

RENALITY

The NEWSLETTER of...

November 2014

South West Thames Renal & Transplantation Unit, **Epsom & St Helier University Hospitals NHS Trust**
South West Thames Kidney Fund supporting the South West Thames Institute for Renal Research
St Helier & Surrey Kidney Patients' Association



MAT LANDS A TT RECORD ON AN ELECTRIC BIKE

FUND-RAISING kidney patient Mat Dibb has broken the lap record for the Isle of Man TT course – on an electric bicycle.

And what's more, Mat's amazing feat has earned him a place in the Guinness Book of Records.

Now his latest epic feat has raised £2,445 for the South West Thames Kidney Fund. Full story—Page 11

DRAGON RACERS RAISE £8,426 IN FUN DAY EVENT

ANNE COLLARD writes: The 2014 Dragon Boat Challenge on Sunday 20th July was another big success for the South West Thames Kidney Fund with perfect weather on tap.

A full team and wonderful volunteers manning our excellent charity stall which was organised and led by Kathryn Harrison (and a special thanks to you Kathryn).

The team have raised £8,000 and a further £426 was raised on the charity stall, so a very successful day all in all.

Many thanks to our team including Dr David Makanjuola and Dr Mark Dockrell - and to those who volunteered on the stall.

As usual your participation is very much appreciated. A picture of the 2014 team (and our charity stall) is posted on

Page 10. To see more pictures of an excellent day visit <https://www.flickr.com/photos/vipdesilva/sets/72157645386916619/>.

Many thanks to Dr Vip de Silva for taking the photos on the day!

Why not take part yourself next year? Anyone who is interested should contact Anne/Kathryn to register. And don't forget to start collecting items for the stall, unwanted gifts, wine, children's prizes etc. Next year's event is on Sunday 19th July!!



ST HELIER & SURREY KPA GRAND DRAW TICKETS ARE INSIDE THIS EDITION. YOUR HELP IN THIS VITAL FUND RAISER WOULD BE MUCH APPRECIATED. More details: Page 5

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Useful Contacts:

RENAL UNIT reception:

020 8296 2283,

020 8296 3100

SWTIRR & SWTKF,

Anne Collard, Administrator:

020 8296 3698

SOUTH WEST THAMES

KIDNEY FUND,

HayleyAnne Fitzgerald,

Secretary: 07974 422424

ST HELIER & SURREY KPA

Dave Spensley, Chairman

01483 426276

There are many many ways in which you can help the **South West Thames Kidney Fund** and help ensure the future of Kidney Research. Further information on all of them can be accessed via the 'support us' page on our new website – or, if you do not have computer access and would like to know more, please do call Anne on 020 8296 3698.

Make a **one-off donation** online, by text to SWKF22£_ to 70070, or by cheque to SWTKF, Renal Unit, St Helier Hospital, Wrythe Lane, Carshalton SM5 1AA

Create a **standing order**

Donate via **payroll giving**

Join our weekly **lottery** and play to win!

Shop 'til you drop and **Give as You Live!**

Recycle your old car at no cost via **GiveaCar** Call them on 020 0011 1664

Sell an item on **ebay**

Volunteer **your time** (we can give you all sort of ideas!)

Buy our **Christmas Cards**

Donate **shares**

Donate your **tax refund**

Please join our Kidney Research supporter email group! We will keep you up to date with our news, fundraisers and any volunteer opportunities that may appeal to you. Email anne.collard@kidneyfund.org.uk to ask her to add you to the group. You will not be bombarded with emails and can ask to be removed from the group at any time.

'Like' us at www.facebook.com/kidneyfund and...

follow us at www.twitter.com/renalresearch

RENALITY

is now available on CD, PDF form & large print

Our thanks go to Joanna Bending who reads and edits the Newsletter and to her colleagues. Thanks must also go to Richard Sammons who produces the CDs and distributes them.

We thank Graham Morrow who produces the electronic version.

If you know of any patient who would like to use these services, please contact: Steve Purcell on

07970 675087 or

email: steve_purcell@btinternet.com

REMEMBER...

our website addresses are:

South West Thames Kidney Fund:

www.kidneyfund.org.uk

South West Thames Institute for Renal Research:

www.swtirr.org.uk

St Helier & Surrey Kidney

Patient Association

www.shskpa.org

RENALITY is sent to all patients of the Renal and Satellite Units automatically unless they have asked not to receive it. If you do not wish to receive this newsletter, please contact Paul Fischer at the Renal Unit on 020 8296 2514.

The opinions and views expressed in this Newsletter are those of the individual or organisation expressing them. There can be no assumption that such views and opinions are supported by any other subscribing organisation or individual.

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Newsletter Editor: Steve Purcell: 07970 675087 steve_purcell@btinternet.com

Camberley Car Show - 2014

KEN BONNER writes:

The 2014 Camberley Car Show took place in and around the main streets of Camberley Town Centre on Saturday 30th August.

This was our third Camberley Show and, as in the previous two years, all donations collected were for the South West Thames Kidney Fund. This year we collected £2,817.46 in cash donations on the day with a further £80.00 collected through 'Just Giving'.

Over 170 vehicles travelled from far and wide to take part in the static display and we are very grateful to the owners for giving up their time and lending their support for the Kidney Fund.

A fantastic selection of vehicles from all eras and from many manufacturers was on display on the town's main streets which were closed to all other traffic for the day.

Racing legend Jody Sheckter provided, free of charge, his magnificent 'Wolf' F1 racing car from his collection - so it was not so much 'The Wolf of Wall Street' but more the 'Wolf of Camberley High Street!'

With the great variety of vehicles ranging from a 1911 Cadillac to a selection of Hot-Rods, Dragsters, Motorcycles, Live Music, Street Entertainers, free Face-painting, Characters in Costume, etc., the event was estimated to have enjoyed in excess of 47,000 visitors in the town centre on the day and even Batman brought the Batmobile along!



We had great support from many friends and family on the day. Our thanks go out to Martin and Cynthia Banton who own a classic car and attended last year's show. They offered to help out and support this year as Martin is a kidney transplant recipient and together they manned a SWTKF gazebo in the High Street throughout the day.

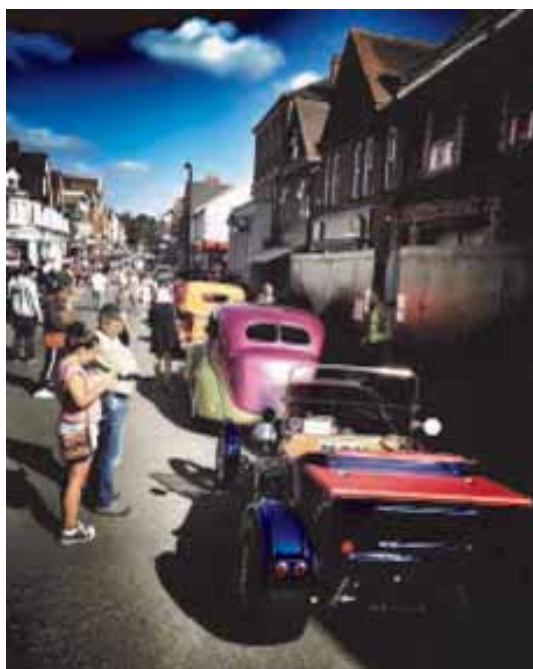
Having seen details of the Event in a previous edition of Renality, where we asked for volunteers to help out on the day, Chris and Clare Barrett from Hawley, Hampshire, responded and really helped out in a variety of chores. Chris again is a kidney transplant patient having received a kidney donated by his father.

