RFHKPA
ROYAL FREE HOSPITAL
KIDNEY PATIENTS ASSOCIATION
REG. CHARITY NO. 277711

OCTOBER 2015

Newsletter

MAKING A DIFFERENCE FOR ROYAL FREE KIDNEY PATIENTS

Half full or half empty?

Fulfilling a shared dream

See donor transplant story

The KPA meets with the Royal Free renal team

Members of the KPA (Andy Forbes, Nii Plange & David Myers) met up with the renal team (Maddy Seeley, Lee Gutcher, Emma Davidson) for our bi-monthly team meeting on 6th August.

This is a regular meeting where the Royal Free renal team informs the KPA about changes and improvements that affect our kidney patient's. Our KPA team is able to let the renal team know about patient issues or concerns.

CAB service

Our patients have not fully understood how the CAB service has been set up to look after patients concerns over benefits or personal issues. The service attends at our St Pancras and Tottenham sites with the possibility that Edgware patients will have access later in the year. It was confirmed that twilight patients can access the service and home visits can be arranged where appropriate. The renal team has been asked to update the CAB leaflet and repromote so that all patients know who and how to contact the service.

Ophthalmology at St Pancras

The KPA was updated that Ophthalmology works were to commence in August. Communication letters have been sent to all staff member to disseminate and inform patients. Works will cause minimal disruption to the unit.

10th Floor kidney wards

A flow co-ordinator is now working on the 10th Floor kidney wards with the object of reducing the number of outliers on our wards. Secondly, an ex-nurse is carrying out the role of an 'inpatient navigator' – to facilitate discharges, filling out forms for communications to community organisations and help with outliers. This is intended to reduce nurses' workload and over time it is hoped this will have a positive impact on the in-patient experience as patients will have a named person to contact.

New patient communication

The KPA highlighted the fact that new starters to dialysis are unaware of the role of the KPA and the support service we provide to patients. The renal operations team will consider adapting an existing project to update information given to new patients to include details about the KPA along with contact information.

Transport concerns

The meeting discussed the ongoing issue relating to transport concerns. Representatives of the KPA are working closely with the Royal Free facilities team *(transport management),* to find solutions to current problems.

RFHKPA Update

By David Myers President RFHKPA, Governor Royal Free London Hospital NHS

So what does the RFHKPA do?

It's quite surprising but although the **RFHKPA** has been in existence for many years and as an organisation with myself and Andy Forbes having been amongst the best known of our team over the last 12 plus years, there is still confusion about what we do and the role we play in representing Royal Free kidney patients.

There are many patients who recognise the work that we carry out but there are still plenty of patients who don't know we exist. We of course promote ourselves in areas such as this Newsletter but data protection laws mean that the hospital can't tell us directly the names and details about our fellow kidney patients. You have to tell us that you want to be a member of our association, in spite of the fact that every kidney patient is entitled to free membership of our association.

Many patients think that when they contact one of our team that there are a whole group of us sitting in an office waiting to act swiftly to answer your concerns or solve your problems immediately. We don't apologise for appearing to be professional and showing our fellow patients care and consideration. However, we are all volunteers so no one gets paid, we merely do our best to help you as much as we can using our personal knowledge or experience, or to put you in touch with the person or department that can help you if we can't.

Apart from Andy and myself, our key unit representatives, Nii Plange, Louis Toussaint and Jaycinth Eki are regular visitors to their respective units and our membership secretary Jill Slann is often the first point of contact for many new patients. Our team of KPA committee members has a wide experience of the many parts of the renal journey from dialysis to transplantation, so there are lots of personal experiences to listen to.

Donated Funds

We take our responsibility to look after donated funds in a professional manner. We still are able to put these funds to good use. For instance, thanks to the generosity of Farshad Mardani, friends and family of one of our Edgware patients, the late Mrs Fatemeh Soleymani, fellow patients there are now able to enjoy the use of an ice dispensing machine. Anyone who understands how dialysis patients have to manage fluid restrictions will understand how much sucking on ice cubes can be such a relief when drinking has to be restricted.

Thanks to donations made in the memory of Barnet patient, the late Gloria Deller, we have been able to contribute towards the cost of an ECG machine, which should improve the way in which patients' care is provided at our Barnet unit.

Fundraising

We continue to see fantastic loyalty from so many patients and family members.

There isn't room to mention all our supporters but I do want to congratulate Valerie Nouge and her husband Ben and daughter Elia for raising over £1500 from friends and family in support of their taking part in the London 10k run. We are very grateful.

Dialysis patient Michael Epstein and his wife Barbara have been regular fundraisers for **RFHKPA.** It seems as if every birthday or special occasion has seen support for our charity. Even their daughter, Suzi, has been raising funds for us. You can read her story on P18 of this Newsletter.

And whilst many of these stories have happy endings, there is one story that is tinged with some sadness. Colin Chui ran in the Ealing half marathon on 27th September to raise funds for the **RFHKPA** in memory of his sister Emily, who passed away in March. In 2013, Emily ran in the same race for the **RFHKPA** because Emily & Colin's father received a successful kidney transplant at the Royal Free Hospital where he still *"is receiving excellent care"*. We are grateful for this continued support.

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The glass was always half full

By transplant donor, Dahlia Levy

I'm a 44 year old woman, mother of three children (ages 17, 15, 11), working as a clinical psychologist in Israel.

Fulfilling a shared dream

As a 21 year old college graduate, I moved to New Haven, Connecticut, to work for two years at the Yale Child Study Centre on a study investigating the effects of prenatal cocaine use on child development in the first six years of life. I met my husband Jack, moved to New York, and completed a doctorate in Clinical Psychology. Ten years after moving to the USA, with two children and pregnant with the third, we decided to move to Israel, fulfilling a shared dream and determined to give it a try. 12 years later, we are still here!

Life here is rich with colour, emotion and intensity

Today, I work as a clinical child psychologist both in private practice and as part of a therapeutic team treating children with autism in the school system. Life here is rich with colour, emotion and intensity. My husband works as a venture capitalist investing in Israeli start up companies that are involved in clean technology (water, agriculture, solar...). My children are all in school.

My father never really defined himself as an ill person

My father, now 72 years old, was diagnosed with gradual kidney deterioration many years ago. Elevated blood pressure was, at first, assumed to be a symptom of heart disease, but was in fact, a symptom of shrinking kidney function. My father, Marcel, is an eternal optimist. The glass is always half full and he will never turn his back on a new experience. He never really defined himself as an ill person, but went about his life as usual. I am quite certain that this positive and upbeat attitude helped him stay well for so many years with very little medical intervention. As the years progressed, he became more tired more quickly. He would become breathless and needed to sleep during the day. In addition, he began to feel cold easily. For us all, this was a significant symptom because my father was always considered the human heater. As his kidney deterioration progressed, we were surprised to see him wear jumpers, scarves and additional winter gear.

His will to live healthily and happily overcame initial emotional barriers

In 2012, Dr. Woolfson at the Royal Free, suggested that my father consider the possibility of live donation within the family. For a while, my father would not hear of it. He couldn't imagine putting any of his family members at any risk for his own sake, especially his own children. My father is the quintessential family man – loves being with his children and grandchildren. He couldn't fathom asking anyone to donate him an organ. My sister, brother and I didn't really give him much of a choice and insisted on meeting with the live donor nurse specialists to hear more. He agreed, ultimately knowing that dialysis, and hence a different and more difficult life, awaited him otherwise. His will to live and to live healthily and happily overcame those initial emotional barriers.

