Transplanted back to ANcient Rome

Three weeks before William Marshall, 70, was due to receive a kidney from his daughter, Sharon Edwards, their garden centre business suffered a catastrophic fire.

But as the couple began their recovery - and rebuilding work began on their business - archaeologists discovered several Roman kilns. Their farm had apparently been at the centre of one of Roman Britain’s most important pottery and ceramic-making areas.

“It was amazing to think that we were standing on the same ground as the Romans did and this was, quite literally, under our feet,” said Sharon, 50. “To see it being uncovered was wonderful. The land we are on was an ideal location for pottery making because it has both clay and sand and a means to transport the pots to London via the River Slea.”

As several items of historical interest had been found on the land at Osborne Farm at Kingsley, near Bordon, Hants, over the years an archaeological dig had to be carried out before re-building work could begin. As well as the Roman kilns and several pots, an Iron Age mill stone and a medieval ditch were found. William is fully recovered and back on his tractor and looking to the future - with one eye firmly on the past. Full story: P 5

WORLD FIRST FOR ST GEORGE’S

Surgeons at St George’s have performed a blood-free kidney transplant between Debra and Jade Gouldbourne, two Jehovah’s Witnesses—despite the patients not being a donor match.

The transplant team decided to go ahead despite the problem of the organ not being compatible. But it was made more complicated by the mother and daughter’s faith which dictates that they cannot accept blood transfusions—meaning surgeons had to strictly limit blood loss.

But four months later, the social worker has fully recovered with no signs of the kidney being rejected.

‘Accepting a kidney from my daughter has been a very emotional experience,’ Ms Gouldbourne said.

‘We built up to the surgery together, so we shared a huge emotional journey as well as the physical recovery.’

The procedure is believed to be the first time an incompatible kidney transplant has been conducted between two Jehovah’s Witnesses.

Jade, 27, said: “Despite the disappointment of the compatibility tests I was determined that if there was a way to make it work we would try.”

Jade and Debra (seated) are pictured with surgeons Nicos Kessaris (left) and Mohamed Morsy. Full story: Page 3
The FSI (Foundation for Social Improvement) is working with small charities to gather items that could be sold in the Small Charity Week eBay Auction in June.

We are looking for **outstanding products**. Items of a unique or high value do particularly well on eBay auctions. They don’t just have to be material items – they can be once in a lifetime experiences too! Anything with celebrity or star association will do extremely well, but following is an idea of items that have done well in previous high profile auctions:

- Internships with high profile entrepreneurs like Julian McDonald
- Limited edition items e.g. clothing, books, photos etc
- Signed items e.g. football shirts, books, photos etc
- The opportunity to meet celebrities, leading journalists, inspirational figures
- Music memorabilia (or memorabilia of any kind)
- Exclusive fishing/countryside experiences

A range of various items similar to those listed above will be accepted and entered into the auction. **Due to the nature of this auction the FSI cannot accept general items**, these include anything that can be sold on a regular basis or that is easy to acquire by the public such as:

- Goods available for commercial sale
- Goods with unknown provenance

100% of the funds raised by your auction item will be given to your Charity – South West Thames Kidney Fund! If you have, or know of, anything that might sell well in this auction, please contact Anne on 020 8296 3698 or email anne.collard@kidneyfund.org.uk as soon as possible.

Please join our Kidney Fund 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.

**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.
‘BLOODLESS TRANSPLANT’
A FIRST FOR ST GEORGE’S

Mum receives daughter’s kidney in St George’s first tissue incompatible kidney transplant

The transplant team at St George’s Hospital has performed its first tissue incompatible (also known as HLA incompatible) kidney transplant on a patient from London. Debra Gouldbourne, from Catford, was born with a condition that caused her kidneys to fail and received her first kidney transplant in 1986. In 2010 this kidney also began to fail and Debra’s daughter Jade came forward as a potential donor. Jade was tested as a match for Debra but, disappointingly, the results showed that her body would attempt to reject the organ. Despite this setback, innovative medicine and the support of a multi-disciplinary healthcare team meant the transplant could still go ahead. Normally when a donor receives a tissue incompatible organ, the body’s immune system will attack the kidney with antibodies and cause it to fail. In Debra’s case a complex series of treatments successfully bypassed her body’s natural response, allowing her to accept the organ. A month before her operation Debra was given an infusion which removed some of the white cells – cells responsible for producing antibodies and triggering an immune response – from her blood. She also went through a treatment known as double filtration plasma exchange, which reduced the unwanted antibodies already present in her bloodstream to very low levels. The very low levels of antibodies in Debra’s bloodstream allowed the kidney to be accepted and, over four months after the transplant, Debra has fully recovered and there has been no sign of rejection. Though

Consultant renal transplant surgeon Mohamed Morsy (recipient surgeon) said: “Debra’s faith dictates that she cannot receive any blood transfusions. “Therefore a key challenge to the theatre team was making sure that we absolutely minimised blood loss during the operation. Though we put into place special measures in line with her faith to control blood loss, she bled very little which was the perfect result for us. “The transplant went well in all aspects: removal of Jade’s kidney was very straightforward and likewise Debra’s operation went ahead successfully without complication.”

Consultant renal transplant surgeon and lead in antibody incompatible transplantation Nicos Kessaris (donor surgeon) said: “The surgery was a big success, but this is not a story about surgery alone. “The preparation for surgery is what made this whole procedure possible and that is down to the talented multidisciplinary team of doctors, nurses, clinical scientists and surgeons we have at St George’s Hospital. “Debra was perfectly prepared for the procedure when she reached the operating table. “Suppressing her immune system so that she could successfully accept Jade’s kidney was very challenging and is a huge achievement for the team. “It has led to a very positive outcome for Debra and her family and we are very pleased for them.” It is believed that this first incompatible kidney transplant at St George’s Hospital is the only time in the world that the procedure has been conducted between two Jehovah’s Witnesses.

