and regularly updated information leaflets and two fully trained, experienced advisers providing a 5 day a week service to kidney patients, carers and healthcare professionals.

The NKF Helpline is open from 9am until 5pm Monday to Friday on 0800 169 09 36
e: help2@kidney.org.uk

If you want to raise funds for the NKF plan an event, make a donation to the NKF or discuss leaving a legacy to the NKF please contact Pete Reveill (NKF Head of Fundraising).

T: 01263 722287
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If you require a larger print version of this issue, these are available by contacting the NKF Helpline on 0800 169 09 36
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CHRONIC KIDNEY DISEASE
Kidneys play a crucial role in keeping our body healthy. Amongst other things kidneys remove toxins, regulate blood pressure, help produce red blood cells and maintain healthy bones. Chronic Kidney Disease is when the kidneys don’t work as well as they should and is a long-term condition.

Two of the most common reasons for CKD are:
- High blood pressure
- Diabetes

Recent research suggests that 1 in 10 of the population may have CKD, but less than 1 in 10 people with CKD ever require dialysis or a kidney transplant.

SOME TIPS FOR CKD
Unfortunately, few of the causes of CKD are curable. So it can help to make some lifestyle changes.

The following are a few tips recommended to those diagnosed with CKD:
- Lose weight if you’re overweight or obese
- Take regular exercise
- Stop smoking
- Reduce the amount of salt intake to help control the blood pressure
- Eat a healthy balanced diet

DIAGNOSIS OF CKD
Quite often CKD has no symptoms but can often be detected through a blood test, urine test, a scan or an x-ray of the kidneys.

LEADING A NORMAL LIFE WITH CKD
Most people with CKD should be able to lead normal lives. CKD does not normally run in families but some specific types of kidney disease can. If you think you may have CKD or if you want to see if it runs in your family then check with your health care team to see if further testing is required.
SIX KIDNEY TRANSPLANTS IN 30 HOURS:
A RETRIEVAL SURGEONS’ PERSPECTIVE

Receiving a kidney transplant is life changing. It releases patients living with kidney failure from the many challenges of dialysis, affords freedom to work and travel, and allows a more normal diet and fluid intake. The number of organ donors and therefore the number of kidney transplants has been increasing steadily over recent years, and initiatives such as changes to the law on consent for organ donation have the potential to improve things even further.

Unfortunately, despite the recent improvements there still aren’t enough organs available for patients who are waiting to receive a transplant. The uncertainty of waiting and not knowing when (or if) a phone call will come with that life changing offer is one of the biggest challenges for patients on the kidney transplant list. The uncertainty of when organ offers will be made is also a challenge for those of us who run and work in transplant units, and this article describes some of these difficulties.

Every transplant operation starts many hours before the operating theatre with a phone call to the transplant unit. The transplant team are informed that a potential donor kidney has been matched with one of their recipients, and a huge amount of information about the offer is made available for consideration. Each individual offer is carefully assessed by the team, who must decide if this particular kidney is likely to work for this particular recipient, without causing any unacceptable complications.

Considering such offers requires many years of experience and this means that every transplant unit in the country will have very senior doctors available around the clock to consider all possible organ offers, whatever the time of day or night.

The process from the time of the offer until the time of starting the transplant procedure is actually quite lengthy, usually many hours in duration. The organ offer tends to come before the organ has even been retrieved from the donor, and the process of procuring the organ usually takes several hours. The kidney will then need to be transported from the donor hospital to the transplant centre, and given that we have a UK national scheme for matching kidneys, this again often takes several hours.

Once the kidney finally arrives in the transplant centre there may need to be a final cross matching process to ensure a safe match between the donor and the recipient. Only then can the kidney be taken down to the operating theatre and prepared for implantation.

Once the surgeon has seen the kidney and ensured it is healthy, the anaesthetic team will start the process of putting the patient to sleep so the transplant operation can commence.

The whole pathway from organ offering to commencing the transplant procedure often takes 12 hours or more. During this time the transplant team will have received additional pieces of information as they become available, such as the anatomy of the kidney (the number of blood vessels affects how we perform the surgery). All of these must piece together in the correct way to allow the transplant to proceed.
It’s not uncommon for transplant centres to be considering several organ offers at the same time for multiple recipients. All kidney transplant centres also have active live donor programs running in parallel with their deceased donor activity which, although scheduled and therefore easier to manage, also include of course an extra patient (the donor). Living donors are incredible people who put themselves through an unnecessary operation purely for the benefit of someone else, sometimes even a stranger they will never meet. Obviously, maintaining the safety of the donor is of paramount importance. Making sure all of the decisions and the logistics of these complex procedures line up in the right way to allow transplants to happen takes a lot of experience and skill.