In February 2012, I flew to London to meet my new baby nephew and took the opportunity to meet Bethan Hood *(Specialist transplant nurse)* at the Royal Free. Lovely, warm and sensitive, Bethan spent time answering all my questions, and continued to do so throughout the donation process. I also met Dr. Gareth Jones and Mr. Neil Banga.

We both offered to donate

Within two weeks, my sister and I received notice that we were both good matches for my father. In all honesty, my initial reaction was fear and anxiety.
I hadn't really thought about what I would do if I were a match. Bethan informed us that we would need to decide who would donate as only one of us could go forward to the next stage of extensive testing.
My sister Sylvie and I are extremely close. We couldn't quite figure out how to go about deciding. We are both fit, active, past childbearing years, and emotionally capable of withstanding this process.
It turns out that this is not such an easy decision! Finally, we called Bethan and she suggested she raise this decision at the team meeting to identify any medical/biological factors that might decide for us.

Even before Bethan sent us an answer, Sylvie and I were able to come to a mutual decision. We took our children and spouses into consideration, their life stages, and how each would respond to the upheaval required for kidney donation. During these weeks, we realized that open and honest communication between family members is critical when making a family-based decision that will ultimately impact everyone either directly or indirectly.

In April, I flew once again to London for the battery of tests required. In May, I made another trip for a cyctoscopy and kidney biopsy to determine the cause of blood traces in my urine. Results showed that I have *"thin basement membrane disease"*. In a phone conversation with Dr. Jones, I was reassured that donation was still possible but that it was entirely and completely my choice.

My father grappled with the idea that he didn't really have a choice

By now, it was clear to me that I was going to donate. I had needed time to get used to the idea and with each passing week, I was more and more certain that I was ready for whatever lay in store. I had already booked August 1st as our date, knowing that a month off in August was easier for me than a month off during the school and work year. My father grappled with the idea. He kept asking me if I was sure and if perhaps we should wait a bit longer. His anxiety about me kept his anxiety about himself at bay. My husband supported this decision and never once asked me to question it or doubt it.
I continued to email Bethan with any questions or thoughts I had, a support I found calming and helpful. Friends here in Israel showered me with warm, encouraging words, thoughtful gifts and letters. I was overwhelmed by all the support and it all made an enormous difference for me.

Struck by an ability to talk to us in clear and sensitive ways

On July 31st, we checked into the Royal Free to participate in a research study and to hear about all that can go wrong from our surgeons before signing a consent form! Whist waiting, we noticed a newspaper with the headline *"why your risk of dying in hospital will rise by more than 6% tomorrow"* (a reference to new junior doctors starting work on 1st August). We had a good laugh about that!

We then went back to my parents' house for supper and to spend time with my wonderful mother, who cooked, baked and took care of everything each and every day. At 6 am on August 1st, I woke up, anxious but glad to know it would all be behind me in a few hours. Mr. Colin Forman was my surgeon and Mr. Neil Banga was my father's surgeon. Mr. Banga continued to care for us post-op and I was always struck by his ability to talk to us in clear and sensitive ways. He was extremely kind and communicative. The fact that he always sat down to talk to us made it seem as if he wasn't in a hurry *(which I'm sure he always was)* and that we had his undivided attention.

I felt quite overwhelmed

The operations were a great success. In the recovery room, I was told that my kidney was being transplanted and was already functional. My father's creatinine dropped several hundred points within hours. When my brother came to see me later that day in the ward, he told me, *"Wow Dahlia, Dad looks unbelievable!"* His colour returned and his body lost water it had retained. He looked healthy, as if he'd just woken up after a long, long sleep! I, on the other hand, felt exhausted and would do so for several days.
24 hours after surgery, I went to see my father. I think we were all quite lost for words. I felt quite overwhelmed.
My head felt fuzzy from the morphine *(which I had stopped taking early that day)* and I couldn't quite fathom all that was happening. My mother wept and my father kept introducing me to the nurses on duty as his hero. It all felt quite embarrassing actually and somewhat surreal.

Two days later, just before I was discharged from the hospital, I went to say goodbye to my father. He was resting, recovering well. I entered his ward and sat next to him. He held my hand and said, *"Dahlia, you're my hero. Thank you, thank you."* We wept together. I felt such a release of tension and all the emotion that had built over the weeks before just came flooding out, and continued to do so for two to three days after.

"Look at me everyone! Look at what I did!"

There are certain moments that stand out for me during my recovery. I experienced some frustration at not being able to do things quickly and efficiently in the ways I was used to. When I returned to Israel three weeks post donation, I remember power walking down the street in my effort to regain my strength quickly and feeling completely euphoric, wanting to scream out to the world, *"Look at me everyone! Look at what I did!"* I began running again six weeks post-op. About two months post-op I returned to yoga, gingerly testing out my body's ability to bend and twist into those familiar yoga poses. Exactly three months post-op I ran the 10K in Tel Aviv and felt great. Today, I continue to run actively and am an active yoga practitioner. My father is thriving. He's given up his afternoon nap and his hands are warm again. One year after his transplant, we celebrated his 70th birthday here in Israel. It was poignant and very moving.

Life is only altered for the better

Three years on, I can easily say that I am grateful for having had the opportunity to donate a kidney. It is only a small physical challenge. Recovery is quick if all goes smoothly and life is only altered for the better. Whilst in hospital, I met and spoke with other patients who had undergone transplant. I wrote to all of our friends and family urging those who had not registered themselves as organ donors to do so. I received many, many replies.

I was particularly moved by one friend's description of his family dinner table that week during which he had discussed my story with his teenage children in an effort to explain to them the importance of organ donation as they near the age in which they will decide for themselves. He told me that they had been very moved and were all keen to register when the time came. My own children took this all in their stride in a way I think only children can, but I know they were deeply affected. In fact, when my oldest son had to choose an ethical issue to research in 10th grade, he chose to research the ethical dilemmas associated with kidney donation.

I think it is especially important to share kidney donation stories with the Israeli population due to the many myths that surround religion and organ donation.

RFHKPA update continued from page 3

National Transplant Week

Pip Madhoo & Joan Dyhll

National Transplant Week was the week starting September 7th and as usual, the KPA played its part in promoting the event with committee members working hard to persuade visitors to the hospital to sign up to the Organ Donor Register. Nii Plange organised a team of committee members including Pat Hennessy, Pip Madhoo, Joan Dyhll and Louis Toussaint. The team were ably supported by Keith Hunt's complimentary therapies team, who continue to give such great service to our kidney patients.

Fiona Stevenson providing massage treatment

Many smaller donations to our charity are used to pay towards the wonderful massage service that Keith's team provide to our patients at our Barnet and Tottenham satellite units.

Summer events

I know many of you look forward to the photos of your friends and fellow kidney patients when we report on our main summer events, the Summer Garden Tea Party and our Summer Day Trip, this year to Margate. Unfortunately, the quality of photos taken was not good enough and sadly all of the photos from Margate featured people soaked and looking miserable! The photos do not reflect the fact that many still had a great day out, in spite of the weather. Let's hope the weather is better next year!

Key roles need to be filled

Whilst the **RFHKPA** team continues to carry out its responsibilities, as an organisation we are still suffering from a lack of willingness from patients or new committee members to take on the senior roles within our charity. Andy Forbes continues as acting Chairman but is eager for someone to take over the role and bring fresh ideas and renewed energy into our activities. We have been without a Treasurer for the last six months and our financial matters are being looked after by Andy and myself, but only on a temporary basis.