Consultant renal transplant surgeons Nicos Kessaris and Mohamed Morsy performed a transplant in an operation similar to the one pictured above

Debra will continue on immunosuppressive medicines for the rest of her life, she is back to everyday life with normal kidney function. Debra said: “It was scary but the clinical team at St George’s were really reassuring and gave me great confidence. “They really did everything they could to make both of us comfortable and keep us informed so that we understood what was happening. I can’t thank them enough for what they’ve done for us.” Both Debra and Jade are Jehovah’s Witnesses so cannot accept blood transfusions, which made the surgery more complicated, but overall a greater achievement.
Steve Simper, General Manager, Renal Unit

Well, I thought summer had arrived early but it seems it was just passing through. Never mind, I will remain optimistic and keep the shorts and T-shirt toward the top of my drawers.

I have been pondering about what to tell you all in terms of renal news since Christmas. There has been a great deal going on but much of it very boring. We have been looking to close the finances for 2011-12, agree new budgets for 2012-13 and negotiate with our commissioners regarding activity and new standards of delivery - time consuming but not of great interest.

However, you may wish to know that we were delighted to formally open the Carpenter Suite and have now installed the patient TVs and are about to purchase some new medical equipment with funding from the KPA. The KPA has also agreed to fund some profiling beds which makes it easier to support and care for patients with limited mobility. We are also about to complete work within Harry Secombe ward to install a brand new RO plant – again, not very interesting but essential equipment to enable in-patients to dialyze at their bedside.

Everyone in the new administration team arrangement are working hard to embed the new processes and Renal are succeeding in achieving our targets. We welcome back from maternity leave, Dr Mona Whaba and Dr Kate Shiell and wish Sara Jobson (Service Manager) well as she will commence maternity leave in June.

One other item which I thought you would like to know about is the current situation regarding holiday dialysis. The department does have a clear policy on this but as ever, we have to continually update this to meet the changing requirements of the NHS. So, for now, please see the item on Holiday Dialysis on Page 19 which I hope will be of help.

Further information can be obtained from Lindsey Blazey, Holiday Coordinator on 020 8296 3454.

I hope you have all had a lovely Easter and look forward to updating you all further in the next issue.

Very best wishes to all,

Steve

THE WORK OF THE BRITISH KIDNEY PATIENT ASSOCIATION

The BKPA is a well known national charity that really cares about the personal circumstances of individual kidney patients and their families.

We know that life with kidney disease can very tough at times and patients and families have to cope with numerous hospital visits as well as the impact of the disease on work, family life and finances.

• We provide information, support and advice.
• We give grants to help patients and families cover the costs of domestic bills, hospital travel, education and holidays
• We provide financial support to kidney units throughout the UK to help improve kidney services and patient care

What makes us different from other charities is the level of financial support that we can give to patients, families and kidney units during times of financial difficulty.

In addition, we’ve just set up a new support phone line for patients in units with no counsellor or social worker.

Find out more from the BKPA website www.britishkidney-pa.co.uk    Tel: 01420 541424

Email: info@britishkidney-pa.co.uk
SHARON EDWARDS gave one of her kidneys to her father William Marshall, 73, nearly two years ago now.

Sharon, 50, writes: The operation was successful and we were fortunate enough that I was the first person to come forward and get tested.

We are farmers, growers and have a garden centre, which sadly burnt to the ground only three weeks prior to the transplant.

The rebuild of the garden centre has been fraught with delay and, as you can imagine, there was so much to do after such a major fire (pictured below).

Over the years items of historical interest have been found on the farm, which meant that an archaeological dig had to be done on the site before any building would be allowed.

Several Roman Kilns were found directly under the site together with many whole and broken pots from that time.

They also discovered an Iron Age mill stone and a medieval ditch! Despite the delay, it was fascinating to see what was hidden under ground.

Whilst the dig was happening here, it was amazing to think that we were standing potentially on the same ground as the Romans did and this was literally under our feet. To see this being uncovered was wonderful.

The land we are on was an ideal location for pottery making, because it has both clay and sand and a means to transport the pots to London via the River Slea. Alice Holt Forest, (which is at the edge of the farm) and surrounding areas were one of the most important centres for the industrial-scale production of domestic ceramics in Roman Britannia, supplying up to 60% of all pottery found in excavations at Staines and London and being transported across south-east England throughout the period from AD60 to the early 5th century.

I am not an expert on the subject, but am interested in it all. It is like touching history!

All of the pieces that were found have been taken away to be cleaned, checked and registered before being returned for us to put on display within the new centre.

Everything has been removed, although the kilns themselves have now been re-covered upon the recommendation of the archaeologists.

We were so lucky with the kidney operation, because of my fathers age and of course for me to be a match. My kidney has found a new home and has settled in very well and we are extremely happy for it.

Prior to the operation, we were all understandably nervous, as so many others are, when faced with the same position.

We cannot praise the staff at both St Helier and St George’s enough. They were superb with the information they gave prior to the operation, and with all the aftercare and queries. We would like to encourage others who are contemplating this type of surgery that it is worth it - life is amazing and we can achieve so much if we give it a try.

Once my father had recovered from the operation he was straight back out on the farm. (Above: Sharon and, right, William on his digger).

We are now clear to start the re-build of our 60,000 square foot shopping centre on the farm. We have always been into the greener aspects of growing and lifestyle.

My father has been out digging a lake which will collect rainwater and then be circulated through a plant to be used in centre for watering plants, flushing toilets etc.

We are also hoping to rebuild the centre using straw which we will be growing on the farm this year. Yes, I did say STRAW! It is very ecological and is made into panels on the farm and put together on site like building blocks. It will be a very interesting and worthy project and the first in the country.