Jackie Magnus a Camberley resident and kidney recipient also helped out, as last

year, by enthusiastically collecting donations in and around the town centre. Angie Morrow and sons (Graham was under the weather) helped out for a time by collecting funds. My wife Glenise and, her sister Jenny who donated a kidney to her in 2010, were also fully involved throughout the day as were many other friends and family to whom we are most grateful.

Video and images from the day can be viewed at www.camberleycarshow.co.uk (News page) and the 'Just Giving' link is still active on our web-site so if anyone would like to support and make a donation to the Fund it can be accessed through the Home/Welcome page.

The date for the 2015 Camberley Car Show has been set as Saturday 22nd August.



KPA Donations

St Helier and Surrey KPA would like to thank the following people for their much appreciated donations to either the KPA's general funds or the "No Place Like Home" appeal:

Mr & Mrs P Steele

Emmanuel Kaye Foundation

M & J Saxby

Stella & Peter Smith

KPA Memorial Donations

St Helier and Surrey KPA would like to thank all of those individuals who have donated in memory of

Graham Paul Balfour

Ramniklal K Sodha

Dale Gray

HOW TO RAISE £1.4MILLION

Camberley Car Show organiser Ken Bonner writes:

With every edition of Renality received I am always really impressed at the many and varied reported methods that people employ to help raise much needed funds for kidney and diabetes research.

For example, the latest August 2014 edition of 'Renality' has details of money raised through 'Wing Walking', 'Memorial Donations' for loved ones, 'Elsa the Kidney Dog' hoping to raise £1,000, Children making and selling 'Loom Band Bracelets', 'Football Fund Raising', 'London Marathon Runners' and there was also a list of other fund raising activities and monies received from various donors.

It is great to see that some renal patients, their families and friends go out of their way to raise funds in an attempt to try to give something back to the renal unit that supports them.

In the same August 2014 edition, I was astounded to read in an article 'A Word in Edgeways' by Dr Peter Andrews, that the St Helier Renal Unit serves 1.4 million patients - quite unbelievable!

It made me think that if each of these **1.4 million** patients gave just a £1 annual donation to the SWT Kidney Fund it would raise **£1.4 million** - what a difference it would make!

So come on, if you haven't got the time or the inclination to raise funds, please make a donation on-line now, it's so easy. I have a 'Just Giving' account set up for the Camberley Car Show at: <https://www.justgiving.com/ken-bonner/> with all donations going directly to the Kidney Fund - it only takes a few clicks!

A message from your Chairman

I am nearing the end of my eighth year as Chairman and I am more than happy to continue for another year. I hope that the patients and staff are pleased with the work that the Committee has done on your behalf and on a personal note I would like to thank all of the Committee members, all of our Volunteers including those on the Servery together with the Renal Unit staff all of whom provide invaluable support throughout the year.

We have over 750 members so we're kept pretty busy dealing with the many and varied requests which we receive so I thought a review would be in order to show how we have distributed our funds during the past year. These include

- 2 Profiling beds for Farnham
- 2 Dialysis chairs for St Helier
- 8 TVs for St Helier together with aerial and power installations.
- Body Composition machine for St Helier
- Bariatric Dialysis bed and dialysis chair for St Helier
- 4 Patient examination couches for St Helier
- 3 Portable DVD players for St Helier
- 60 Renal Overlays for St Helier and its Satellites
- Replacement televisions for Kingston Satellite Unit
- Patient bedside chairs and tables for St Helier
- Enhancement of Richard Bright ward
- Wheelchairs for Mayday.
- Renal bedside folders and shared care pamphlets
- Home therapy DVDs
- 2 Patient information tablets for St Helier
- Financial assistance with Holiday Allowances, Travel Benefits and Amenity payments



Financial support of the participants in the St Helier Team at the Transplant Games

Supporting of a number of buffet lunches and PEP's

This has all been possible due to the generous donations and a legacy that we have received and fund raising events reported upon in previous editions.

With this edition you will find our Grand Draw tickets and whilst I know that times are tough for some of you could I please urge you to purchase them as this is one of our main fundraisers and makes a huge difference to our funds and our ability to continue to help the Unit, its Satellites and its Patients.

If you feel that you are unable to purchase them can I please ask you to return it to the address printed on the tickets as we had requests for additional books last year?

The draw will be made at the renal unit at St Helier on Saturday 13th December around 12 noon, As there isn't a patient lunch this year we'll be asking the renal staff and patients to draw the winning tickets.

Committee/Patient Representatives

The KPA Committee has a couple of new members but it would be lovely to have every Satellite represented. We need reps for Kingston and Sutton.

Ideally we would love to have some younger Committee Members to enable us to represent the entire age range of St Helier's patients.

The position isn't onerous; we meet once a month in the Blue Room within the Renal Unit at St Helier at 7.30 on the first Wednesday of the month.

If you can help please contact me on 01483 426276 or email daspensley@btinternet.com.

I think that is all I have to report on so may I be one of the first to wish you all a very Happy Christmas and a happy and healthy New Year.

Best Wishes ...

Dave Spensley, Hon Chairman

View from the sidelines...

By David Andrews

Life as a 'medical orphan' is, by most accounts, not a bad one. I am privileged to belong to a family where my father has a secure and well-paid job, even if it means not seeing much of him during the week (some doctors do actually work fairly long hours, it would seem).

Perhaps this is of benefit to family cohesion, however, as we have rather similar personalities and family discussions can escalate rapidly at dinner (the phrase 'an unstoppable force meets an immovable object' springs to mind).

As you will have read in my father's article, the increasing abuse our family has hurled at him seems to have finally resulted in positive action.

I am doing my bit by commandeering all the chocolate in the house – strictly, of course, in his best interests!

Having toyed with medicine as a career, I have instead decided to indulge my passion for argument by studying Politics & Economics. I have not long returned from a trip Interrailing around Europe. In 18 days we visited 8 cities in 6 countries, and since my return to the UK two things have struck me.

First, how little public smoking there is in the UK compared to the mainland, contributing to a more pleasant and much healthier environment.

Let's try to continue this positive trend for the benefit of all.

Secondly, on a less positive note, it was noticeable how much thinner Europeans seem to be compared to the UK. I looked this up, and only Iceland and Malta have higher rates of obesity in Western Europe.