I continue my role as President of **RFHKPA** which is one of a number of other voluntary roles I have within the Royal Free and the NHS but my own health issues are stopping me from being as involved as I have been in the past. I don't know how much longer I will be able to spend on KPA activities and that may mean that if patients don't come forward to take on responsibilities, many of our activities will disappear. In particular, it may not be possible to continue to produce this magazine, in its current format, if at all.

We should all be concerned about the long term stability of the **RFHKPA.** **So please make it your business to come along to the RFHKPA AGM on Sunday November 22nd at 2.00 pm. Meet the KPA committee, listen to the charity's annual report and get your opportunity to ask one of the Royal Free renal team of consultants anything you want to know about your kidney concerns. We'll look forward to seeing you.**

9-way kidney transplant

Recently there have been some amazing stories about transplants but none more special than the news about a marathon 9-way kidney transplant which took place in San Francisco in June. The 36-hour chain of operations was a highly co-ordinated effort, and considered to be the longest kidney transplant chain performed in one city. In all 18 surgeries were performed.

Aries Merritt successfully undergoes kidney transplant

Also of interest to sports fans, Olympic champion and world record holder Aries Merritt, who, just four days after winning a bronze medal in the 110-meter hurdles at the 2015 IAAF World Championships in August, successfully underwent a kidney transplant at the Mayo Clinic in Phoenix. The kidney was donated by his sister LaToya Hubbard.

In 2013, Merritt went to the hospital and was told by doctors that his kidney function was less than 15% because he was dealing with a collapsing variant of focal segmental glomerulosclerosis. He was told that he would need a transplant in May, but he decided to continue competing through August's global championship in Beijing. Amazingly, he still summoned enough strength to compete at the highest level and his achievement to win a bronze medal in the World Games is astonishing.
Happily, all has gone well since his kidney transplant and Aries expects to make a full recovery and will attempt to defend his Olympic gold medal in Rio de Janeiro next year.

IndyCar driver Justin Wilson saves the lives of six people by donating organs after racing death

By Kelly Mclaughlin for dailymail.com

The 37-year-old former British Formula One driver died on August 23rd when he was hit in the head by a large piece of debris that broke off Sage Karam's car when it spun into a wall at Pocono Raceway in Long Pond, Pennsylvania, the previous day. It knocked Wilson unconscious and his car veered into an interior wall. His brother Stefan Wilson announced that organs had been donated to six people and saved their lives

Justin - who was known for supporting different charities and openly discussing his dyslexia - had chosen to donate his organs. No further information about the donations was released.

He was airlifted to hospital in a critical condition after debris broke off Sage Karam's car when he spun into the wall during the closing laps of the penultimate race in the IndyCar Series.

A highly competitive racing driver

With deep sadness, the parents of Justin Wilson, Keith and Lynne, his wife Julia, and his brother Stefan shared the news that Justin passed away after succumbing to injuries suffered during the Verizon IndyCar event. They issued a statement reading. 'Justin was a loving father and devoted husband, as well as a highly competitive racing driver who was respected by his peers. The family would like to thank the staff at the Lehigh Valley Health Network Cedar Crest Hospital, Pocono Raceway, Andretti Autosport, and the Verizon IndyCar Series as well as the entire racing community for the amazing outpouring of support from fans around the world. The family has requested that in lieu of flowers, donations be made to the Wilson Children's Fund care of INDYCAR.'

Friends show great respect

Several of Wilson's peers took to Twitter to send support to the driver's family, including his wife and their two daughters, aged seven and five. Formula One star Lewis Hamilton tweeted: *"I am so devastated to hear of another passing of a great man & driver. I'd met Justin Wilson a few times growing up & he was the ultimate gentleman."*

Mark Miles, CEO of Hulman & Co, the parent company of IndyCar and Indianapolis Motor Speedway, said: *'Justin's elite ability to drive a race car was matched by his unwavering kindness, character and humility — which is what made him one of the most respected members of the paddock.'*

Wilson had suffered several injuries in the last few years. In 2011, he broke a bone in his back at Mid-Ohio. He missed the final six races of the season and wore a back brace for more than two months as he was restricted from any physical activity. The injury kept him out of the season finale at Las Vegas and the race where fellow racer Dan Wheldon died.

Injuries did nothing to change his perspective

Wilson also broke his pelvis and suffered a bruised lung in the 2013 season finale at Fontana. He said in 2012 his injuries and Wheldon's death did nothing to change his perspective or make him question his career choice. '*I've had the conversation with Julia - this is what we do, and you try to make the best plans if that ever happens,'* Wilson said on his return in 2012. *"You've got to know the risks and work out if those risks are acceptable. To me, it's acceptable. But I'm not going to stop trying to improve it. All the drivers, this IndyCar, we're always trying to make it safer, but at the end of the day, it's a race car. We're racing hard, we're racing IndyCars and it's fast. When it goes wrong, it can get messy.'*

The accident was a grim reminder of the dangers of open-wheel racing. Indianapolis 500 winner Dan Wheldon died in 2011 after his car became ensnared in a fiery 15-car pileup, flew over another vehicle and landed in a catch at Las Vegas Motor Speedway. Wheldon's head hit a post in the fence and he died instantly. He was the last fatality in a form of racing that saw drivers Scott Brayton (1996), Tony Renna (2003) and Paul Dana (2006), among others, die after wrecks. After Wheldon's death, Wilson became one of three driver representatives to serve as a liaison between the competitors and. IndyCar. It was no surprise: The 6-foot-4 Wilson, easily the tallest in the series, was well liked by everyone in the series.

Hunter-Reay, the winner of the race at Pocono was one of many who was discussing safety measures - and not his win - for the open-cockpit series.

Competed in 20 Formula One races

Wilson, who was born in Sheffield, won seven times over 12 seasons in open-wheel racing and finished as high as fifth in the Indianapolis 500. An acclaimed sports car racer, he won the prestigious 24 Hours of Daytona with Michael Shank Racing, and he competed in 20 Formula One races in 2003 before moving to the U.S. to join Champ Car.

He finished third in the Champ Car standings in 2005, and was runner-up in both 2006 and 2007. To support his career, his management team in 2003 created a program that allowed fans to invest in the driver. Hundreds of people bought shares in Wilson, who was dyslexic and a strong supporter of foundations related to the disorder.

A grim reminder of the dangers of open-wheel racing

'Maybe in the future we can work toward something that resembles a canopy. Something that can give us a little bit of protection and still keep the tradition of the sport. Just to be an innocent bystander like that and get hit in the head with a nose cone is a scary thought.'

http://www.dailymail.co.uk/news/article-3211115/Tragic-IndyCar-driver-Justin-Wilson-saves-lives-six-people-

Royal Free Dietetic Column

Celebration Time, Come On!

By Jacqueline Newman & Roshni Patel (Registered Renal Dietitians, Royal Free London NHS Foundation Trust)

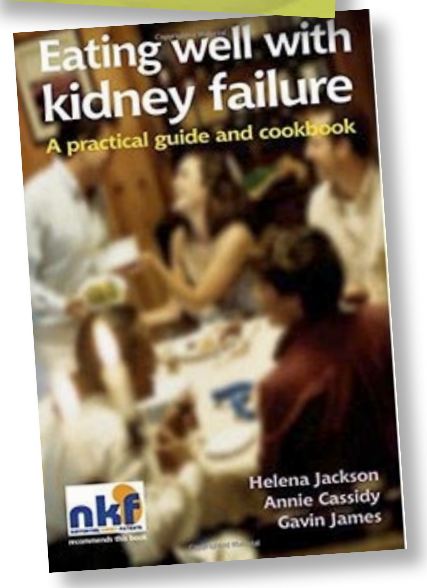
Whether it's a birthday, wedding, a religious festival or anything that warrants a celebration, food and drink are often an integral part of the event. Different cultures have different traditions and therefore often have different foods which may be served at a celebratory event. The food served can be different from that eaten on an everyday basis and is often more what we call "Treats" or "Indulgence" foods.