It is impossible to predict when a suitable deceased donor organ offer will become available and therefore transplant units are set up to be able to consider organ offers at any time. Given the length of the process and the multiple important decision steps that are contained within it, this can be a particular challenge.

In the transplant unit in Cardiff, we made a decision several years ago that missing out on suitable organ offers because our expert team are too tired or too busy was not a situation we were willing to accept. We therefore designed an on-call system for our consultant surgeons where there are always two available for every hour of every day. This provides a number of advantages; it allows us to share difficult clinical decisions, it allows us to operate together in complex cases, and it also means we are able to cover each other if one is in theatre operating or is in need of some rest.

For 15 weeks of the year we will also have a third consultant available to do the organ retrieval surgery, travelling around the country attending the donor hospital and retrieving not just the kidneys but also the liver and pancreas for other transplant centres. We benefit from the same service in return from other transplant centres and the whole process is expertly co-ordinated by NHS Blood and Transplant (NHSBT). The system works very well, but as there are only seven consultant surgeons in Cardiff, each of us spend a large number of days a year available and committed to emergency transplantation.

The benefits of this system were illustrated at the beginning of August this year when our team was able to successfully transplant six kidneys in a period of a little over 30 hours. This required multiple consultant surgeons working both in parallel and together, plus of course the usual amazing support from our expert nursing and wider multidisciplinary team.

Six transplants in such a short space of time is unusual, but we need to be available to respond to such peaks in activity. The rewards are clear; seeing the change in the life of patients receiving a kidney transplant is an incredible privilege. I am without exception humbled by the donors and their families who have made the decision to allow life to go on for a stranger after their death, and ensuring their altruism achieves the best possible outcome is of great importance.

However this level of work can take its toll and there are issues around both infrastructure capacity and also staff burnout in transplant centres across the UK. These issues are at present the focus of attention from NHSBT and the British Transplant Society, but the solutions aren’t simple. It takes many, many years to train a transplant surgeon and likewise to train all of the other members of the team who provide the glue that sticks the whole process together.

As a surgeon one of the key parts of our training is in understanding and accepting when tiredness could affect our judgement or ability. It doesn’t matter how experienced or skilled, your performance will drop with extreme tiredness, no one is super human! In situations like this we rely on our colleagues, and in the NHS we are very fortunate to have a fantastic team around us.

In transplantation this is even more obvious and without this teamwork transplant programmes couldn’t continue.
Did you know?

AMAZING FACTS AND FIGURES ABOUT NKF.
The national kidney charity run by kidney patients for kidney patients:

- Established for 40 years
- 46 KPAs that have come together as the controlling Council of the National Kidney Federation
- 116 MPs from the All Party Parliamentary Kidney Group representing and fighting for the welfare of renal patients
- Patient Information Library written by medical specialists
- Largest provider of information leaflets in the UK covering a variety of medical topics relating to Kidneys
- The NKF website is viewed by more than 1,000,000 users worldwide
- HELPLINE takes between 250 to 300 calls a week from patients and carers covering topics such as holidays, dialysis, diets, transplantations or simply just listening to those who have no one to talk to
- Helpline run by experienced staff who form a core part of the NKF
- Kidney Life magazine is distributed four times per year to renal patients and professionals
- Active support from 17 industry partners and rising
- The NKF hold an annual conference which is attended by patients and health care professionals

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The Renal Support Team (RST) at Lister Hospital have been working hard to set up their first Renal Peer Support Service in collaboration with the Lister Area Kidney Patient Association (LAKPA).

The RST service is about people sharing their particular experiences and understanding of how renal disease has impacted their life, whether as a kidney patient, live kidney donor, carer or relative. Whilst healthcare professionals are crucial to an individual’s treatment, people often find it invaluable to meet with someone who has lived through the experience of what they are going through.

The service is based on matching someone (the service user) who needs help with a particular matter with someone else (the peer supporter) who has been through something similar. Sometimes this may involve a patient speaking with another patient about their condition, a carer speaking with someone who now finds themselves in the new position of caring for someone with a renal condition or it could be a live kidney donor speaking with someone who is thinking about becoming a donor.

Peer supporters attend two training sessions, developed and delivered by RST, as well as a training session delivered by the trust volunteer service team. The training aims to give peer supporters a comprehensive understanding of their role and the boundaries of the service, develop their listening skills, and prepare them for any possible tricky situations.