As mentioned in dad's article, there are a huge number of personal reasons to avoid becoming overweight. What's interesting to me as a Politics and Economics student is the



huge cost to society. Health problems associated with being overweight or obese cost the NHS more than £5 billion every year.

That's 4.6% of its budget for 2014. Consider for a moment all the other things we could spend that money on.

The NHS is an amazing institution, as are many of the people who work for it.

But I doubt that back in 1948, when the world's first public healthcare system was launched, anyone imagined it would be spending so much money on problems generated by people having *too much* to eat.

So I applaud my father's fitness drive (about time but better late than never), and I commend it to you all. Because not only will you save money, you'll also look a lot better, feel a lot better, and be doing your bit to ensure that our NHS spends precious resources on the things it really needs to.

David Andrews, controversial student
(6'2'', 78 kg, BMI 22 kg/m²)

Elsa the Kidney Dog

Dear Renality Readers,

As you will have heard from the pack leader, my attempts to storm the internet were unsuccessful. So I will not be pursuing my plan to send updates via Twitter on **Elsakidneydog**.

Thank you to those who did check in.

I am not sulking, however, because I can now devote even more of my attentions to my main (and hardest) task: reducing my master's waistline!

I will do my best to keep him exercising in the cold winter months ahead, glad of course that I have a thick fur coat, even if he doesn't. And I shall report on progress – whether he wants it or not....

Meanwhile, I attach a recent photo. I'm told the insides of a toy duck look a little like snow. Whatever that is!



Weighty Matters

Peter Andrews, Clinical Director

I start by mentioning two other articles in this edition of Renality.

First, you will find a few words from [elsathekidneydog](#).

You will remember that, in the last edition of Renality, it was suggested that readers consider following her on Twitter, in a light hearted attempt to keep in touch and to raise money for kidney research.

Sadly, this initiative did not appear to hit the mark. I guess the idea of 'following' a dog was a little off beat, and I share many people's dislike of electronic media. So thank you to those who showed an interest, but this initiative will fold.

Second, you will also find a few words of wisdom from my eldest son, David, on the page opposite. David is starting an amazing gap year before heading to university, and for the first time in many years finds himself relatively free in the evenings. I therefore suggested he might like to pen a few words about the life of a 'medical orphan'.

Much to my surprise, he has responded! I hope you find them of interest.

I now turn to another important Andrews family initiative, and the title of this article. Like many men of a certain age, I have grown increasingly concerned that my youthful profile has become more and more of a distant memory.

[Isn't it strange how one's self-image often fossilises at a point when one is young, slim, and hirsute?]

A line in the sand was reached when I recently hit the magic 100 kg, which for me marks the spot where middle aged spread has begun to have more significant health implications. This has been confirmed – at length – by my family, and by review of the poolside photos from a recent holiday.

So, the bottom line is that I am now – for the first time ever – committed to a serious attempt at weight loss. And I am announcing this in print so that there is no turning back. My aim is to lose 15 kg (approximately 2½ stone) to return to my previous fighting weight, and to the middle of the recommended range.

Why lose weight?

The health benefits are incontrovertible.

- Increased energy levels
- Lower cholesterol levels
- Reduced blood pressure
- Reduced aches and pains
- Improved mobility
- Improved breathing
- Better sleep
- Less heart disease
- Lower risk of sudden death and stroke
- Lower risk of type 2 diabetes



- Lower risk of bowel and some other types of cancer
- Live longer

[Less abuse from the children, nicer family photos]

It rather begs the question: why not do it earlier?

This effort started two weeks ago, and have made a good start by losing ~½ stone (3 kg) to date.

However, I know that the first few pounds are the easiest, so please hold me to account should I waver.

Weight loss is difficult, but it is fundamentally an issue of strength of mind.

No-one ever forces you to eat that chocolate, or have that second helping. If you want to lose weight badly enough, you can do it. And if I can do it, you can certainly do it.

So here is my challenge to you all. As many as 60% of the population are significantly overweight.

Look at the list of reasons to lose weight in this article, look in the mirror, and ask yourselves whether you should join me in my journey.

I may be rubbish at setting up a Twitter account, but if I can persuade even a handful of you to take strong measures to help yourself, this will be my best Renality article yet.

And as a small incentive, I offer a bottle of champagne to the best effort at weight loss up to the Christmas break, together (if desired) with a chance for five minutes of fame in Renality.

Be strong. Eat less. Eat better. Exercise more. Be healthier. Feel better about yourselves. It's all in the mind.

And if you need any further motivation, consider this: the average life expectancy in the UK is now 79 years for men and 83 years for women. But how many overweight people do you know in their eighties?

Peter Andrews, Clinical Director

(6'4", 101 kg, BMI 27 kg/m² – and falling!)

A warm welcome to our new Clinical Research Fellow, Dr Pritpal Virdee

By **MARK DOCKRELL,**
Institute Director

Only an academic would think of October as the start of a new year. Nevertheless for those of us whose lives are, at least in part, governed by school or college terms the end of summer hails a new beginning.

This year is particularly significant as it is the start of a new 3 year cycle; a new South West Thames Kidney Fund Clinical Research fellow.

The very first fellow is a consultant here at St Helier, a national expert in chronic kidney disease and one of those influential doctors who write the guidelines for The National Institute for Health and Care Excellence (NICE); our very own Dr Hugh Gallagher!

Talk about a hard act to follow.

In Hugh's day the Institute was a very different place just starting on its path.

The newest fellow is Dr Pritpal Virdee, some of you may know him because Pritpal did some of his early clinical training with us. As Pritpal comes to the Institute many things have changed both nationally and locally.

The Department of Health is beginning to catch up with Dr Mike Bending and those early pioneers of the Kidney Fund; now the need and value of research is enshrined in the NHS "constitution" (Business Plan 2014/15), one of the 8 key activities of the NHS.

Our national profile has grown with St Helier holding two seats at the top table in the UK renal world with Dr Becky Suckling and myself on the national executive of the Renal Association and the Institute has established a national and a growing

FUNDING



RESEARCH



CURE

international reputation for its groundbreaking research with collaborations in Europe and the US.

This, of course, could never have been achieved without your support. The 2 grants we've been awarded this year, £60 000 from the Department of Health and £140,000 from Kidney Research UK, are the fruit of the investment from you in those early years. You and the Kidney Fund have shown incredible foresight investing in the future.

Of course with our growth come growing ability and ambition to improve the lot of the renal patients who come through the doors of our hospitals every day.

Pritpal joins us at a very exciting time. Some of you will remember the name of ISIS Pharmaceuticals (shame the name has been pinched by a rather more unsavoury organisation).

I have been building ties with ISIS Pharmaceuticals for three or four years now as we have developed our project to use a novel form of gene therapy to develop a new treatment for kidney disease. Just to briefly remind you; in the last 20 years we have learnt that the human body has



far fewer genes than we expected and that a single gene can make many proteins.