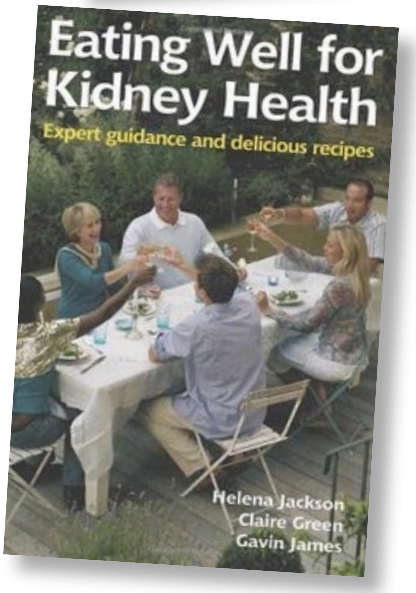
As a kidney patient, it may be recommended that you limit certain foods in your diet and so knowing what you can eat at a celebration event, can be a challenge. Some events such as Christmas are just once a year and so dietary recommendations can often be sensibly relaxed to enjoy the day. Every patient has varying degrees of chronic kidney disease and may be receiving different forms of treatment.

Celebrity chef recipes can be used safely or slightly adapted

In addition to this, patients may have other conditions where diet needs to be considered such as diabetes or heart disease. It is often difficult to provide recipes which are suitable for every patient however the following tips should be useful when deciding what food or meals to prepare. In most cases, "special recipes" are not required and many standard cookbooks or celebrity chef recipes can be used safely or adapted slightly with some imagination to be made more renal friendly.

There are some cookbooks which have been designed for Kidney patients such as **'Food for Thought'** by the National Kidney Federation (NKF), '**Eating Well for Kidney Health'** by Jackson, Green & James, **'Eating well with kidney failure'** by Helena Jackson, Annie Cassidy, and Gavin James. The internet is a good resource for lots of recipes too.





Here are a selection of recipes to use when thinking about dishes to serve at your celebration

"Kidney friendly" lemon cheesecake (serves 6)

INGREDIENTS

2 oz- margarine
4 oz -digestive biscuits
Powdered sweetener - if wanted
Filling

- **12 oz - 'Philadelphia' soft cream cheese**
- **Powdered sweetener**
- **Juice of 2 large or 3 small lemons (6 Tablespoons)**
- **1 - grated lemon zest**
- **2 Tablespoons of cold water**
- **½ oz - gelatine* *(Agar can be used as a gelatin Substitute for Vegetarians or vegans)***
- **¼ pint double cream**

INSTRUCTIONS

1 Melt the margarine in a saucepan.
2 Remove from the heat and add the crushed biscuits and a little powdered sweetener if wanted.
3 Mix well and turn into a 7" flan tin or dish 1 and 1/2 inches deep. Press the mixture firmly around the sides and base; then chill for half an hour.
4 Beat the cheese, lemon juice and zest in a bowl until smooth - add sweetener to taste.
5 Put the water into a small saucepan, sprinkle on the gelatin and leave until it turns spongy.
6 Place over a low heat, stirring all the time until the gelatin* has dissolved.
7 Strain the gelatin* into the cheese mixture, stirring continuously.
8 Whip the double cream until it is just stiff and fold this into the cheese mixture.
9 Turn it all into the crumb lined tin and chill in the refrigerator for at least two hours

Shortbread Recipe

INGREDIENTS

- **125g/4oz butter**
- **55g/2oz caster sugar, plus extra to finish**
- **180g/6oz plain flour**

METHOD

Heat the oven to 190C/375F/Gas 5.
Beat the butter and the sugar together until smooth.
Stir in the flour to get a smooth paste.
Turn on to a work surface and gently roll out until the paste is 1cm/1⁄2in thick.
Cut into rounds or fingers and place onto a baking tray. Sprinkle with caster sugar and chill in the fridge for 20 minutes.
Bake in the oven for 15-20 minutes, or until pale golden-brown. Set aside to cool on a wire rack.

Why not try a new flavour?
Add Lemon zest for a lovely Lemon Shortbread.
Add cinnamon for a warm scent and flavour.

Pumpkin and rosemary muffins

Ingredients (Makes 12)

- **60ml/fl oz vegetable oil, plus extra for greasing**
- **180g/6½ oz self-raising flour**
- **130g/4½ oz wholemeal flour**
- **1 tsp baking powder**
- **½ tsp bicarbonate of soda**
- **pinch salt**
- **3 fresh rosemary sprigs, finely chopped**
- **2 free-range eggs, lightly beaten**
- **100ml/4fl oz plain yoghurt**
- **275ml/10fl oz milk**
- **1 tbsp honey**
- **240g/8½ oz cooked pumpkin, cut into ½cm/ ¼in cubes**

Method

Preheat the oven to 200C/400F/Gas 6. Oil a 12-hole muffin tin and line with 12 squares of baking paper. Push the squares down into each hole so that the paper sticks up.

Sift the flours, baking powder, and bicarbonate of soda into a large bowl.

Stir in the salt and rosemary. *(Reserve any wholegrain left in the sieve.)*

Meanwhile in another bowl, mix the eggs, yoghurt, milk, honey and vegetable oil until well combined.

Pour the wet ingredients into the dry and fold the ingredients together, but be careful not to over-work the mixture. Stir in most of the pumpkin, reserving a little for the top of the muffins. Spoon the mixture into the muffin cases.

TIP: To reduce the potassium content, boil the pumpkin first!

Sprinkle the reserved wholegrain, pumpkin and the pumpkin seeds over the muffins. Bake in the centre of the oven for 20–25 minutes, or until the muffins are well risen and a skewer inserted in the centre comes out clean.

Serve and eat at any time of the day.

Pastilla (Moroccan style chicken pie)

Ingredients (serves 4)

2 tbsp. veg oil & 2 tbsp. water, plus extra for oiling
8-10 chicken thighs, bone in
2 cloves garlic, peeled and finely chopped
4cm piece of fresh ginger
1 tbsp. ground cinnamon
1 tbsp. ground coriander
Pinch of saffron threads
2 big squiggles of honey
Finely grated lemon zest
2 handfuls of toasted flaked almonds
1 bunch of fresh coriander, roughly chopped
Black pepper (aim to leave the salt out!)
270g shop bought filo pastry
115g butter, melted
3 eggs, beaten
Icing sugar for dredging
9inch springform cake deep sandwich tin

METHOD

1 Oil the cake tin. Remove the bones from the chicken pieces and slice the meat into chunks.

2 Heat the oil in a frying pan over a gentle heat, add onions and fry for 10-15 minutes, or until translucent, softened but with no colour. Add garlic and fry for a further 1 min. Remove the onions with a slotted spoon.

3 Add little more oil to the pan, add chicken and fry quickly to brown it. Do this in 2-3 batches so the pan does not get overcrowded and just 'steam' the meat.