Referrals to access the service are taken from staff as well as patients themselves. The RST have been promoting the service via email, leaflets, conversations and articles in various publications; including the dialysis unit newsletters, the trust’s email newsletter and LAKPA’s newsletter.

Once the service user and peer supporter have been matched, based on their preferences (which may include meeting with someone of a particular age, background or treatment), the supporter and service user meet for about one hour either at the hospital or in a public place (such as a cafe) to discuss an issue which the service user has some knowledge or experience of such as having dialysis, receiving a transplant or donating a kidney.

Both staff and patients feel that the peer support service has been a valuable addition to the provision that patients already have access to.

Dom Willison, Peer Support Facilitator (funded for two years by LAKPA & the Organ Donation Committee) who is also a peer support volunteer, said:

“I have seen the patients change the longer I speak with them. They start off very nervous and unsure of themselves and by the end of our conversation they have a better understanding.”

Hope Clayton, Health Psychologist and Renal Peer Support Service Lead, said:

“We are very excited to keep improving and expanding the service. We are currently in the process of recruiting more volunteers for further training sessions, as well as promoting the service to patients so that they know this service is available and easy to access.”

If you would like to find out more about the Renal Peer Support Service or have any questions, please contact Hope Clayton on 01438 284 957 or email renalsupportservice.enh-tr@nhs.net.
A rising proportion of people who die in need of a transplant are from a black, Asian or ethnic minority backgrounds. Recent figures from NHS Blood and Transplant indicate that more people from these backgrounds die waiting for an organ, when compared to data from a decade ago.

In March 2018, I donated my kidney to my niece Shakti, who had been on the transplant waiting list for a few years. Shakti, a 25-year-old government policy advisor, had suffered from chronic kidney disease from childhood and spent a lot of time in and out of hospital. Despite this, Shakti managed to graduate from York University, complete her Masters at King’s College, London and started her first job.

Earlier this year her condition deteriorated and she was forced to spend several months on dialysis. When we first learnt that she needed a kidney I had no hesitation in taking the test and offering her one of my own.

Unfortunately, I was not a good tissue match for Shakti, not great news. However, following discussions with the experts at the Royal Free Hospital, we joined the National Living Donor Kidney Sharing Scheme as a ‘paired donation’ to increase Shakti’s chances of finding a match.

This scheme attempts to pair donors and recipients across the UK. Kidneys are swapped between one incompatible donor and recipient and another mismatched pair. After successfully completing rigorous medical and psychological tests over many months, our details were included in the national database of those waiting and those willing to donate. A match was found and we received the news of the final go ahead in February 2018.

Shakti and I had our operations on the same day. My kidney has gone to a person unknown to me on the waiting list and Shakti has received a donation from a generous soul unknown to us. My four-hour operation was carried out by consultant vascular and transplant surgeon Colin Forman and with my permission, filmed for BBC News to raise awareness amongst the black and minority ethnic groups.

Six operations around the UK took place that day in this chain

Six operations around the UK took place that day in this chain. It was a tense day for all, but most of all for Shakti’s mum Jayshree. She was by my side before my surgery and then waiting until midnight when Shakti was brought back to the ward after her operation. Over the next few days, we were wired up to all kinds of machines and were given a lot of medicines for pain relief. We received fantastic care from the NHS nurses and doctors and after six days we both came home with a good working kidney each.

One kidney is enough to lead a normal life

One kidney is enough to lead a normal life. Knowing the difference it will make to Shakti’s life, I had no hesitation in donating. It’s one thing to donate when you are no longer on this earth, but it is quite another to do so when you’re still alive, both have a role to play.

Talking about her surgery Shakti said,

“I am very grateful to have received a kidney and the care I received from the doctors and nurses was fantastic, including preparing for the transplant and ensuring that the recovery was as smooth as possible. I was not nervous before my operation, and it was helpful that I was able to meet many of the surgical team beforehand and knew that I would be in safe hands.”
Shakti continues, “I already have more energy than I have had in years and generally feel a lot healthier. My life now seems brighter with new opportunities and possibilities. Having returned to work, I am now looking forward to progressing at work and plan trips abroad, something I was not able to look forward to before.”

Colin Forman said,

“Nationally one in three patients waiting for a transplant are from a BME background, but they make up only 6 per cent of donors. Tissue type is like blood group, you are more likely to get a good match from the same ethnic background as yourself, but because of the lack of donors, patients wait a lot longer. Anybody can come forward as a donor and the tests to check compatibility are quite painless.”