Our project centres on regulating the genes. We have been building up this project steadily; we just published one paper on the subject and will be publishing another next month.

Our project uses state of the art technology from ISIS to guide a particular gene away from making a disease causing protein to making a safer one.

Pritpal is going to join us on this project to set up pre-clinical trials to test this technology. All the evidence we have accrued suggests this is going to work, of course the nature of science is you don't know till you do the experiments but I'm very excited about this. I'm really looking forward to getting Pritpal on board, training him in the techniques and working with him to bring in the results.

As you know Pritpal is not the only researcher in the Institute and his project is not the only one we are working on.

As excited as I am about this project I'm not one to put all my eggs in one basket nor all your money in one project.

We're still working on a project to improve the survival of kidney transplants and our project to diagnose progressive diabetic kidney disease earlier both of which I hope to up-date you on in the next issue of Renality.

But for now it's back to the lab - it's your support that keeps us going.

FAMILY PUT WHEELS IN MOTION TO AID OTHERS

CHRIS and Becky Haw and their children aged seven and nine cycled the 41 miles from St George's Hospital to their home near Fleet to raise money for the South West Thames Kidney Fund.

Mrs Haw writes: "Chris was diagnosed in 2003 with end stage renal failure and started dialysis in February 2004.

"He was very fortunate to undergo a kidney transplant at St. George's Hospital, Tooting on Tuesday 21st September 2004. The operation was a complete success and the donor kidney continues to function faultlessly, significantly improving the quality of Chris's life.

"We wanted to do Something to raise money to help others like Chris.

"Despite the high mileage it was a very pleasant family day out and I am very proud of our children, aged 7 and 9, who cycled the whole way."



WEDDING COUPLE EXCHANGE VOWS AND GIVE UP PRESENTS FOR KIDNEY FUND

Rich and Helen Potts write:

"My husband Rich and I decided when we got engaged we didn't need any wedding presents so wanted instead to ask our guests to make a donation to our favourite and meaningful charities.

We chose Macmillan Cancer Research and South West Thames Kidney Fund (Research Unit).

My Mum Linda Wichall has been a patient of St Helier since 2004 suffering with acute kidney failure, undergoing years on dialysis. Three years ago she received a life changing kidney transplant on the 12th October.

Mum has done so well since she received her new kidney, and is a supporter of the research unit herself.

She also often talks about her consultant Dr Hugh Gallagher who works at St Helier, raising funds through charity work for the unit.

Although we can only offer a sum of £195, we really hope this helps in some small way. The hospital and all its staff have really been paramount in Mum's treatment over the years and we are so grateful for this.



Dragon boat team members and stall helpers



RUNNERS HIT THE ROAD

Many thanks to Clarice Wamba, Andrew Grant and Holly Lomax who ran the British 10k London Run and raised funds for the Kidney Fund this July.

Holly said: “The run was good - lovely course around lots of sights of London. I didn't realise how big it was, they said around 20,000 runners. I ran it in just over 50 mins - not very happy with the time but difficult to run with so many people.

“I was supported by my partner, Mum and son. My son loved travelling on the train to watch, saw me a few times so he could cheer me on and then I got a medal at the end!”

Well done all of you!

Next year's British 10k London Run will take place on Sunday 12th July. Why don't you reserve your place, and raise funds for the Kidney Fund next July by visiting <http://www.thebritish10klondon.co.uk/runner>. Once you have your place you can contact british10k@kidneyfund.org.uk and we will supply you with fundraising information and a T-shirt.

NO CALL FOR CALENDARS

There was very limited interest in submissions for the 2015 Calendar competition, and as a result we will be unable to produce a calendar for next year.

Thanks to all those that did submit – we had some lovely entries.

If acceptable to you all, we will hang on to this year's entries and in the event that we run a competition next year, we will include them then.

RECORD-BREAKER MAT IS TT-TERRIFIC

KIDNEY patient Mat Dibb has broken the lap record for the Isle of Man TT course – on an electric bicycle.

Mat completed the 38.2 mile circuit in one hour 28 minutes, including a stop of several minutes in deference to the previous holder of the electric bike record who stopped for a cup of tea with his mum half way round.

But Mat’s amazing feat has still earned him a place in the Guinness Book of Records.

He decided he wanted to attempt the course on an electric bike during his annual trip to the TT motorcycle races. And he discovered there was no official record for completing the course in this fashion, despite Conor Cummins, a TT rider, doing an unofficial e-bike lap of 2hours 41minutes a couple of years ago. Now Mat has raised £2,445 for the South West Thames Kidney Fund as a result of his latest fund-raising exploit.

He said: “After a bit of head-scratching and several weeks of trying, I managed to persuade the Guinness World Records to create a brand new category of



‘Fastest Isle of Man TT Mountain Course – Electric Bicycle’. Even with no official record, the earlier time trial by Conor Cummins did give me a benchmark.” Mat is waiting for a kidney transplant and in the lead up to the event he was hit by the bad news that the living donor transplant he was looking forward to would no longer be possible. He said: “My kidney function will deteriorate until I need dialysis in around six months. It looks quite bleak at this point. I don’t know how things will play out.”

Mat regularly clocks up over 140 miles a week cycling to work and at weekends. He switched to an electric bike as his health deteriorated. He added: “The support of friends and, of course, the e-bike shop has been nothing short of incredible.”


Mat completed his TT lap on a 350 watt Moustache Dimanche loaned to him by the e-bikeshop.

Donations are still coming in for Mat at uk.virginmoneygiving.com/MatDibb.

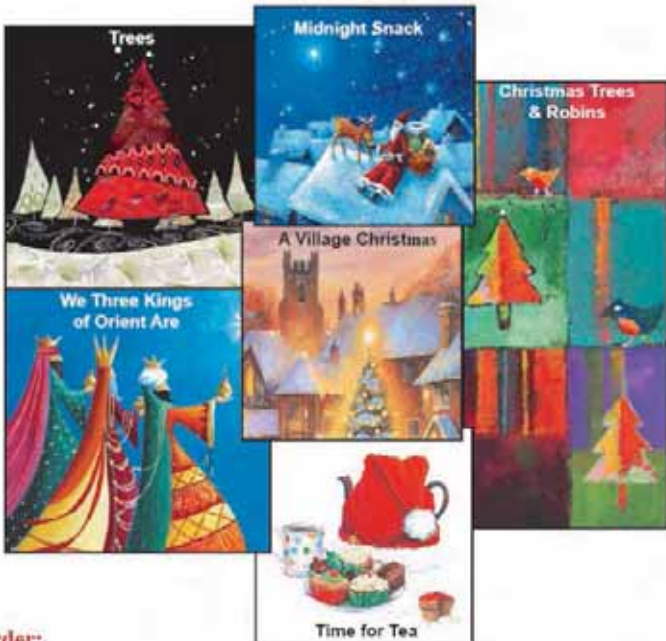
£3.00
per pack of 10 cards
of same design


CHRISTMAS CARDS

benefiting the
South West Thames Kidney Fund
and Research into Kidney Disease & Diabetes



NEW THIS YEAR!