Without the excellent work of the Renal Unit at St Helier and St George’s, my father may not be in a position to be able to strive towards a method of building for the future, which preserves the environment for the future also.

This is a post op kidney transplant patient of 73 who still has his eye on the future!

I believe that this success story, especially coming from a point of poor health and the loss of his lifes work, is an inspiration to others.

I would like to be able to tell others to not give up. When we lost our business through the fire, as a family we were already preparing ourselves for a major event with the inherent risks involved. Now there are exciting times ahead for my dad and mum June as we plan the rebuild for September/October.

Sharon Edwards
Country Market, Kingsley, Bordon, Hants
SHSKPA NEWS

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:

L Ware
St Teresa’s School, Dorking

Mike and Theresa Booth
A Donovan

C May
Kathryn Johns

J Burch
J R Rodway

The Charities Trust
Mr and Mrs P Steele

A special mention to our generous friends at the British Kidney Patients Association (BKPA) for their grant towards a piece of specialist medical equipment.

KPA Memorial Donations

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

Kevin Webbe
George Armstrong

Clive Bradshaw
Mary Chuard

Joan Nuttall
Pamela Wessier

WKD 2012: Swan Walk, Horsham
07:30 to 16:00... a long, long day!

With many thanks to the management of Swan Walk, Horsham – they allowed us to hold a collection and an Organ Donation/Transplant information stand within the centre.

Two nurses (Karen Smith and Jo Burley came out to record BP’s and give simple health advice.

The collectors were: Shirley Rae and Mary Quek (pictured), Dave and Di Spensley, Paul Connolly, Steve Morley (home HDF patient), Steve’s partner and carer, William Watkinson (other half to a home HDF patient) and me...when I was not gassing to constituents!

Last year we raised £303, this year £472 !!!

And here is a date for all your diaries, the 14th March 2013 ..................next year’s World Kidney Day, see you then! JIM RAEE, Treasurer
A message from your Chairman, Dave Spensley...

Another edition of Renality, where does the time go?
This is a relatively quiet time of year so not a lot to report on.
The changes brought about following the Taking Stock exercise have been completed and the new regime regarding reception, booking staff and secretarial support are in place.
After some initial problems and delays things seem to be settling down albeit there seems to be regular periods when the reception desk is closed and this is a situation that I have raised with the General Manager. The KPA will do it can to ensure that the situation improves.

World Kidney Day
The KPA held an awareness day at Swan Walk shopping centre in Horsham and thanks to 9 volunteers and 2 St Helier nurses doing blood pressure checks we raised nearly £472. Thanks to everyone and to Jim and Shirley Rae for organising the event.

Golf Day
Following the success of our previous golf days we are holding another event playing the superb Milford Golf Course in Surrey. The event will be held on Friday 22nd June 2012. This is a lovely venue which will provide a great day of golf for players of all abilities, it would be great to get 70 players or more so if you’re a golfer please book your place and bring a friend. A poster on the event is included within this edition.

Purchase of Equipment
We have recently purchased a specialist machine similar to a doppler which helps identify the position of veins, arteries and fistulas.
This purchase was made possible due to a generous donation of £5,000 from the British Kidney Patients Association (BKPA) and another donation secured by Dr Ginny Quan.
Our sincere thanks go to both for enabling us to make this purchase.
We are currently purchasing 5 specialist profiling beds and mattresses at a cost of £15,000. These beds will improve the comfort of patients and as always, they have been purchased as a result of donations received, thank you!

Other Matters
The KPA Committee is still desperate for new members and patient representatives for Kingston, Farnham, Purley, Epsom and Sutton.
The present Committee has served for a number of years doing an excellent job but it would be lovely to have some new members, with fresh ideas, to enable us to continue to represent you, the patients.
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.
May I, on behalf of the Committee, wish you a happy and healthy 2012.

Best Wishes,
Dave Spensley, Hon Chairman
John Edward Foxwell
Memorial Golf Day
In Aid of St Helier and Surrey
Kidney Patients Association
(Registered Charity Number 266391)
Milford Golf Course
(Surrey)

Friday 22nd June 2012

Cost — £40.00 Per Person

The day will comprise of:

- A shotgun start
- A Singles Stableford Competition (Full Handicap)
- Prizes for “Longest Drive” and “Nearest the Pin”
- Three Course Sit Down Post golf meal (Please advise of any vegetarian dietary needs)
- Auction & Raffle

For Further Details or to book a place please contact:

J G Rae
Hon. Treasurer
St Helier and Surrey KPA
24 Beaver Close
Horsham
West Sussex
RH12 5GB

Telephone: 01403 242601 or 07810 608678
Email: raedar@supanet.com

Cheques should be made payable
to St Helier and Surrey Kidney
Patients Association
whose members thank you
for your support
It is always gratifying and slightly anxiety-provoking when I think of Renality.

First, the thought of all the work that goes into making this such an excellent and valued publication, which speaks to so many audiences.

I know from experience the huge effort that goes into generating copy, reminding people about contributions, and writing against a looming deadline. This is then dwarfed by the effort of typesetting, arranging advertising and sponsorship, and printing.

When that is achieved there is the small matter of stuffing envelopes, fixing address labels and postage, and lugging to the post room. And behind the scenes is the essential work of maintaining address lists, balancing the books, and all the other administration that is so often overlooked.

So let me start by thanking everyone who has contributed to the KPA, and to the publication of this issue.

In many ways, the above could also have been written about the staff of the Renal Unit.

While there is the high profile of the ward doctor or nurse, or even manager, behind them is a small army of people without whom the show could never get off the road. We try to recognise this by the ABC award, which is awarded monthly to the Renal Unit staff member who has performed ‘Above and Beyond the Call of Duty’.