Recently I met the Junior Health Minister Jackie Doyle-Price, at her campaign regarding the importance of donation from black and ethnic minority communities. At the launch she said, “I am delighted that this year more people than ever from black, Asian and minority ethnic backgrounds have received life saving transplants. This shows great progress, but the fact remains that if you are from any one of these communities you are more likely to need a transplant, for the simple reason that you are more likely to suffer from a disease that requires a transplant. At the same time, you are less likely to get a transplant than if you were white. The campaign we are launching today will be a driving force to save more lives. For now, I would ask on behalf of everyone who has received a transplant, and everyone who is waiting, sign up to donate and give the gift of life.”

I’m happy that many people are helping to raise awareness on this issue. Shakti and I are now helping to promote organ donation in our communities and raising funds for important research, led by Shakti’s surgeon, Mr Reza Motaliebzadeh, to find ways to reduce rejection. This will help hundreds of people who suffer chronic kidney rejection after transplants are carried out.

Prafula and Shakti
If you loathe cold nights and wait in anticipation for the hours of daylight to increase and the coming of spring, then we have the perfect recipes to make your life that little bit more pleasant. In this issue, Kidney Life delivers to you four quick recipes that each take about 35 minutes from preparation to cooking!

The first is an Italian inspired pea and ham frittata, that takes 15 minutes to prepare and another 15 minutes to cook. This enjoyable dish is perfect when served with a simple green salad.

The next beautiful recipe has a low phosphate content and is suitable for patients who are following a low protein diet. It is the charming spaghetti with sweetcorn, chilli and broccoli.

Now no recipe column is complete without desserts and we have whipped up two stunning recipes. The first recipe will surely welcome the spring season with appreciation – it is fresh lemon curd. Very high in calories, so do be careful if you are watching your weight. But how can you resist a recipe that lasts over a week in the fridge, and is a great alternative to jam or just on some toast or crumpets for a change.

The final recipes only takes 15 minutes from start to finish and it’s an easy way to get calories in for those who have a poor appetite or are losing weight. The bircher muesli is perfect with a spoonful of raspberries and some dry rolled oats on top. Add more sunflower seeds if you like.

Enjoy having a go, whatever the result and send pictures of your creations to us at Kidney Life or on twitter (@Lawrence_Keogh) and Instagram (lawrence_keogh)

Pea and Ham Frittata

INGREDIENTS

480g cooked spaghetti
50ml olive oil
150g diced ham
200g cooked frozen peas
1 clove garlic, chopped
10 twists of pepper
6 whole free range eggs beaten
¼ tsp grated nutmeg

METHOD

Place a large frying pan on the stove on a medium heat, add the olive oil and the diced ham and cook for a few minutes.

Add the garlic and cook without colouring for approx 1 minute. Then add the spaghetti. If the mixture is quite thick, add a splash of water to help loosen.

Season with pepper and nutmeg, add the peas and then add the beaten egg.

Mix thoroughly and make sure the heat is moderately low on the pan – keep moving the mix away from the sides of the pan.

Lift the edges with a spatula or palette knife, and when brown underneath place a large plate over the top of the frying pan to cover the frittata; using a cloth to protect your hands from the heat, quickly flip over on to the plate then slide the frittata back into the frying pan so it heats the uncooked side..

When done, slide the whole frittata on to a serving plate and portion. Serve with a simple green salad.
**Spaghetti with Sweetcorn, Chilli and Broccoli**

**INGREDIENTS**
- 350g broccoli cut into small florets
- 150g sweetcorn
- 200g spaghetti
- 8g garlic (approx 4 cloves sliced very thinly)
- 100ml extra virgin olive oil
- 50g salted butter
- 16g red chilli (approx 1 cut into fine strips with pips)
- 15g fresh rosemary
- Freshly ground black pepper

**METHOD**
Heat 2 large pans of water to boiling, one for the spaghetti and one for the broccoli. Cook the spaghetti for approx 8 mins, or until the spaghetti is tender but with a little bit of a bite, drain and keep warm. Note: Do not throw all the pasta water away.

Cook the broccoli until it is slightly tender (approx 6 mins or bright green in colour) and drain. Keep warm in a colander.

Place a large frying pan on the heat and add the olive oil and the garlic – be careful not to burn it, just gently sweat it with no colour. If the pan is too hot add a bit of pasta water to it.

Add the chilli, sweetcorn and the rosemary.

Add the butter, mix well, then pour in the spaghetti. Have the pan over a low heat at this stage and then fold all the ingredients in together with the broccoli and a little of the pasta water – this helps to make the sauce.