To order:
email christmascards@kidneyfund.org.uk or phone 0208 296 3698. The cost of postage will be £1.20 and up (depending on the number of packs you order).

Cards will also be available to buy at the St Helier Renal Unit Reception Desk and at some of our satellite units.

YOU CAN RUN LONDON MARATHON 2015

The Kidney Fund has charity Gold Bond places available for the 2015 London Marathon! If you or anyone you know is interested in applying for a place and raising sponsorship for the SW Thames Kidney Fund please email londonmarathon@kidneyfund.org.uk to find out details ASAP.

OUR HEARTFELT THANKS GO TO...

The Reuben Foundation for their donation of £500

June Owen for making the Kidney Fund the beneficiary of her 80th birthday and raising £445 for us! A belated Happy Birthday from us all June!

Elizabeth Saben for donating her car to GiveACar – which raised £84 for us.

Kate Shipton, Guy Olden and their many helpers at the NGS Open Gardens Event on the 21st and 22nd July in the garden of **Steve and Pam Hibbert**. The event raised £930 for the Kidney Fund! Many thanks to Steve and Pam!

Helena Shiatis for her continuing support in memory of her husband Michael.

Mr & Mrs Alan Andrews who raised funds for us selling their plants at the Dragon Boat stall and the NGS Open Garden Event mentioned above.

Mr & Mrs Robert Bogin for making the Kidney Fund the beneficiary of their 40th Wedding Celebration. Many congratulations to you both!

The staff at Linden Homes Chiltern for the £46.45 raised during their Dress Down Day!

Brenda Harris for the proceeds from raffling off her home made quilt!

The members of Castle Green Bowling Club who raised money for us at their charity Bowling Afternoon.

The Webmart charitable Trust for the £1,000 they donated.

Allan & Sally Beer for the £100 raised from their plant sale this year.

Jenny Tyson-Jones who raised £200 for us at her event at Drayton House School, Guildford on the 14th June.

Maggie Vickery and the Wellington Arms Pub in Sandhurst for the proceeds totalling £112.50 from the pub quiz!

Ken Roffey for asking for donations to the Kidney Fund for his 70th birthday, as a thank you for the transplant his daughter Claire received in March 2009.

And, to all those who have been involved in ANY way – donating, supporting, helping, advising! We are so grateful for your participation in our work!

We have received donations in memory of:

‘Tom’ Alfred William Brown

Joan Hilda Bailey

Ernest George Stone

Gaylene Janice Maisey

Joyce Patricia Sturgeon

Anne Thorpe

Michael Palmer

RIDE LONDON-SURREY 100K

Right up to the actual date for the Ride London-Surrey 100 the weather was perfect and then it broke!

The decision was made early the morning of the big day to cut out the Surrey climbs of Box Hill and Leith Hill and their potentially dangerous descents under conditions of torrential rain and surface water.

Despite the wet conditions, some 20,709 gallant riders pedalled beneath the finish gantry on The Mall by 5pm, their faces dripping with a mix of sweat, mud and rain.

Included in those 20,709 were our five riders – Deborah Wills, Katie Downes, Jeremy Humphrey-Davies (Jez), Ben Bawden and Adam Blaker (Sophie, Adam's wife ran the marathon for us just a few months earlier).

Sadly Robin Amy had to drop out due to a training injury but he hopes to take up his place again in 2015 and stay injury free! And in their words, here's what the day was like for some of them:

Jez: It was very challenging, especially when stuck in a bike jam in Richmond Park for 30mins in the pouring

rain, but the 2nd half was fast and fun once the rain stopped. We will have to do it again next year to do the hills!

Ben: It was "challenging" shall we say. The middle third was particularly bad, with torrential rain and frequent localised flooding. But the final third, once the rain had stopped was really good fun.

I think it's safe to say I enjoyed it a bit more last year than this year! Shame they shortened the route, but definitely the right decision. Still a fun event, and I'm glad I did it.

Katie: Well done to everyone for completing. It was a big challenge to just get to the finish line yesterday!

I agree with Ben's ride summary. I didn't do last year, so it was all new for me, but despite the horrendous weather, riding through ankle deep puddles and driving rain, (I don't think I have ever been wetter!) I still had a really fab time and coming round the bend and onto The Mall at the end was just the best thing ever (and the big bath I had when I got home too!).

Really proud to have completed and to be riding for the SWTKF and to not let down all my sponsors.

Adam: Whilst I didn't participate last year I would describe Ben's assessment as pretty spot on. The first and last miles were speedy and enjoyable!

Deborah Wills and her husband **John**, who also took part in the event, were somewhat disappointed that they did not get to tackle Leith Hill and Boxhill, especially as they had built in the hills as part of their 4 month hard training programme.

Both can at least say that they had cycled all the route – just not on the same day!

Deborah, unlike John (who completed the London to Paris bike ride a few years ago and raised over £3,000 for SWTKF), is not a cyclist and therefore was elated when she crossed the finish line.

Although John and Deborah didn't actually ride together, at least both her kidneys made it to the finish line albeit at different times.

A great achievement! (Deborah donated her kidney to John in May 2008, just 6 months after they got married).

Anne Collard writes: Between them all, our riders raised a fantastic total of £7,200.00 – thanks so much to them all.



GIVEACAR Halloween Competition

Enter Giveacar's Halloween Competition and win a £200 donation to The South-West Thames Kidney Fund and some fantastic prizes for yourself!

We want you to get creative - Take a picture of your Halloween festivities - This could be a pumpkin carving, homemade costume or creepy house decoration!

To enter: Post your picture on Facebook or Twitter with the tag @Giveacar and make sure you mention the charity! You can also email entries to charity@giveacar.co.uk

We will announce winners during the first week of November and the deadline is 2nd November so get snapping!



Do you have unanswered questions about **Kidney Transplantation?**

Help shape future research



We would like to hear from **clinicians and patients, their families and carers** who are:

- Transplant recipients
- On the transplant waiting list
- Living kidney donors

Take part in our survey now:



www.transplantpsp.org/kidney/survey



Oxford JLA coordinator on **01865 223298**



Oxford Biomedical Research Centre
Enabling translational research through partnership



The BKPA is the biggest grant-giving charity for kidney patients in the UK.

This year we will be giving over £3.2 million in grants. A quarter of our grant aid has gone directly to patients and families to help to improve daily quality of life for those living with chronic kidney disease.