4 Once the chicken is cooked, return it to the pan, grate in ginger and add ground ginger, cinnamon, ground coriander, saffron, honey and lemon zest. Cook for 1 minute and stir in flaked almonds and chopped coriander. Season to taste with black pepper, aiming to use a pinch of salt at the most. Remove pan from the heat and set aside.

5 Brush each piece of filo liberally with melted butter to prevent it from burning in the oven and layer the pastry over the base of the pan and up the sides so that pieces of filo overlap, drape and hang down the edges of the pan.

For extra safety do about 5 layers.

6 Tip the chicken mixture into the pastry and spread it out evenly, then pour the beaten eggs on to the chicken. Fold the draped-over pieces of filo on top of the pie. Brush some more filo pastry sheets with butter, then scrunch them up and place them on top of the pastille.

7 Dredge the pie with icing sugar and bake for 20 minutes, or until the pastry is golden and crisp.

8 Leave to cool for 1 minute before gently removing the pie from the tin to a serving plate with a large spatula.

Helpful hints when considering what dishes to have

Salt

A small amount of normal salt can be used in cooking but the less the better!
Taste food before adding further salt, add a bit less than the recipe suggests!
Avoid using salt substitutes e.g. lo salt or reduced sodium varieties.
Try using more fresh or dried herbs, spices, pepper, garlic or chilli.
If using butter or margarine, choose the unsalted varieties.
Limit using smoked or salty foods e.g. smoked bacon, olives, salami.
Use cheese sparingly as this can be salty
It is a good idea to make your own sausages, burgers kiev's etc. as homemade ones will have significantly less salt in them than pre prepared ones, especially the lower quality, cheaper ones.

Low Phosphate

If dishes contain cheese, try using this sparingly *(can grate to go further)* or choosing a lower phosphate cheese e.g. cream cheese, cottage cheese.
Double cream, crème fraiche or double cream plus water are a good alternative to single cream, milk, custard or yoghurt.
White fish is a good option
Egg whites are lower in phosphate than egg yolks e.g. meringues
Avoid processed foods such as breaded chicken, cake mixes, instant sauces, dark coloured drinks as they often contain phosphate additives which are easily absorbed
Careful of raising agents when making breads and cakes, use in moderation

Low Potassium

Try using rice, pasta, noodles, couscous or breads instead of potatoes.
Potatoes and many vegetables can be soaked or par boiled before being added to recipes e.g. carrots, broccoli or cauliflower in a curry
Bean and pulses dishes are a good substitute for meat dishes but try and avoid using alongside meat or chicken in the same meal.
For dishes that contain high potassium vegetables e.g. mushrooms these could be substituted for lower potassium vegetables e.g. courgettes, green beans.
You could also have a small amount with a rice or pasta accompaniment e.g. mushroom risotto
Drained tin fruit is a good choice to add to pudding dishes.

Fluid

Avoid very runny sauces or too much gravy.
Rice and pasta are OK to have, even though they absorb water and they are a good choice if on a potassium restriction.
Beware of some puddings e.g. jelly, custards etc. as these will contribute to fluid intake so consider overall fluid intake for that day.

You can contact the Royal Free renal dietetic team on:
020 7830 2616

Rice

Pasta

Noodles

Couscous

The first Lupus and Vasculitis patient information and discussion evening at the Royal Free

By Dr. Sally Hamour

Photography by David Bishop (Medical Illustration)

On Monday 10th of July, over 100 patients and relatives gathered in the Sheila Sherlock Centre at the Royal Free hospital for the first Lupus and Vasculitis patient information and discussion evening.

The evening was attended by both patients and relatives from the Royal Free and beyond, and also by David Myers, president of the RFHKPA, and David Newman from the London Vasculitis Support Group. After an introduction by Dr Sally Hamour, Dr Aine Burns spoke about the changes in treatment for patients and the evolution of the clinic at the Royal Free over the last 20 years. Professor Alan Salama gave an overview of clinical trials in lupus and vasculitis and how these might bring benefits for patients. He also outlined some of the novel research being carried out here at the Royal Free. Professor Caroline Ashley, Chief Renal Pharmacist, discussed how many of the drugs we use work and also their potential side effects and Dr Christine Hanson, renal psychologist, described the service that they offer and particular symptoms or problems that the renal psychology service can assist with, illustrating these with some vignettes.

Helping to identify research priorities in Lupus and Vasculitis for the future

The final two sessions involved a Q&A with the panel and an interactive forum for patient suggestions, both for improving the service locally and for helping to identify research priorities in lupus and vasculitis for the future. During the refreshment break, attendees were able to browse information about the London Vasculitis Support Group and about Patient View and some patients provided feedback on a new patient questionnaire being designed. The feedback received about the evening was generally excellent and the meeting was much appreciated by those who attended. Due to much higher attendance than anticipated, the most frequent criticism was that the function room should have been bigger!

The renal lupus and vasculitis clinic at the Royal Free

The renal lupus and vasculitis clinic at the Royal Free looks after over 300 patients with autoimmune kidney disease, i.e. disease caused by over-reactivity of the body's own immune system. Most of the patients in the clinic have either lupus *(also known as SLE)* or vasculitis, although a number of patients have other immune-mediated kidney diseases, and patients come from a wide geographical area for the specialist input available here, many of them from outside London.

Lupus or SLE is a multi-system disease which most commonly presents in young women although men can also be affected. It frequently affects the skin, joints and kidneys but can affect almost any organ system in the body.

In contrast, ANCA-associated vasculitis is most often a disease of older people. It commonly affects the kidneys but in some cases can also affect the skin, lungs, eyes and ear, nose and throat (ENT), as well as causing generalised joint pains and fatigue.

Both of these conditions are chronic, so they cannot be cured, and tend to have a relapsing and remitting course, so they can come and go over time. They usually require long-term treatment with medications to suppress the immune system. Without effective treatment, many patients would lose their kidney function and require dialysis or transplantation. However, with appropriate treatment, disease can be well-controlled in the vast majority of patients who can enjoy a very good quality of life.

Photography by David Bishop (Medical Illustration)

From l-r, Christine Hanson, Caroline Ashley, Aine Burns, Sally Hamour, Alan Salama

There are three consultants at the Royal Free who specialise in the care of kidney patients with lupus and vasculitis, Dr Burns, Dr Hamour and Professor Salama. The main clinic runs on a Monday afternoon and there is a smaller acute clinic on a Friday morning for patients who require more intensive treatment and follow-up. The specialist nurse in the clinic, Sister Ruth Yang, plays a role in research and supervises patient schedules on intravenous drug treatment. The team is additionally supported by renal psychology and dietetics and specialist pharmacy input as required. They also have close links with the ophthalmologists at Moorfields, the ENT and respiratory teams at UCLH, ENT team at Charing Cross hospital as well as the rheumatologists and dermatologists here at the Royal Free, to ensure that patients who have multi-system disease are able to have multi-disciplinary input as it is required.

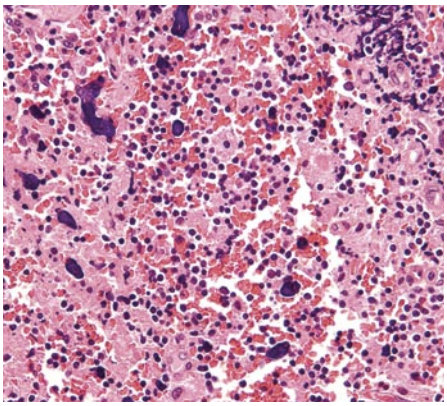
All the consultants in the clinic are all actively involved in clinical research in lupus and vasculitis and Professor Salama also supervises a laboratory group carrying out basic science research in immunemediated kidney disease.