*Season with ground fresh pepper and serve.*

**Bircher Muesli**

**INGREDIENTS**
- 150g rolled oats
- 150ml apple juice
- 1 Granny Smith apple
- 50ml approx juice of half a lemon
- 100g tinned peaches chopped roughly
- 2 tsp/10ml honey
- 1 level tsp of ground cinnamon
- 30g sunflower seeds
- 1 tin of raspberries in light syrup

**METHOD**
Soak the rolled oats in the apple juice (this can be done the night before and refrigerated). Add the chopped peaches, honey and cinnamon and mix.

Cut the apple into 4 and de-core, then grate it and mix it into the oats. Add the sunflower seeds and stir.

*Serve in a bowl or a glass with a spoonful of raspberries and some dry rolled oats on top. Add more sunflower seeds if you like.*

**Fresh Lemon Curd**

**INGREDIENTS**
- 2 lemons juice plus zest (approx 100ml juice)
- 1 medium free range egg
- 3oz/85g castor sugar
- 4oz/110g unsalted butter

**METHOD**
Add all of the ingredients together in a saucepan, and place over a very low heat, stirring continually with a wooden spoon.

After a while the mixture will start to thicken. Turn off the heat and remove the pan from the stove. Pour it into an airtight container or a small bowl, cover with clingfilm and refrigerate.

*It can last over a week in the fridge, and is great served with ice cream or some toast or crumpets – or better still shortbread.*
In our previous issue of Kidney Life, Andrew Norton kindly shared his experience of travelling whilst on dialysis. Here is another journey Andrew shares which we hope will inspire you to travel, even on dialysis.

In my previous article about holiday dialysis in the winter issue of Kidney Life, I mentioned that South Africa was my next target. I chose South Africa as my next adventure because it’s a place where I have many memories.

In the late 1970’s my family and I lived in a suburb of Johannesburg called Kempton Park. During that period gambling was prohibited in South Africa, but not in the homelands. So, a Jewish entrepreneur called Sol Kerzner invested a large sum of money to build a resort called Bophutatswana.

‘Sun City’ as it was called, opened in 1974, it had all the gambling machines like slots and roulette. Naturally, this was a magnet for weekend visits. After Nelson Mandela came to power in the 1990’s, gambling was legalised. Due to increased competition, Sun City ceased to be the place you went to gamble, so it re-invented itself as a resort destination.

I visited in 1998, just as they launched their timeshare complex and we were excited by the possibilities of ownership. Today, twenty years later, we have not regretted the decision and have had many wonderful trips. The resort has hotels and restaurants, a huge wave...
pool, a lake with water sports, two championship golf courses and many other attractions. Most importantly, at a five minutes’ drive away it is surrounded by a resort and on three sides is South Africa’s fifth-largest game reserve, the Pilanesberg.

This is 500 square kilometres of bush, with many habitats. It’s full of all the animals you expect including the ‘Big Five’ – Lions, Leopards, Elephants, Rhinos and Buffaloes. There are 80 miles of roads and tracks, all passable by car, so you can drive from the resort in a hired car and create your own safari. If you wish to be driven instead, there are many companies providing that service in Sun City.

Another great thing is that you are completely safe in the resort, so walking around in the amazing gardens and visiting the attractions is safe, at any time of the day or night. A free bus service also operates right through the resort. There is truly nowhere else like it in the world.

So how did I manage to dialyse out in the bush?

The surrounding area is well known for platinum mining and the nearest town Rustenberg, is served by excellent roads which are only a 35 to 40 minute drive from Sun City. Through my research online, I found that the local hospital offers dialysis to locals and visitors. There are other units within the area, run by Fresenius. But I found these to be more expensive than the one I found, which is National Renal Care (contact details below).

They were easy to communicate with and quite responsive through e-mail. A fee of around £120 per session was charged, which is very reasonable in comparison to many other places I have visited outside Europe.

National Renal Care operated four sessions a day, starting at 5am and finishing around 1am. I was attracted by the free time they were able to offer me. This was an overnight session starting at 8pm and finishing around 1am. Once the dialysis session finished, the chairs are made flat into beds so I was able to catch a few hours of sleep. At 4.30am the lights would come on and I would drive home and slip into bed to complete the night.

Driving to and from the unit during the night was not as scary neither difficult as the roads are busy with miners going to or from shifts. Daytime slots were available if night time dialysis was not suitable. The unit is small, but clean and professional and refreshments were provided (even on the night sessions). Payment was done by electronic bank transfer before arriving, which made it easy and simple.