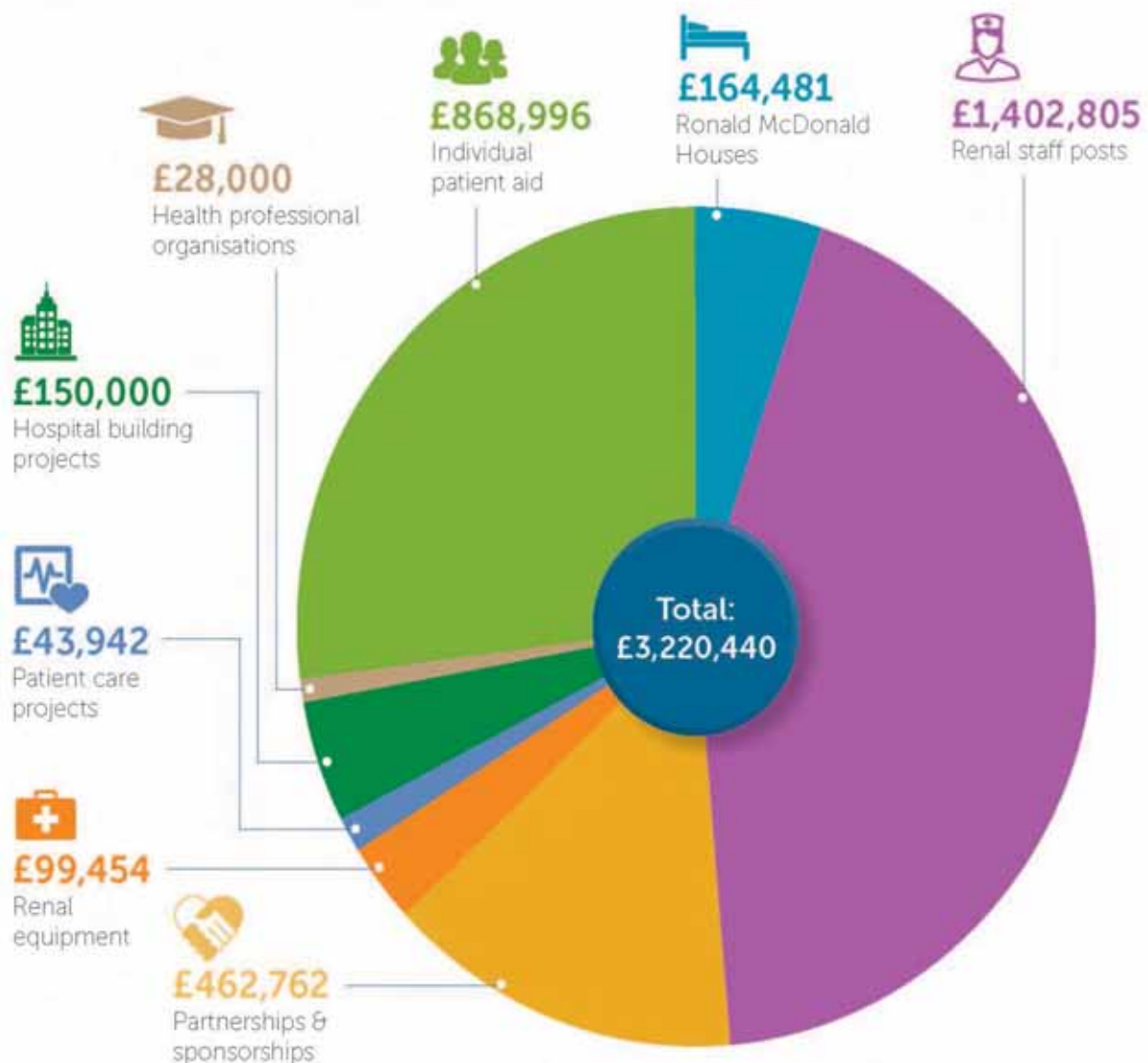
Whilst the BKPA has money invested and uses the income to fund some grants, we also rely heavily on donations, fundraising and legacies. We'll be increasing our fundraising efforts over the coming months and years.

We want to thank all our supporters and hope you will enjoy reading about the impact that grants are having on the lives of kidney patients and their families.

To find out how to apply for hospital grants or individual grants please visit www.britishkidney-pa.co.uk/grants

The BKPA continues to make a real difference to the everyday quality of life for kidney patients through its individual grants. We award over 40 grants each week to patients and families.

BKPA Grant Commitments for 2014



Let's make Dialysis Better Together: Shared Care

I'm sure the concept of 'Better Together' was ours? Over the last few months it seems to have been rather hijacked for the 'Scottish Question'. Never mind the event in Scotland the answer is YES, we are better together!

By Debbie Noble, Sister for Home Haemodialysis

3. The Kidneys and what do they do?

In the first article we discussed Fluid Balance and in the second it was Blood Pressure. In this, the third article, I would like to talk about the kidneys and what they do? You might say if they are not working why do I need to know? Well the reason is that if you know what the kidneys are supposed to do, it will hopefully help you understand your treatment better.

Where are the kidneys?

Although the body can work very well with one kidney most people have two. Healthy kidneys are bean-shaped organs each about the size of a fist.

They sit well protected by muscle and fat just below the rib cage in the middle of the back,

one on the left and one on the right.

They have a fantastic blood supply with the Renal Artery taking blood to the kidney and the Renal Vein taking the blood away after it's been filtered.

Although it varies with your size; the average person has about 5-6 litres of blood in their body.

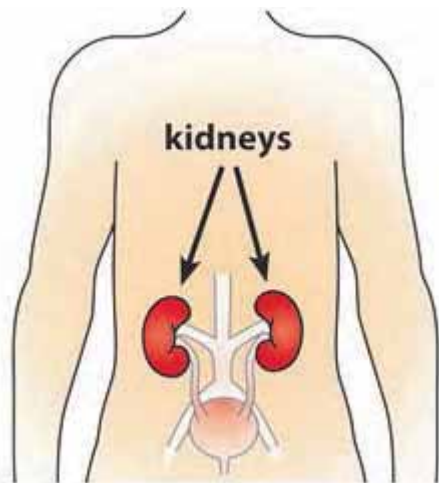
Every day 2 healthy kidneys will process about 150-200 litres of blood and filter off about 1-2 litres of urine, so you can see that the kidneys are constantly analysing and adjusting your blood over and over.

I think it's fair to say that we don't really consider what the kidneys do until they stop doing it.

Tell your family and friends to look after their kidneys, perhaps have a Blood Pressure check because as the saying goes "you don't know what you've got till it's gone!"

So what do they do?

The major role of the kidneys is to produce urine. But they also make hormones; these are chemical messages that are posted directly into the blood. The message is then sent via the blood to the part of the body that is waiting for that message. The kidney makes three chemical messages: Erythropoietin, Renin and Active Vitamin D.



What is healthy urine?

We don't normally talk about urine and we don't really notice it as it disappears down the loo, but urine is a carefully balanced liquid. As well as removing waste products from the body the kidneys are also responsible for balancing important electrolytes and minerals (such as salts, potassium and phosphates), not too much but not too little either. So, while continuously analysing your blood the kidneys regulate the vital electrolytes and minerals, they filter the waste products and then dissolve them in the extra water that the body doesn't want. This is urine.