To my knowledge, this has never yet been awarded to one of the medical staff – which could be taken in many ways, but I believe has to do with the excellence of our support teams. So again, thank you to them.

This month has seen one important clinical development that I would like to highlight. One consequence of our highly centripetal philosophy of care (i.e. the bringing of renal staff to the patients, rather than the other way around) is that all the Consultant staff have regular outreach commitments.

While this means that many patients are spared a long journey to St Helier, it does mean that the Consultants cannot always be quickly available in the event of an emergency on the wards at St Helier, and that colleagues on site often have to cover. This is especially true for those doctors with more distant outreach commitments, such as at East Surrey or Frimley Park.

We have wanted for a long time to improve this system of ward cover. For this reason, the imminent appointment of a new Consultant has allowed us to adopt a new way of working, known as ‘Consultant of the Week’.

In effect, the duty Consultant will no longer have outreach commitments for the week on call, but will be based solely at St Helier. This duty Consultant will be tasked to see all new acute admissions, conduct twice daily ward rounds, and be available to see patients and relatives on a much more flexible basis.

Increased support and teaching of junior grade staff will also be possible, together with a new Consultant-led follow-up clinic for patients recently discharged from the wards.

We hope that this system will make a big difference to the quality of care, and the efficiency of the wards. We will be monitoring the effect of the changes, which will be phased in over the next few weeks, and would welcome any feedback.

We believe that this is one of the few reorganisations over the last few years that will actually improve patient care!

And now to finish with a dose of reality.

I am touched and amazed at how much feedback I receive from writing these articles. Perhaps the most remarkable has been the recent offer of not one, but two dogs from readers who have taken pity on my lonely, pet-free existence [I will not dwell on the third reader who offered me the shared use of his pet rat].

However, I am sadly resigned to my wife’s ultimatum of ‘the dog or me’, and my accountant tells me that the dog is simply not a viable option.

So I will have to content myself with taking any excuse to visit Steve Simper in his office, where his guide dog Jenny is always happy to see me.

At least it means that the managerial channels of communication are always kept open!

Have a very happy Spring.
A BURNS NIGHT TO REMEMBER

Burns Night 2012 was a wonderful evening! Maggie Porter, assisted by her family, some friends and some kidney fund volunteers, outdid herself with the organisation of the evening at the Chipstead Cricket Club.

They cooked for, served and cleared up after, 70 plus guests, producing a delicious traditional Burns Night Supper feast of cock-a-leekie soup followed by haggis, neeps & tatties (mashed tatties for 70 produced by Richard & Carol Sammons!) and, for pudding Clootie Dumpling and custard. For those of you that don't know - a Clootie Dumpling is very tasty but can be a bit tricky to cook - those that volunteered to cook one can attest to this!

The evening was completed with a piper in full dress and the Address to a Haggis read out by our very own kilted Scot, Dr Mark Dockrell.

Approximately £2,000 was raised from the tickets sales and the raffle for the South West Thames Kidney Fund. Thank you Maggie and all who helped - including Maggie Guitar, who very generously supplied the whiskey - and please, let's do it again next year!

QUIZ KINGS RAISE OVER £1,300

Civil Servants across London have been showing their broad range of knowledge at a series of quiz nights run by Ian and Kathryn Harrison. Kathryn, who works for the UK Border Agency set up the first quiz in Croydon at the end of last year and has since run two more in Central London with teams of colleagues from across UKBA as well as the Serious Organised Crime Agency and Ministry of Justice taking part.

"We have had great fun just preparing the quizzes" said Kathryn. "Ian and I have very different interests and so have been able to come up with a wide range of subjects to test people's knowledge, from the standard music and sport type rounds to a "Doctor's Orders" round where every question had some reference to a doctor and, hopefully, there was something for everyone. Try out these, for example: What was Dr and The Medics only UK number one hit? If you started a game of scrabble with the word “doctor” placing the d on the pink square in the middle, how many points would it be worth?** That one brought about some groans.

The quiz nights have been such a hit that teams had to be turned away from the last one and the next one on 3rd May is already fully booked. So far they have raised over £1300 for the South West Thames Kidney Fund and Ian and Kathryn are delighted to have hit upon a way of raising money and giving people a good night out at the same time. They have also used the events to promote the work of the Kidney Fund and raise awareness.

Kathryn has asked that special ‘thank you’s’ go to her friend and colleague Tanya for helping to arrange and run the evenings and for her generous donations of prizes and to Mark “the marker” for his excellent services in marking papers and keeping score.

*Answers in the next edition of Renality!

CLAIRE TYNE would like to say a huge thank you to all those who took part in the incredibly enjoyable charity pub quiz on 29th March at the Waggon and Horses, Surbiton. A fantastic £570 was raised on the night from the generous donations of over 70 people. There will be another charity pub quiz later in the Autumn this year. There is still the opportunity to donate to Claire's fundraising drive at www.justliving.com/tiger-kidney
THE MAD HATTERS

It’s said that it takes 40 repetitions for learned behaviour.

Well it’s only my third time to host a St Patrick’s Supper in aid of SWTKF and already it’s anticipated by my friends with relish!

This year I threw the invitations out even wider among them (expecting the odd refusal) but word is out, and everyone accepted.

It’s only fair to say that a request to my lovely husband Mike to knock a wall down was met by an absolute NO. He did however borrow 15 more chairs and a long table from our Scout Group.

As usual all the girls brought something to raffle, some wine and made a donation for their supper. They arrived sporting amazing green concoctions upon their heads, each one outdoing the next, all competing for the ultimate prize – a St Patrick’s Day rosette!