I hope my adventure inspires others to travel, even on a trip to the wild side, like South Africa. There are many other places to stay and receive dialysis treatment besides Sun City. Through a little research and determination, I was able to travel across the world and dialysis did not stop me.
Fundraising

Free case of water

This April we want you to take up the 30 day water challenge, it’s very easy, just drink water for a month – no tea, no coffee, no fizz and no alcohol (normal intake of food is required)

By taking up the challenge, you will feel so much better, you could boost your metabolism, save money, see a weight loss and some say just drinking water can slow down the ageing process.

If you would like to take up the challenge and raise money for kidney patients, please email your name and address to nkf@kidney.org.uk. The first 84 people to register will receive a free case of Fonthill water delivered to your door.

Thames Bridges Trek

Setting out from Putney Bridge we head downstream towards the city, zig-zagging over the array of historic bridges, each with its own fascinating story and a mid-point stop in Vauxhall for some snacks & drinks. 25km later, it’s a finish line celebration in Southwark past the majestic Tower Bridge.

The Thames Bridges Trek is a great opportunity to get out, get fitter, meet others and explore the very best of London!

For more details pete@kidney.org.uk or call 01263 722287

Would you like to advertise your business or products in Kidney Life?

If so, Kidney Life is the perfect platform that reaches thousands of readers, from patients to healthcare professionals. Advertising in Kidney Life can help increase your brand awareness and business growth.

To advertise in Kidney Life in 2019 please contact the NKF head office.
**Simply the Best**

For the past six years, supporters of the NKF have been taking part in the Ben Nevis trek, everyone comes away from the weekend loving the experience and this year it could be you on June 21st.

The weekend starts on the Friday where you are picked up from the train station or airport, and taken to your accommodation where you enjoy an evening meal. The next morning after a hearty Scottish breakfast you trek up Ben Nevis. After climbing the highest mountain in the United Kingdom, you have celebratory dinner and drinks and the next morning another breakfast and transport back to the station or airport.

**Spring draw**

Enclosed in this copy of Kidney Life you will find 3 books of draw tickets, if this is not the case and you would like some tickets, please contact NKF@kidney.org.uk or call 01909 544999.

The spring draw has some exciting prizes, the first prize is £1,000 to spend as you wish this summer, maybe a nice holiday? The second prize has been donated by Dudley KPA and it’s the use of their lovely caravan in the Cotswolds and this is for up to six people for a week (subject to availability) we also have 20 other prizes of £50 for a little treat.

**Running for Kidney Patients**

Here at the NKF we offer a vast array of running events, 10k, half marathons, full marathons and even Adrenaline events, some of these are out of the UK like the Paris Marathon.

Contact pete@kidney.org.uk for a full list of 2019 events to take part in.
3D printing used in life-changing kidney transplants

One of the UK’s busiest and most successful foundation trusts has once again used cutting-edge technology to achieve better patient care.

Since 2015, Guy’s and St Thomas’ NHS Foundation Trust has twice used 3D printing technology, to support the successful transplantation of an adult kidney into a child. Recently, this helped a three-year-old boy receive a life-saving kidney transplant from his father.

Additionally, in 2015, teams at Guy’s and St Thomas’ pioneered the world’s first use of 3D printing to support the successful transplantation of an adult kidney into a two-year-old girl. During this, the team successfully created models of the two-year-old girl’s 10-kilogram abdomen and the adult’s kidney by using Guy’s and St Thomas’ 3D printer. This helped surgeons accurately plan the highly complex operation to minimise the risks. Furthermore, the 3D printer also helped identify in advance any issues that may involve with transplanting an adult sized donor kidney into a child’s small abdomen.

Based on measurements obtained through CT and MRI scans, the 3D printer produces a model of liquid plastic, moulded under ultraviolet light to replicate the body parts’ size and density. This enables surgeons to assess the feasibility of the transplant and to rehearse each step of the operation with the 3D models.

Mr Pankaj Chandak, a transplant registrar at Guy’s and St Thomas’ whose idea it was to use 3D printouts, says: “Our exciting use of 3D printed models to help plan highly complex kidney transplant surgery in children brings all sorts of important advantages for our patients and the surgical team.

“The most important benefit is to patient safety. The 3D printed models allow informative, hands-on planning, ahead of the surgery with replicas that are the next best thing to the actual organs themselves. This means surgeons are better placed than before to prepare for the operation and to assess what surgical approach will offer the greatest chance of a safe and successful transplant.”