If my kidneys aren't making healthy urine, apart from dialysis what will I need to do?

If your kidneys aren't working and you are not able to regulate your blood you will be asked to follow a special diet.

It is important to eat well. There is no single renal diet and advice will vary, depending on things such as your weight and blood tests.

You could be asked to control the amounts of salt, phosphate or potassium. You may not need to restrict all of these, and recommendations are likely to change with time but the renal dietitians will advise you.

You *may* be prescribed medicines called Phosphate binders e.g. Phosex, Calcichew, Renagel, Fosrenol. In addition to your diet, these medicines will help prevent you absorbing too much phosphate/ phosphorous from your food.

It is really important that you take these tablets as directed.

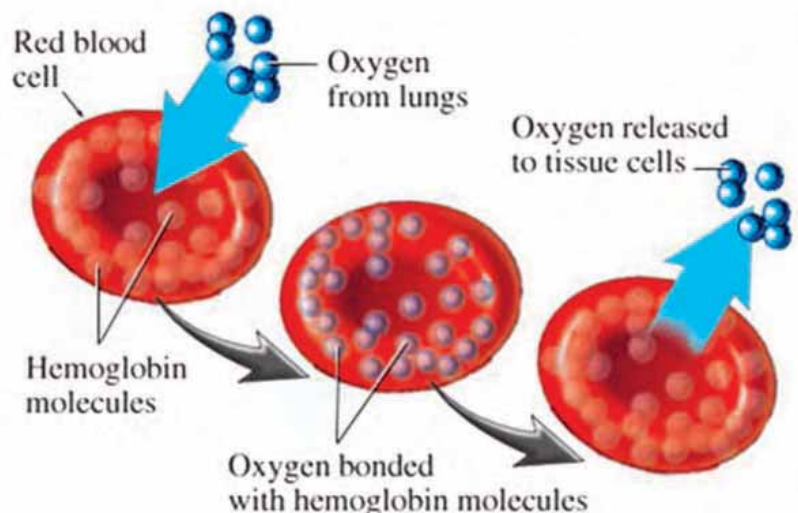
They do all taste a little bit different; some you swallow whole and some should be chewed, some are before the meal, some are with and some just after.

Some binders work like magnets, while others work like sponges. They must be taken at the same time as eating the food because they bind or soak up phosphorus during digestion.

This stops it from being absorbed into the blood stream and the binders and phosphorus are then emptied out of the gut when you have a bowel movement.

If binders are required and are not taken, phosphorus can accumulate in the blood. This can lead to weak and brittle bones that break easily, itchy skin and damage to your heart, blood vessels and lungs.

So just to recap, if you are prescribed binders then do



whatever it takes - put some in your coat/ jacket pockets, car, handbag, take them to work, leave them by the fridge, or wherever but, please take them when you eat.

The three chemical messages made by the kidney:

Erythropoietin

Erythropoietin, also called EPO triggers the bone marrow to produce more red blood cells. It is these red blood cells which exchange oxygen and carbon dioxide in the lungs and with body cells.

At best, red blood cells only last for about 4 months but in dialysis patients it's less; so they constantly need replacing. Almost all EPO is made by kidneys, so when they don't work they aren't able to make EPO. Without EPO most people will have too few red blood cells.

Drug companies make EPO in different strengths, so if you need it we will give you the appropriate EPO injections.

If you are unwell or are bleeding somewhere please tell your nurse or doctor, otherwise we will monitor your blood tests and prescribe accordingly.

In conjunction with your EPO we also have to consider your Haemoglobin. Red blood cells are able to carry oxygen so efficiently because of a special protein inside them called Haemoglobin.

To make Haemoglobin your body needs Iron, vitamin B12 and Folic Acid. If your blood tests tell us that these are needed we will give you intra venous iron, vitamin B12 injections or folic acid tablets.

If your levels of red blood cells or Haemoglobin are low, we say you are anaemic.

Renin

Not strictly a hormone but very similar, Renin is produced in the kidneys and its job is to help regulate blood pressure and fluid balance in the body.

Normally if a kidney receives the right stimulus it secretes Renin. This starts a series of chemical reactions in your body that play a part in raising your blood pressure by constricting or narrowing your blood vessels.

However, diseased Kidneys get confused and often make too much Renin, even when they shouldn't, causing your Blood Pressure to rise.

Some types of high Blood Pressure medicines, often used by the renal doctors, work by blocking this Renin chain of reaction. These are known as ACE inhibitors and ARBs.

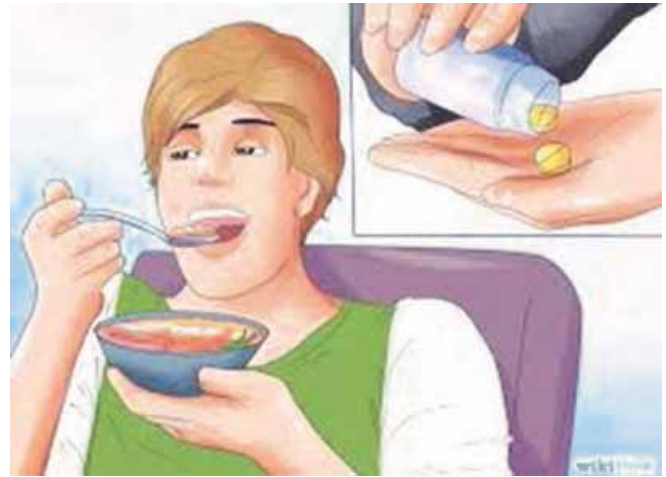
Examples of ACE inhibitors include Ramipril and Lisinopril.

Examples of ARBs include Candesartan, Irbesartan, Losartan

Active Vitamin D

We get vitamin D from sunlight and some foods but vitamin D also needs to be activated by the kidney. When kidneys fail, they aren't able to do this important task.

Without the activated vitamin D to control calcium and phosphorus levels in the blood the Parathyroid Gland (found



If prescribed, always take binders when you eat

near the thyroid gland in your neck) will try to compensate by secreting a Parathyroid Hormone (PTH).

In kidney failure, the Parathyroid Glands can produce too much PTH which then tells the body to pull calcium out of the bones and put it in the bloodstream.

The excess calcium in the blood stream can leave deposits all over the body which may cause serious problems, while the bones become weak and brittle.

Because of this, PTH levels are routinely monitored in Kidney patients with a blood test.

If a person with chronic kidney disease develops a high PTH their doctor will prescribe activated vitamin D, usually in a tablet (alphacalcidol) which will slow down the PTH production.

PTH levels are checked regularly to make sure the dose of the medicine is correct and that PTH is adequately suppressed but not over-suppressed.