The winning hat was called ‘A Pot of Gold’ which was appropriate as we raised £363 which will also be gift aided. Mike has been Dr Marsh’s patient for 8 years and I hope to donate a kidney to him in the future.

Hosting this event is great fun (with a bit of labour), and not only do we raise some funds for SWTKF but also awareness among our friends and extended friends and their families about kidney donation.

So while Mike accompanied the Scouts on a night hike, the Mad Hatters danced to the strains of ‘The Walls of Limerick’ on our patio. Next year we look forward to ‘The Siege of Ennis’ on our drive. I’ll need more chairs!!!

Marie Moore

BUMPER BIRTHDAY BONUS

TWELVE years ago, Udhyam had a kidney transplant - and on 17th December 2011, he was fortunate enough to celebrate his 50th Birthday with his wife, Bhavini, his family and dearest friends.

A staggering £2,600.15 was raised on the night. This was rounded up by Udhyam and Bhavini to £3,000 which was presented to the South West Thames Kidney Fund’s chairman, Dr Michael Bending.

The evening was enjoyed by all and Udhyam and Bhavini Amin would like to thank all their family and friends who donated so generously in aid of the Kidney Fund and kidney research.

Udhyam also made a personal please to all his friends to register with the organ donor program.

If you would like more information on how to register as an organ donor, please visit www.kidneyfund.org.uk/become-an-organ-donor
WORLD KIDNEY DAY 2012

The Kidney Fund would like to thank all the volunteers who outdid themselves with their hard work and enthusiasm at the 2012 World Kidney Day event at the Bentall Centre in Kingston upon Thames on March 8th.

They worked from 8:00 am until 9:00 pm, asking for donations, handing out literature to raise awareness of kidney disease and the importance of signing up to the organ donation register, and raised over £420!

We also had a visit from St Helier Hospital Chief Exec. Matthew Hopkins, who stopped by unexpectedly and had his blood pressure taken; and a visit from Marianne Vennegoor from the International Foundation of Kidney Federations who stopped by to say hello.

High blood pressure is one of the leading causes of kidney disease and renal unit nurses, Nimmy Logeswaran, Mary Mukuruva and Mary Thomson worked pretty much non-stop all day and into the evening doing ‘free blood pressure checks’. Many passers by took up the offer of a free check and the results were shocking!

Out of 154 random blood pressures taken, 64 were high! We are keen to point out that a shopping centre is not the ideal place for a health check and that the snap shot is only an approximation BUT results showed that 1/4 of all women tested had blood pressure higher than the ideal recommended and for the men it was worse, with half of all the men tested having higher than recommended blood pressure.

Of those that were tested and found to be at risk, the youngest were 18 and 19, while the oldest were in their 80s. The team had a word with those at risk and suggested action they could take including reducing salt in their diet and taking more exercise, while others were urged to see their GP as soon as possible.

One of the Kidney Fund volunteers commented "the really worrying thing is that people don't realise the risks of high blood pressure".

High blood pressure significantly increases your risk of heart disease, stroke and kidney disease. "One poor lady we saw had blood pressure that was quite literally off our charts; she's a walking time bomb and if that bomb goes off she could be left desperately ill for the rest of her life."

We urge you to spread the word to your friends, family, work colleagues and acquaintances about the dangers of untreated high blood pressure.

When they visit their GP, if they are not offered a blood pressure check, they should ask for one to be done routinely and as a matter of course.

LOTTERY WINNERS

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6 Good Reasons to join the Kidney Fund weekly Lottery:

1. You may win!
2. It’s easy to do and it costs just £1 per entry per week.
3. 50% of your £1 and everyone else’s £1 will go to the winner (which could be you!)
4. 50% of all the £1’s will go towards kidney research
5. The more members, the bigger the prize
6. The more members, the more funding for kidney research which will eventually result in prevention or a cure and then … WE’LL ALL BE WINNERS!

Funding = Research; Research = Cure

To join the lottery go to: www.kidneyfund.org.uk, ‘support us’ and select ‘join our lottery’
or email: lottery@kidneyfund.org.uk
or phone: 0208 296 3698
By the time you read this our team will have taken part in the 2012 London Marathon run on April 22nd. If you would like to see how they have done, please visit www.kidneyfund.org.uk/london-marathon where their times will be posted. Sadly unforeseen circumstances and injury have caused two of our runners to put their dream of running the London Marathon on hold. Their places will be carried forward to next year if possible, they will run then.

It's not too late to show your support to Simon, Keri, Kirsty & Richard (above, l-r) for their incredible hard work and dedication to run this arduous race and for taking on the responsibility of raising a personal £1,250 each. As a team they can be sponsored by visiting http://www.justgiving.com/kidneyfund2012 or you can send a cheque to the attention of Anne, SWTKF, Renal Unit, St Helier Hospital, Wrythe Lane, Carshalton, Surrey SM5 1AA.

Many many thanks to all of those who have already sponsored this very worthy cause!

Frank Elsmere ran the Hastings Half Marathon for the Kidney Fund on March 25th.
He writes: Having run the Paddock Wood half marathon last year and raised a sizeable sum for the fund I decided to run the Hastings half marathon this year which was quite a different experience.
First the course was much harder with substantial hills to complete over the first five miles but the difficulties were abated by the ambience and atmosphere created by the race sponsors and the public.
Obviously being a sunny day helped although it did get quite hot to run in later on. On route church services were held outside, bands and groups played, orchestras were playing at two locations from container trucks and the public were out in force, no place to hide!
The last three miles were along the sea front and flat. To date I have raised £550.00 but am hopeful this figure will increase over next weeks. Frank Elsmere

Garry Oakley
Our thanks to Garry Oakley (above) who ran the Fleet Half Marathon on March 25th.
He writes: “I recently ran the Fleet half marathon in memory of my mum and dad who have sadly passed away.
Dad was a frequent visitor to St Helier and was looked after very well by all. Mum looked after him constantly but she also died recently.
This year I decided to raise money for the South West Thames Kidney Fund by running the Fleet Half Marathon on March 25th.
I managed to raise over £650.00 which I am very proud of and would like to thank everybody that sponsored me.
It was a good day with lovely weather and I managed to get round 2hrs 14 minutes. This was a quicker time than last year which makes it even better.”