Recently, Pankaj won the Royal Society of Medicine’s Norman Tanner Medal for his contribution to innovative surgical research and improvement of patient care. Pankaj says: “It’s a huge honour and I’m absolutely thrilled for this award that recognises the team’s efforts in overcoming barriers to
transplantation. It’s a great privilege to work with an inspirational team of surgeons and medical physicists at Guy’s and St Thomas’. Everyone at the Trust has been so supportive in developing our use of 3D printing and it’s fantastic that this new technique is now helping our patients.”

Michael Wright, Head of Health Investment at Guy’s and St Thomas’ Charity, says:

“The 3D printer is one of the many examples of how we are working with the Trust to transform healthcare and radically improve the experience of patients. Clinicians from many specialties are embracing the new technology and we expect to see more pioneering uses in the near future.”

For avid art connoisseurs, the Science Museum is exhibiting these life-changing 3D models on permanent display. This will be part of the Museum’s new Medicine Galleries, which are due to open in 2019. The new galleries will showcase cutting-edge health innovations like 3D printing alongside medical breakthroughs from throughout history.

Selina Hurley, the Science Museum’s Curator of Medicine, said: “At the Science Museum, we endeavour to collect stories as well as objects to join the national collections. These models represent a powerful example of one family’s story of a life-changing transplant operation but also the potential uses of 3D printing technology in surgery and medicine.”
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Dialysis Unit to be Developed on the Island of Bute

By Andrew Norton

The course has been set as Argyll and Bute Health and Social Care Partnership (HSCP) in partnership with the Bute Kidney Patients Support Group (BKPSG) and the Dr J N Marshall (Island of Bute) Memorial Trust announced that a Dialysis Unit will be built in the Victoria Hospital in Rothesay on the Isle of Bute.

The BKPSG launched the campaign for a Bute Dialysis Unit and started fundraising in October 2015. Shirley McFarlane, Secretary for the BKPSG says: “The current dialysis patients have to travel by ferry, then by hospital transport on the mainland to dialyse. An arduous journey which takes a long time. They also have to contend with stormy weather, which can affect the ferries. Sometimes, the patients have to be transported by helicopter off the island, if the weather is constantly bad for a few days.”

The community and BKPSG united behind the campaign and raised £122,000 in three years. After this, the Dr J N Marshall (Island of Bute) Memorial Trust indicated it would support the creation of the Unit and provide the remaining funds and help reach the fundraising target of £300,000.

“The representatives from Dr J N Marshall (Island of Bute) Memorial Trust were so moved by the plight of the patients and the fact that the community had responded so positively, it offered to meet the costs required to get the unit built,” says Shirley McFarlane.

Donald Reid, one of the Trustees in the Dr J N Marshall Trust, said:

“Our trust was founded to support the local community in Bute and we are pleased and honoured to be able to provide funds which help to move this project from an aspiration to a reality. We admire the sustained courage and good humour of the patients on Bute who currently travel three times a week to Greenock for dialysis. The prospect of gaining for them such a facility on the island itself is a huge incentive. We salute the commitment of the Support Group over its years of hard work in fundraising and are very impressed by the enthusiastic espousal of the project by HSCP and the strongly motivated high calibre personnel it has tasked with bringing to our little island such a valuable asset.”

The HSCP also recognises the huge contribution the local community have made to support and fundraise for this development on the Island.

However, there is considerable work required within the hospital to adapt the existing facilities to create the dialysis unit while ensuring that all the current facilities within the hospital are maintained. There will also need to be a specialist nurse recruited and training delivered to the existing nurses and work has begun to plan for this.

Kristin Gillies, the HSCP’s Senior Service Planning Manager who will be the Project Manager for the dialysis unit said:

“This is an extremely exciting time for the hospital and the community on Bute. There is a great deal of work to do but Argyll and Bute Health and Social Care Partnership are committed to delivering a safe and sustainable dialysis service.”

“Having a local unit will make such a difference.”

All campaigners and fundraisers are absolutely delighted, and it is hoped that the unit will open very soon and eventually offer holiday dialysis to those coming to the island on a break.

“Having a local unit will make such a difference. The NHS had no money to help us get a unit but we just felt we had to do something to help these patients. It just shows that if you want something enough, you can achieve it. I also hope it gives other rural/remote areas the motivation to push for a local unit,” says Shirley McFarlane.