Sometimes it is necessary to introduce another medicine called Cinacalcet and occasionally you will need to have an operation to remove your Parathyroid Gland/s. It is important for all kidney patients to keep phosphate and calcium blood levels within a normal range. The renal dietitians work closely with people on dialysis to ensure that they are not eating too many foods rich in phosphate and to make sure phosphate binders are taken correctly.

I hope this has helped you understand what the kidneys do, where they are and how we treat kidney failure.

Including you in your care (Shared Care) is so important that my colleague Clair Laidlaw is taking the lead and visiting some of the satellite units talking to patients and encouraging them to get involved with their treatment.

If you have any questions about this or the article then you can contact Clair or myself by phone 0208296 4531

or email clair.laidlaw@esth.nhs.uk or

deborah.noble@esth.nhs.uk

You can contact the Dieticians on 0208296 2673

For anaemia related questions call 0208296 4511 or renalanaemia@esth.nhs.uk

For Blood Pressure questions please email

susan.kareem@esth.nhs.uk

Very best wishes, Debbie Noble (Sister for Home Haemodialysis)

S.H.S.K.P.A Holiday home

St Helier and Surrey Kidney Patients Association



Come and enjoy a relaxing and fun-filled family holiday in our new holiday home for up to six people, to suit all ages. The Holiday Home has a ramp with decking to enable all patients to enjoy its facilities.

It is situated on 42 acres of grassland with tree-lined roads and the caravan centre sits on the edge of the popular seaside town Bognor Regis.

Children are well catered for, with The Riverside Rascals Club (4-13s) with its program of fun activities and games. A clubhouse also offers entertainment for the whole family, including cabarets, disco, live music, bingo and dancing. Please check with the reception office for entertainment and leisure facilities available during the period of your stay as it varies throughout the season. The Riverside Caravan Centre also has an indoor heated swimming pool and spa pool, outdoor heated swimming pool, outdoor heated children's fun pool, shop, amusement centre*, bar/off-licence*, pool table* and launderette*. Some of the clubs entertainment requires a membership for the duration of your stay and can be purchased from the reception on a daily or weekly charge. However S.H.S.K.P.A as a club member provides 6 free club memberships. (*chargeable)

2011 Patient Rates

March	£160
April	£160
May	£160
June	£230
July	£230
August	£230
September	£200
October	£190

To contact us:

Nita and Ravi Patel

3 Darcy Road, London, SW16 4TX
 Tel: 020 8407 2525 Email: nita@nitapatel.com
Web: www.shskpa.org

Message from Holiday Home Managers:

We would like to welcome new and different members to book our holiday home. It has been newly furnished with crockery, cooking utensils, duvets, a new TV and DVD player. It will provide a very good break for new and regular patients alike.



© Niyam Patel

South West Thames Kidney Fund Weekly Lottery

** Calling all kidney patients, their families, colleagues and friends **

To earn £500 a week (£26,000 a year) for our research we need 1,000 entries in our lottery.

As of this writing, we have 250+ entries, so we are asking you all to muster enthusiasm from everyone you know and get us the additional 750 entries we need to reach our goal.

If every one of the '1.4 million patients served by the St Helier Renal Unit', mentioned by our Clinical Director in his article last issue, was to join the Kidney Fund lottery, we could pretty much stop fundraising and put all our energies into the research, but for the time being we would be content with just 1,000 patients helping us.

It costs just **£1 per entry per week** with 50% of the weekly entry money going to the winner and 50% to research.

Please get involved and help us reach our goal

THANK YOU!

OUR WINNERS SINCE 11TH APRIL 2014

18/04/2014	101255	Woking	£122.00
25/04/2014	101218	Sutton	£123.50
02/05/2014	101242	Staines	£122.00
09/05/2014	101075	Fleet	£124.00
16/05/2014	101229	Bramley	£124.00
23/05/2014	101186	Rudgwick	£124.00
30/05/2014	101243	Chipstead	£124.50
06/06/2014	101219	South Croydon	£124.50
13/06/2014	101023	Birmingham	£126.50
20/06/2014	101248	Farnborough	£126.00
27/06/2014	101227	Addlestone	£124.00
04/07/2014	101160	Belmont	£127.00
11/07/2014	101123	Farnham	£126.50
18/07/2014	101129	Burgh Heath	£126.50
25/07/2014	101234	Addlestone	£126.00
01/08/2014	101087	Charlwood	£126.50
08/08/2014	101235	Leeds	£127.00
15/08/2014	101232	Folkestone	£127.00
22/08/2014	101215	Sutton	£127.00
29/08/2014	101036	London	£128.00
05/09/2014	101239	New Malden	£128.00
12/09/2014	101238	Farnborough Cinderford,	£126.00
19/09/2014	101228	Glous.	£126.00
26/09/2014	101094	Reigate	£126.00
03/10/2014	101029	Purley	£126.50

To Join the South West Thames Kidney Fund Weekly Lottery:

please complete your details and either the 'Standing Order Mandate' or 'Cheque Payment' part of this form and return to: **The Lottery Office, c/o 10 Pelton Avenue, Belmont, Sutton, Surrey SM2 5NN**

Title: _____ Initials: _____ Surname: _____
Address: _____
Postcode: _____ Home Phone: _____ Mobile: _____
Email: _____ Add me to kidney research supporter email group _____
Please note that to save on postage we prefer to communicate either by email or telephone. Please tick here if you require a letter.

There are two ways to pay. Choose one of the following:

1. Standing Order Mandate

My Bank's Name: _____ Branch: _____ Post Code: _____
My Account No. _____ Sort Code: _____ Date of 1st Payment: _____
Name _____ Signed: _____
Pay to: Kidney Fund Lottery; Bank: CAFbank Ltd, West Malling; Account Number: 00019588; Sort Code: 40-52-40
Monthly Payment: _____ entry(s) @ **£4.34** per month = £ _____ & thereafter each month
Quarterly Payment: _____ entry(s) @ **£13** per quarter = £ _____ & thereafter each quarter
Half-Yearly Payment: _____ entry(s) @ **£26** per half-year = £ _____ & thereafter each half-year
Annual Payment: _____ entry(s) @ **£52** per year = £ _____ & thereafter each year

2. Cheque Payment

I wish to buy _____ entry(s) each week for _____ **13 weeks;** _____ **26 weeks;** _____ **52 weeks** and remit a cheque for £ _____
(each entry costs £1 per week). Please make cheque payable to: The Kidney Fund Lottery.

If you have any questions or would like more information, please phone Anne on 020 8296 3698 or email lottery@kidneyfund.org.uk

South West Thames Kidney Fund. Registered charity no. 800952

**SOUTH WEST
THAMES
KIDNEY
FUND**

**PLAY OUR
WEEKLY LOTTERY**



*to join our weekly lottery please
complete and return the form overleaf*

**Over
£21,000
prize money
paid out
so far**

**Over
£21,000
earned for
kidney
research**