Calling all volunteers!
This year's Dragon Boat Challenge will be on Sunday July 15th at Canbury Gardens, Kingston-upon-Thames. We are once again entering a 'Sweaty Kidney Scientists' team and have reserved space for a charity stall. It has become a huge event with approximately 50 teams competing throughout the day. Each team races at least 3 times with the semi finals and finals starting around 4:00 pm. You don't have to be a swimmer to do this. Everyone MUST wear a life vest, and teams are given a few practice runs before they actually race.
Please contact Anne on 020 8296 3698 or email anne.collard@kidneyfund.org.uk if you can:
• be a team member, man a paddle for a race or two or three and raise £250 in sponsorship for kidney research
• volunteer to organise and/or man the stall
• have good ideas for raising money on the stall
• volunteer to source donated prizes for games (or maybe you have something or things that would be suitable).

Many thanks, Anne Collard
Greetings to all our readers and welcome to another update from the labs of the Institute for Renal Research...

Every year there are a couple of conferences that I attend, these are useful excursions to keep up to date on recent advances, meet up with collaborators and get feedback from other workers in the field on our research.

In March this year our post-doc, Felicia, and I had the pleasure of attending a European meeting where Felicia gave a talk about some of our results. This meeting with the slightly odd acronym of ERCSG has been running for almost 25 years now and among the keys to its success are; firstly it tends to be at the week-end so people can attend and don’t feel they’re loosing too much time in the lab and also the size of the meeting.

The group is around 100 people with researchers from the Netherlands, Germany, France, Italy, Greece, Spain and of course the UK.

A relatively small group like this allows for a certain type of intimate and constructive discussion. Felicia was talking about a project that I conceived some years ago and have been developing ever since. I’ll try and share the basic idea with you without using too much scientific jargon.

The protein fibronectin is a scar protein critically involved in kidney failure. It transpires that the gene is capable of making different forms of the fibronectin protein and it is one particular form that appears to have a strong role in kidney disease.

So, the project we have been working on is directing the gene away from making the dangerous form of fibronectin and thanks to Felicia’s hard work and collaboration with an American company that specialise in regulating gene expression we are now making some real and exciting progress.

In the words of one of the Dutch delegates at our ERCSG we think we’re “getting close to a therapy”. Of course this is likely to be a long road, we’re going to have iron out some kinks and make some more tests but the comment came from someone outside our group who was giving an objective honest opinion and I believe that matters. Like I said, one of the good things about these meetings is getting feedback from other people.

None of this work would have been possible without the support of the South West Thames Kidney Fund, who have supported this project throughout and currently support Felicia’s salary.

So thank you and I’d ask you to continue to support us. One way of doing this is our very own lottery, why don’t you have a look at the feature on the back page of this copy of Renality.

Remember:

Funding = Research
Research = Cure
SWTKF NEWS

FUNDRAISING... WITH PASSION

The McSweeney family have been fundraising with passion (again!) in support of Kirsty and Keri McSweeney who have two of the 5 Golden Charity Bonds assigned to the South West Thames Kidney Fund for the Virgin London Marathon.

In addition to the gruelling training necessary for the marathon the girls have been creating a variety of fun fundraising events, with the emphasis on 'fun'.

Keri's Quiz Night in February (below) for over 70 people was a resounding success and Kirsty held an amazing cake sale on World Kidney Day at her company Rackspace which raised vital funds for the South West Thames Kidney Fund.

The McSweeney family organised and hosted a dance night on 31 March for over 80 people with dad Derek's band WHY? (top picture) performing free of charge: Derek plays lead guitar!

The target of £2,500 has been reached - the current total is £4,772.30 (with Gift Aid = £5,718.62). This total is before cheques totalling £180 have been banked!

The McSweeneys thank their local community, friends and family for their help, support and for just being there for Derek when he contracted GoodPasture syndrome in 2009: thankfully he is currently Mr 27%!

What will they do next? Tuesday, 19 June at 8pm - Palace of Varieties show in Fleet! All proceeds from tickets sold go to SWTKF. Please come and enjoy an evening of light, fun filled entertainment. Tickets £10 per person from Chris McSweeney on 01252 536276.

MEMORIAL DONATIONS

The Kidney Fund has received donations in memory of:

Kamlaben Patel
R Vidal-Carrera
William Eric Cowl
Philip Tovey
Maria Thorp
Frank McGuire
Alan Harry Kemp
Mervyn Bending
Dorothea Dean
Lawrence Charles Turner
Eileen McCormack
Margaret Brown

DONATIONS: Our thanks to...

The Freemason's Relief Chest Scheme for their donation of £100
Ken & Glenise Bonner for their annual donation of funds raised from their Car Shows and Small Charity Sales
Anita Batish for the £100 raised from her office Cake Sale
Fay Eves for her fundraiser at the Dental Surgery where she works
The £100 donation from Peter Osborne & St John's Church, Tenby
Chris Palin for his fundraiser at the Camphill Social Club
Maggie Lowton for her 'donations to the Kidney Fund instead of gifts' party
Anne Smith for her fundraiser which resulted in a donation of £162.50
The generous donations from:
Roger and Mary Pashley
Mrs Joyce Duguid
Peter Runacres

And our thanks also go to everyone who has donated or helped the Kidney Fund in any way!