For further information see press release at: https://www.nhshighland.scot.nhs.uk/News/Pages/DialysisUnittobeDevelopedonBute.aspx
Here at the NKF we understand that kidney disease can affect anyone, regardless of age, background or ethnicity. The NKF provides a platform for young people with kidney disease to share their experiences and inspire others. Kidney Life is proud to share Sana’s story, a brave girl who underwent dialysis and transplant at a young age. Here, in her own words, she describes the challenges she faced.

November 5th 1998, this was the day I was born. Straight away the doctors knew something was wrong, it was renal failure. My kidneys weren’t working as well as they should. I had regular appointments at the hospital and as a child everything seemed more complex. I understand all of it now, but sometimes I wish I didn’t. I wish I could go back to the days where I was a child, with little worries. Growing up, I had one favourite doctor who had seen me through everything.

I eventually moved to Leeds and was looked after by a different team. This is when my condition deteriorated. My appearance started to change, I got tired easily, but most importantly I was brave and always have been. Dialysis treatments were discussed and I realised this was my only option. So, I decided to start haemodialysis. I was admitted into hospital to get a dialysis line, but I was too young to really understand this sudden change. I started dialysis and was connected to a machine, three times a week for three hours each session.

There were a lot of dietary restrictions whilst on dialysis, but eventually I got used to it. Feeling dizzy, tired and sick was very difficult, but the nurses at the ward were helpful and that made it easy for me.

I was on dialysis for seven to eight months and on the waiting list for two years. My mum had then decided to donate her kidney to me. A number of tests were done and we found out she was the right match for me. We met the surgeons, signed the paperwork, discussed the process and for the first time I felt nervous and scared. The transplant was cancelled twice; the first time my mum had a temperature and the second time I got it, but third time lucky and it happened!

On the night I got admitted, I heard my favourite doctor was on call. I guess that was another sign of luck too. The following day, I was taken at around 1pm and one of the nurses from dialysis came with me for support. I was scared and kept crying, but the nurses managed to calm me. When I woke up it only felt like a few minutes. I saw that there were tubes and drips all over me. A couple of minutes later my favourite doctor came to see me and had tears of happiness in his eyes. Calls came in asking how I was and thankfully everything went well. I was on a lot of medication and had to drink a lot of water. Since then, the medication and amount of water intake has decreased, but I have to take the medication for the rest of my life.

The two weeks were over and I was sent home. I was on the road to recovery. Staying indoors for three months was really difficult. Being on a lot of strong medications made me gain weight. It was also mentally very challenging. It’s now seven years since my transplant and it is a day I will never forget. The day my life changed.
The NKF relies completely on sponsorship and donations to continue its vital work supporting kidney patients and carers.

Last year generosity from our supporters has helped us campaign for more living kidney donors, it helped us put a stop to dialysis patients being charged for travel costs for lifesaving treatment and we received over 3,000 calls to our Helpline, free of charge to the patient and carers, plus not forgetting tens of thousands of leaflets were printed and posted out free of charge.

Please help us continue our work and give kidney patients a brighter future.

We have different ways to help our charity...

Support NKF each month

£20 a month
Will help with the ever increasing printing costs to enable our Helpline to continue to produce, and distribute, patient information leaflets. There are over 150 titles in the Kidney Matters series which are printed ‘in-house’ and distributed, free of charge, to all patients calling our Helpline telephone 0800 169 0936.

£10 a month
Will help towards the ever increasing postage costs incurred in sending out information to patients, and renal units nationwide.

£5 a month
Will help the NKF to spread the word about the importance of Organ Donation.

£2 a month
Pays for your Kidney Life magazine.

Leave a Legacy to NKF

A will is a legal document, so it’s best to get the advice of a solicitor to make your instructions legally valid. To find a solicitor you can look in the Solicitors Regional Directory which is available in your local library.

Donate to the NKF - via Payroll Giving

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To give to us in this way, your Employer will need to operate a scheme, if you aren’t sure that they do, fill in the form anyway and we will let you know if they don’t and perhaps we can suggest to them that they introduce one.

There are now FOUR ways to pay NKF...

1. **Online at www.kidney.org.uk**
   Book or pay here using a credit or debit card

2. **Pay by Credit or Debit Card by calling 01909 544999**

3. **Pay by Direct Debit. Fill in the direct debit form overleaf and return to us**

4. **Send a cheque, made payable to ‘the National Kidney Federation’**

You will find more information to help you make your will at:

- www.solicitors-online.com
- www.make-a-will.org.uk

The NKF Helpline on 0800 169 09 36 can give you advice on how to include NKF in your will.

PAY No Tax – Because the donation is taken from your gross pay, every pound you give will only cost you 80p, or only 60p if you are a higher rate tax payer.
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