Research has really helped to improve treatment

A variety of treatments are available for patients with these conditions. The mainstay of treatment is the use of a combination of drugs to suppress the immune system, usually including steroids. Although many of these drugs are extremely effective, they do of course all have side-effects. One of the important considerations, particularly at the beginning of treatment when higher doses of drugs to suppress the immune system are usually used, is an increased risk of infection. The competing risks of active vasculitis or lupus in the kidney and infection have to be very carefully balanced. One of the ways in which research has really helped to improve treatment for patients over the last 20 years or so, is by demonstrating through clinical trials that lower doses of some of the drugs already used, such as cyclophosphamide, can be just as effective for treating disease, but with lower risk.

Potential to dramatically change the way we treat this condition

There are other considerations of long-term treatment too, such as the effect of long-term steroids on bone density for example. In selected patients, the RFH clinical team have successfully used a new protocol for treating vasculitis with a much shorter duration of steroids than in standard protocols with excellent results and avoiding the undesirable effects of weight gain, increased infection risk and thinning of the bones. This is now being developed as a national trial and if the results are replicated, will potentially represent a dramatic change in the way we treat this condition with huge benefit for patients. In Lupus, the team are also involved in recruiting patients into a new trial called RITUXILUP. This is examining reduced steroid dose in treating patients with kidney disease from Lupus by substituting an alternative drug call rituximab.



Systemic lupus erythematosus. Light micrograph of a section through a glomerulus (blood filtration structure) from kidney tissue in a case of SLE.

Patients in clinic contribute

Other projects with which the consultants are involved include the national registry of vasculitis patients (UKIVAS registry) to which many of the patients in clinic have contributed, use of the vagal nerve stimulator for patients with headache and facial pain, exploring the factors which influence how closely patients adhere to their medication regimes and a number of national trials. In Professor Salama's laboratory team, a number of projects are underway including the identification of a molecule called calprotectin as a potentially new marker of disease relapse in vasculitis.

In the Royal Free lupus and vasculitis clinic, the combination of consultant-led clinical care, involvement of the team in local and national clinical and laboratory research, and multi-disciplinary team working mean that we continue to strive for the very best outcomes for our patients.

For further information
www.lupusuk.org.uk
You can call us on (00 44) (0)1708 731251 and we will be pleased to respond between Monday to Friday, 9am to 5pm.
You can email LUPUS UK as follows: headoffice@lupusuk.org.uk

www.vasculitis.org.uk
You can contact the Vasculitis UK Helpline for information and advice about vasculitis.
Helpline Telephone: 0300 365 0075 or email john.mills@vasculitis.org.uk

Nurse prepares to donate kidney to save family friend

Craig Binch, an orthopaedic senior matron at the Royal Free Hospital in Pond Street, Hampstead, was due to have his right kidney removed in late September at Guy's Hospital in London.

The kidney will then be air-lifted to Nottingham, where it will be transplanted into his mother's friend.

The 36-year-old said: *"The friend was diagnosed with polycystic kidneys six or seven years ago. Since then, her kidneys have gradually become worse and it has now got to the point that, without a donated kidney, she would need dialysis."*

He decided he wanted to help out, and was tested to see if he was a match.

Mr Binch said: *"They gave me the full MOT. I had an ultrasound to check the size of the kidney and a CT scan to check the anatomy. The ultrasound was fine, however the CT scan found that I had abnormal anatomy – I have an additional vein on my right kidney and an additional artery on the left kidney."*

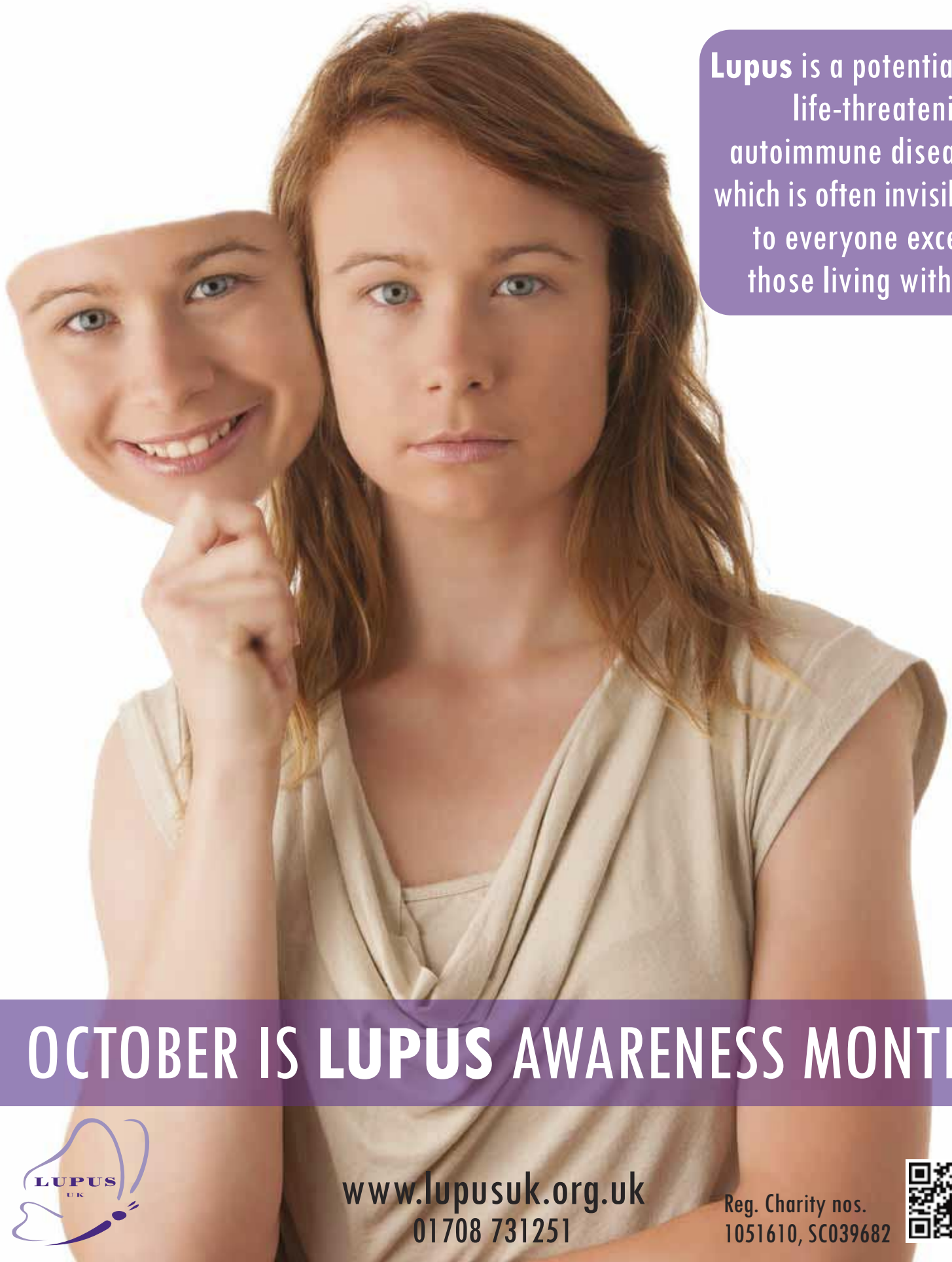
The surgeons said that, although there was more of a risk because of the additional vein, they were happy to carry out the operation.