Waitrose Community Matters: In just the past three months we have received the following: Worcester Park (£450), Twickenham (£291), Cheam (£150), Caterham (£250)

Do stop by your local Waitrose and ask for a form to nominate the South West Thames Kidney Fund as one of their monthly charities! If you need any help completing the form contact Anne.Collar©@kidneyfund.org.uk or call 0208 296 3698. If you see our charity name on our of the boxes at the exit, be sure to drop your green token in there!
Dear Kidney Funder,

We human beings are “inherently lazy” (I speak for myself) and "what they need is a stick or a carrot". (Or in my case both at once.)

That is why magazine editors groan at the slothfulness of their contributors. (Steve certainly does) But I think I have found a new way.

I was finding my fifth excuse for action this week when I received a text message from an old patient to say that he had just become the oldest renal patient ever to be accepted onto the combined kidney/pancreas transplant list to treat his renal failure, and cure his diabetes in one fell swoop. He went on to say this may gain him entry to the Guinness Book of records.

What an INSPIRATION, and of course inspirational stories are rife in the renal community. Others come flooding back to me. Our first Renal Millionaire. Dream on.........There is the lady who was on home haemodialysis in the 1970’s. Dialysis then was often eight hours three times a week, not the three or four hours as now. She demanded that the doctors keep her alive to see her young daughters grow up.

Now after a transplant and another ten years on dialysis and nearly forty years later she is demanding that her doctors keep her alive to see her grandchildren grow up.

How inspirational is that.

What about the senior gent who was rushed in in renal failure shortly after losing his beloved wife. No one could console Ron. After Dialysis was established his son bought him a flight on Concord. A trip around the bay of Biscay, ten miles up and at Mach II with a champagne lunch.

The crew heard of his dialysis, and he had his picture taken on the flight deck, changing his PD bag whilst chatting to the Captain. Fortunately he didn't hang the bag on a vital control switch in the cockpit.

At his next clinic visit he was a local hero, and remembering that he had seen service in the Royal Navy, as a young man, we wrote to the Admiral i/c Portsmouth dock yard, and within weeks Ron was picked up from his home in Sutton and chauffeur driven down to the docks where he was piped onto a nuclear submarine.

As you guessed he was pictured changing his PD bag next to the nuclear power plant, whilst submerged under the Solent. Ron's pictures were published in national magazines for dialysis patients. He became a legend lecturing to fellow subsequent patients, a true inspiration to all.

All renal patients and their families have amazing stories of endurance in the face of the hardships that life threatening illness can bring, and it is this inspiration that drives us on to improve the lot of people with chronic Kidney Disease. It is certainly the reason that we keep coming back to you to ask for support for Dr Mark Dockrell and his team of kidney scientists who are achieving so much in the South West Thames Institute for Renal Research.

It might be good to publish stories of courage in the face of renal failure. It might help to make more funds available. It would certainly be an inspiration for new patients in the future. Please think of letting me know of your own story.

Elsewhere in Renality you will hear of the increasing success of the weekly lottery. Half of the income from tickets is paid out in prizes. If we could continue to expand the subscriptions to this initiative we might be able to fund our first Renal Millionaire. Dream on...

Very best wishes to all supporters of Kidney Research

Michael Bending
If you are interested in a pleasant and relaxing one or two day visit to the Peak District on the weekend of June 29, with a lovely 4K or 10K walk or run experiencing the beauty of the stunning Monsal trail on Saturday 30th June read on!

The 2012 Challenge is being organised by the FSI who support small charities - places are free - and there is no minimum sponsorship to be raised. The 30th June event will be located at Thornbridge Hall, Ashford in the Water, Derbyshire DE45 1NZ. The closing date for entries is the 22nd June 2012.

The South West Thames Kidney Fund is registered as a participating charity, and we would hope to get as many runners/walkers as we can and make this a successful annual fundraiser.

Camping is available for charity runners and supporters!
Toilets, showers and even warm water are provided, so you can camp in comfort. If you're travelling from far away, or simply fancy a camping experience, then you are welcome to arrive on the grounds on Friday evening.

Anybody arriving at the CHALLENGE on the Saturday who would like to stay on the Saturday night is also welcome. Although Thornbridge Hall security staff will be around the grounds you will be left to your own devices. You will have to cater for yourself in the Friday evening and for breakfast on the Saturday and Sunday - or you could pop into the nearby picturesque town of Bakewell for a bite to eat. On the Saturday evening the FSI will prepare a barbecue featuring famous wild boar burgers, delicious sausages and great salads (vegetarian option available). This is not just any old barbecue so there will be a nominal cost of £4.50 per head (paid on the day). Ensure that you notify the FSI on the camping form if you want some barbecue on Saturday evening.

Thornbridge Hall Garden Party  For anyone who wants to stay until Sunday July 1, there will be a garden party at the Hall.

Please call Anne on 020 8296 3698 or email anne.collard@kidneyfund.org.uk for an application form for the 4k or 10k and a camping registration form if interested. Anne can also provide you with sponsor forms or information on online fundraising.

A special Thank You from the SWTKF to JOHN AND JACKIE TREHARNE who run the Wednesday Variety Market at St Francis of Assisi Church Hall, West Wickham for sending us a donation of £1,400. This is from profits made over the year. Also to RON AND LORNA HIXON for the cheque for £100 donated from money raised from the sale of plants and flowers outside the hall every Wednesday. Congratulations. This is much appreciated.

Drop by Allan & Sally Beer's stall at the 2012 Ashtead Village Day on Saturday June 9th. All funds they raise will go to the South West Thames Kidney Fund.

Watch out for the 2012 Great Big Small Charity Car Draw starting June 2012! Organised by the Foundation for Social Improvement (FSI), it is an excellent fundraising opportunities for smaller charities. The FSI holds the gambling license and buys the car. The charities participating in the car draw pay a very small percentage of the funds raised to cover FSI admin cost (last year out of every £2 ticket sold the Kidney Fund received £1.90!)

To maximise sales potential this year, the ticket sales will start in June 2012 and continue through the Christmas period until early January 2013. Tickets will be available online and in paper form. We will be adding a link to the Kidney Fund site www.kidneyfund.org.uk as soon as we know the online address to visit to buy tickets.

Can you help sell tickets?
- Will you be involved in any activities (fetes, fairs, private parties, functions etc.) from June until early January where car draw tickets could be sold?
- Will you be able to give some time to sell tickets in the hospital cafeteria during the lunchtime period when it is busy? (we will reimburse your parking expenses)

When we have the address to buy tickets online (check www.kidneyfund.org.uk in June) will you forward the address to everyone you know and encourage them to buy tickets.

Have you any ideas for how we could go about selling tickets?

please contact Anne 020 8296 3698 or email anne.collard@kidneyfund.org.uk.
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 cabaret, 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 club's 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)

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To contact us:

Nita and Ravi Patel
3 Darcy Road, London, SW16 4TX
Tel: 020 8407 2525 Email: nita@ntapatel.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.
A GUIDE TO HOLIDAY DIALYSIS

We all look forward to holidays, a chance to relax, sit by the beach or explore new locations. So why is this different for people receiving dialysis?

Well, it needn’t be, as many dialysis patients travel near and far and remain well and healthy, receiving dialyses where they decide to have a vacation.

The Trust wishes to support as many people as possible to experience the freedom of going on holiday and for this reason, we employ a dedicated Holiday Dialysis Coordinator, based here at St Helier to help you arrange a well earned break.

So what do you need to do to Get-Away?

Well, the first thing to note is that Lindsey Blazey, our holiday coordinator is not a Travel Agent! She is here to help you sort out your arrangements in relation to dialysis.

You will firstly need to speak with your consultant to ensure you are fit to travel and where necessary you will need a letter from the unit to assist with applying for travel insurance.

Lindsey will also guide you through all of the other steps in relation to gathering necessary paperwork, required tests and identifying local dialysis units, close to where you wish to holiday. There is a lot of work required and as Lindsey will be trying to support many, many patients, we do require a minimum of SIX weeks notice.

For deliveries of PD fluids, Baxter can deliver almost anywhere in the world but this can take up to 16 weeks, so plan early and avoid any disappointments.

What about paying for your holiday?

Well, wouldn’t it be good if the NHS paid for you to sit for two weeks on a Caribbean beach sipping a nice cool drink? Unfortunately, I’m afraid that cost is all yours, so perhaps it will be 5 days in Brighton after all!

What the NHS will do is pay for your dialysis whilst you are away – subject to which country you are travelling to.

You will need to be a UK citizen traveling to a state-run haemodialysis unit within the European Economic Area, Switzerland or Australia. Where there is a reciprocal agreement to pay for emergency health treatment which covers dialysis.

To receive this you must hold a valid European Health Insurance Card, which can be sought through main post offices or from the website at www.dh.gov.uk/travellers.

If you choose to travel to somewhere which does not accept the European Health Insurance Card or is outside the European Economic Area, you will be liable to pay the full cost of dialysis yourself. Please also note that not all EEA dialysis centers accept the EHIC as payment. This is also likely to apply to all cruises.

We also strongly recommend that you have holiday medical insurance; even for those who carry a European Health Insurance Card as this will not provide cover should you need to fly home.

The National Kidney Federation can advise kidney patients about companies that specialize in insurance cover for haemodialysis patients.

There is no issue with holidays in the UK but as these are popular, you should make sure you book early. You can also book as many weeks away as you like each year but once again, this requires a lot of planning so we will need plenty of notice if you are not to be disappointed.

Don’t forget that the KPA owns a caravan in Bognor which can be booked at very reasonable rates. Contact the KPA for more details. (See advertisement opposite)

What if you are on the Transplant Register?

No problem. If travelling in the UK, make sure we have your holiday contact details.

If going further afield, you will be removed from the active register until you return and able to be reactivated. Make sure you let the Transplant nurses know when you are back from your vacation – no need to bring them a stick of rock!

We want to help as much or as little as you need. If you prefer to make most of the arrangements yourself, this is encouraged. Contact the unit first to let us know your plans but if you then wish to go ahead and contact the holiday dialysis units directly this is ok.

The following websites are a good source of detailed information on dialysis abroad and explain where you can expect to be liable for the cost of dialysis.


THE SOUTH WEST THAMES KIDNEY FUND WEEKLY LOTTERY

Have you wondered why YOU should join the Kidney Fund Lottery?

Here are SIX GOOD REASONS why:

You may win!

It’s easy to do and it costs just £1 per entry per week.

50p of your £1 and everyone else’s £1 will go to the winner (which could be you!)

50p of all the £1’s will go towards kidney research

The more members, the larger the prize

The more members, the more funding for kidney research which will eventually result in prevention or a cure

and then ... WE’LL ALL BE WINNERS!

To join the Lottery please complete the form below and return it to the address on the form. Once received, we will contact you to let you know your unique number or numbers.

Return to: Lottery Office, SWTKF, Renal Unit, St Helier Hospital, Wrythe Lane, Carshalton, Surrey SM5 1AA

Title: ___________  Initials: ________________  Surname: ________________________________
Address: ___________________________________________________________________________
Postcode: __________ Home Phone: ______________________  Mobile: __________________________
Email: ____________________________________________________________

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.

Please note that to save on postage we prefer to communicate either by email or telephone. If you require a letter, please tick here ___South West Thames Kidney Fund. Registered charity no. 800952