Mr Binch added: *"When I have told people they have found it peculiar. But it is a good feeling to help someone and I know that my life will soon be back to normal. I am young and I couldn't think of a reason why I shouldn't. The medical staff will look after me; they will make sure I am fine."*

The Royal Free Hospital is one of the UK's largest centres for kidney and liver transplants, and carries out about 150 kidney and 90 liver transplants each year. Despite this, there are not enough organs to go around, and every day three people in the UK die waiting for a donor organ.

http://www.harrowtimes.co.uk/news/13641081.Nurse_prepares_to_donate_kidney_to_save_family_friend/

"NOBODY TAKES YOU SERIOUSLY WHEN YOU LOOK WELL"



Lupus is a potentially life-threatening autoimmune disease which is often invisible to everyone except those living with it!

OCTOBER IS **LUPUS** AWARENESS MONTH

LUPUS UK

www.lupusuk.org.uk
01708 731251

Reg. Charity nos.
1051610, SC039682

Suzi Epstein tells why she raised funds for Royal Free kidney patients

Suzi Epstein with Paul Bragman, Paul Whitehead and Joey

My story starts just over five years ago when my dad, Michael Epstein, had a road accident. Some of you will probably already know about that as he has raised money for various KPA charity events he and my mum have helped organise and his story has been told previously in the KPA Newsletter.

Rock climbing in Devon

My dad is a remarkable man, who defied all the odds after he was told he wouldn't walk, dance or even rock climb. However he has proved the experts wrong and has walked, hiked, ballroom danced every week and last year rock climbed in Devon. He is surrounded by people who love him including my mum, three children, three granddaughters and so many friends you just wouldn't believe.

Supporting the charity that helps keep dad alive

I could only think of one charity to raise money for when I signed up to take part in the London to Brighton Bike Ride this year and that was to support the charity that helps keep my dad alive, the **RFHKPA.** It was a very early start on Sunday 21st June but at 4.45 am, I set off to Clapham Common for my 6 am start time with three other friends.

I had so many donations and I just had to do it

The ride was going along quite nicely and I was really thinking that it wasn't so bad after all, until we were only halfway through and everything felt sore and aching. What kept me going was the knowledge that I had so many donations and I just had to do it. The last hill is called Ditchling Beacon and you could hear a pin drop as we cycled to the top. It is so challenging that no one is able to say a word. A well deserved ice cream at the top of the hill made it all worthwhile!

Seeing my family was so emotional

The atmosphere and the crowds were amazing. There was a brass band playing at one point and lots of rest stops where anything you ate tasted phenomenal. The four of us finally crossed the finishing line after eight hours on the road and the relief and excitement at seeing my family and raising much needed funds was so emotional.

https://www.justgiving.com/Suzanne-Epstein1/
Our thanks to Suzi for this great effort on behalf of our Royal Free kidney patients.
Her justgiving page has raised a total of £442 (£513 incl. gift aid).

A great way to raise funds for RFHKPA

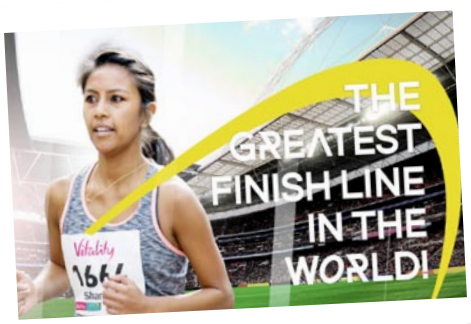
Taking place on **Sunday 20th March 2016,** this truly unforgettable 13.1 mile running event will finish INSIDE the iconic Wembley Stadium, creating what has to be The Greatest Finish Line in the World! Incorporating Saracens' Allianz Park at the half-way point, this is the ultimate Stadium to Stadium race. Experience what North London has to offer; follow in the footsteps of legends and join thousands of runners for a truly epic and memorable half marathon.

You'll receive a ***FREE*** Brooks Running finishers technical t-shirt, an epic medal, premium goody bag, secure bag drop and free post-race massage.
PLUS a 2 for 1 entry offer on Wembley Tours for all participants.

The Vitality Run Series brings together nine of the UK's most exciting running events to provide all runners, irrespective of ability, with the opportunity to take on their next challenge. The Series aims to inspire anyone to reach their own personal goal and is focused on supporting participants on every step of their journey. The Vitality team of running experts will provide training and nutrition plans and by joining the Vitality Running Community you can share your experiences and enjoy special offers and preferred access to events during the course of the Series. We aim to ensure that your race-day experience at a Vitality Run Series Event will live long in the memory.

So kick off spring with a bang at the Vitality North London Half Marathon, places are set to fly, so ***SIGN UP NOW!***

Contact rfhkpa@gmail.com



Call for everyone in the UK to discuss organ donation as

The number of deceased organ donors in the UK drops

for the first time in more than a decade

2014/15 saw more than 4,400 people in the UK have their lives saved or improved by an organ transplant but the number of people that donated organs has fallen for the first time in 11 years.

New statistics released recently in the Organ Donation and Transplantation Activity Report 2014/15 shows the number of transplants has decreased from 4,655 in 2013/14 to 4,431 in 2014/15. This is a 5% decrease on last year and means that 224 fewer people received an organ transplant.

Of the transplants carried out, 1,092 were made possible by living donors who gave a kidney or part of their liver, while 3,339 patients benefitted from organs donated after death. The reason for the fall in donor and transplant numbers is twofold:

* Fewer people died in circumstances where they could donate last year (potential donors 8,157 in 2013/14 compared to 7,450 in 2014/15 representing a decrease of 8.7%)
* There has been no improvement in the consent/authorisation rate which remains stubbornly below 60%.

NHS Blood and Transplant, the organisation that published the report and leads organ donation across the UK, is calling for everyone in the UK to discuss organ donation and decide what they would do if called on to donate.

If there are fewer potential donors then gaining consent/authorisation from everyone is even more important. The consent/authorisation rate has remained stubbornly below 60%. Unless there is a revolution in attitudes to organ donation people waiting for a transplant will continue to die needlessly.

Figures published in the Organ Donation and Transplantation Activity Report 2014/15 reveal that families are much more likely to agree to donation going ahead if they know it is what their loved one wanted. Last year, nearly nine out of ten families said yes when their loved one's decision to donate was known, for example either via the NHS Organ Donor Register or via a previous discussion with them about organ donation. But even when their decision to donate was known, 120 families felt unable to honour their loved one's decision to donate, denying them their dying wish to save others after their death.

NHS Blood and Transplant's Director of Organ Donation and Transplantation, Sally Johnson, said: *"We understand that families are expected to consider donation in their darkest hour. So we would remind everyone to tell those closest to you now if you want to donate your organs - and then record that decision on the NHS Organ Donor Register. Should the time come, your family will know you want to donate your organs to help to save others.*
The decreases we can see across all types of organ transplant will lead to more deaths if we do not reverse this trend going forward. We know there is a combination of reasons for the decreases, but we cannot hope to save more lives unless UK citizens talk about organ donation with their families and agree to donate if ever they are asked."

In 2013, the UK Governments and NHS Blood and Transplant launched a seven year organ donation and transplantation strategy Taking Organ Transplantation to 2020. The strategy's aim is to match world-class performance in organ donation and transplantation so that more lives can be saved in the UK.

To join the NHS Organ Donor Register visit www.organdonation.nhs.uk or call 0300 123 2323.

Better understanding your experiences on home haemodialysis: thank you

Some of you may remember being visited and interviewed by Atish Rajkomar about your experiences of managing your care on home haemodialysis (HHD), and of using the dialysis machine.

In total, 19 patients and families across four NHS Trusts took part in the study, and there were lots of common themes in what you told us:

- about the challenges of learning to do dialysis in the first place (and how scary it was in the first few weeks at home), but how it became routine *("like driving a car")* over time;
- about the challenges of troubleshooting, particularly when the problem was an unfamiliar one;
- about the ways your home care team support you – and might be able to support you better if you had more seamless data exchange with your team;
- about the common difficulties, such as clearing bubbles from the system and remembering to open and close all clamps at the right time; and
- about the various strategies you have discovered for keeping yourselves safe.

The project has now finished, and we've been reporting the findings as widely as possible:

- Atish was awarded his PhD, so particular thanks to you for your part in making that possible.

- We've published a paper in a nephrology journal **(http://www.biomedcentral.com/1471-2369/15/195/)** on patients' and carers' experiences of interacting with home haemodialysis technology, and identified implications for quality and safety. A couple of short articles based on that paper have been published on the Shared Care website on home dialysis **(https://shareddialysis-care.org.uk/home-therapies).**

- A second paper has been published in a biomedical informatics journal **(http://www.sciencedirect.com/science/article/pii/S1532046415001124)**

This focuses on a theoretical approach called Distributed Cognition that was at the heart of Atish's PhD studies. This helped to better understand the social structures that support people's interactions with the dialysis machine.

- A further paper reflecting on how people cope with the demands of HHD has been accepted by the Journal of Renal Nursing.

- We've given talks on the work at various events attended by clinicians, patients and manufacturers.

We hope that this project can 'make visible' your experiences and practices in managing care at home, and that this will help manufacturers to design next-generation systems, and nephrology services in planning effective home care support.

Thank you to everyone *(patients, carers and professionals)* who took part in this study.

Ann Blandford, UCL
a.blandford@ucl.ac.uk

Boris backs campaign to reduce waiting times for life-saving transplants

The Mayor of London is backing a campaign encouraging people from all ethnic backgrounds to sign up to the organ donor register – as new figures reveal black and Asian patients wait up to 12 months longer on average for a kidney transplant.

More people need to sign the organ donor register

Boris Johnson says: *"With almost 7,000 people waiting for a life-saving organ transplant it is important that more people sign the organ donor register. I would particularly urge people from black, Asian and other minority ethnic communities to come forward. Some of these patients needing a kidney transplant can wait up to a year longer for an organ match, so it is vital that more people come forward to help save lives."*

Overall donation consent rate for London families drops in BME groups

New figures published in July '15 by NHS Blood and Transplant show that the overall consent rate for London families agreeing to donate a deceased loved one's organs is 58.4%, but drops to 36.6% for black and minority ethnic (BME) groups. People from BME communities are more likely to need an organ transplant as they are more susceptible to illnesses like diabetes, hypertension and certain forms of hepatitis, which can cause organ failure. Almost a third of patients on the UK transplant list are from BME communities. In London this proportion rises to two-thirds. Organ matches are more likely when the ethnicity of the donor and recipient are close. Last year just 74 of the UK's 1,320 deceased donors were from BME communities.

"A second chance at life"

Boris Johnson met transplant patient Cash Ryan and nurses James Van Der Walt and Paula Watson to show his support for organ donation. Cash, 44, from Camberwell, had a kidney transplant at Guy's Hospital in February 2011. Her kidneys failed due to lupus, an autoimmune disease, and she had been on dialysis for almost five years. She says: *"I was so lucky to receive an organ from a deceased donor. It means the world because it's a second chance at life. I can do so much more with my daughter - she was just a baby when I started dialysis and six when I had the transplant. I'd encourage people of all ethnic backgrounds to join the donor register. It's painful to know a loved one is suffering, so please consider becoming a donor to ease someone's pain."*

It's really important to tell your family that you've done it

James Van Der Walt, specialist nurse for organ donation at Guy's and St Thomas', says: *"Signing the organ donor register is just the first step - it's really important to tell your family that you've done it. If you've talked about it they don't have the burden of having to guess what you would have wanted at an incredibly difficult time, and they are more likely to support your wish to donate. Many families who give consent later find it a comfort to know that something positive came out of tragedy."*

Only around 5,000 people each year in the UK die in circumstances that mean it's possible to donate their organs, so every potential donor is precious. Those waiting for a transplant depend on the families of these potential donors agreeing to donation going ahead. Families are more likely to agree to donate if they know it is what their loved one wanted.

The Royal Free has some of the best five-year kidney survival statistics

Gareth Jones

Gareth Jones, Service line lead – renal transplantation and nephrology, Royal Free London says *"Last year, we did our greatest number of transplants at 140 kidney transplants (4.5% of all UK transplants) with 28% from live donors. Once again, the Royal Free has some of the best five year kidney survival statistics with 90% of first cadaveric kidneys and 98% of first live donor kidneys still working after five years."*

The main point is that comparison of all the kidney transplant units across the UK is now in the public domain and can be found at

http://www.odt.nhs.uk/pdf/organ_specific_report_kidney_2015.pdf

DIARY DATES

KPA COMMITTEE MEETINGS
Oct 5th, Dec 7th
Mondays at 7.15 pm
The Atrium, Ground floor, Royal Free Hospital

CAN I HAVE A KIDNEY TRANSPLANT?
Education session for kidney patients & families
Tuesday 17th November 6.00 - 8.00 pm
Tottenham Hale Unit
Wednesday 13th January 6.00 - 8.00 pm
The Atrium, Ground floor, Royal Free Hospital

RFHKPA AGM "QUESTION TIME"
with leading renal doctors
Sunday Nov 22nd at 2.00 pm
The Atrium, Ground floor, Royal Free Hospital

Andy Forbes *(Chairman)* **01442 262767**
Caryl Bryant *(Secretary)* **020 8411 6268**
Jill Slann *(Membership Secretary)* **020 8886 1483**
Louis Toussaint
(NKF & Edgware Representative) **020 8205 5682**
Nii Plange **07725 347 925**
Jaycinth Ekineh
(Tottenham representative)
Bina Doshi **020 8440 0504**
David Myers *(President) email: rfhkpa@gmail.com*

Newsletter Editorial Team: David Myers (Executive Editor) Jill Slann, e-mail: rfhkpa@gmail.com

The RFHKPA 2015 AGM Special Event

Royal Free Renal Unit Question Time

A panel of leading Royal Free kidney consultants answer your concerns

Mr Ben Lindsey
Service Line Lead - Renal & Endocrine Surgery

Janice Ward
Senior Matron, Dialysis

Dr. Gareth Jones
Consultant Nephrologist Service Line Lead – Renal Transplantation & Nephrology

Dr. Ferina Ismael
Consultant Dematologist

What do you want to ask?

- **Can I have a kidney transplant?**
- **What should my named nurse be doing for me?**
- **Why might it be dangerous for me to sit in the sun?**
- **Why do I need to limit my fluid intake?**
- **Why can't I eat bananas?**

Sunday 22nd November 2015
2.00 - 4.30 pm

The Atrium Hall, Ground floor, Royal Free

Tea, coffee and refreshments will be served. Doors open from 1.30pm