

RENALITY

The NEWSLETTER of...

February 2013

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



NOW YOU SEE IT...

GEORGE MOORE writes: I was asked by a colleague at work to take part in Movember Month to raise money for charity and because of my wife Karen's condition I decided to raise money for the South West Thames Kidney Fund. Fortunately my colleagues at work who know about Karen's illness contributed most of my sponsorship. I was pleasantly surprised to discover how much was raised. George's sponsorship including Gift Aid came to a massive **£1002.50!**

AND NOW YOU DON'T...



**WIN IN 2013
WITH THE
SWTKF
LOTTERY**

Our lottery membership is increasing slowly but surely. The weekly prize is now over £100.

If you join the prize will increase, so it's well worth you taking your chance to join the winners!

The lottery has already paid out £10,486.00 in prizes to the members with the same amount benefiting Kidney Research.

If you haven't joined already it's really easy to do so and we look forward to welcoming you!

For an entry form either go to www.kidneyfund.org.uk/lottery or email lottery@kidneyfund.org.uk or phone Anne on 0208 296 3698.

It's just £1.00 per week to join. From the funds generated each week, kidney research wins 50% and one of our lucky members wins the other 50%.

To see who has won recently, turn to Page 13.

PAUL'S PARTY THANK YOU ON HIS BIG FIVE-0



KIDNEY Patients' Association honorary vice chairman Paul Connolly marked his 50th birthday with a very special thank you to staff at St Helier Hospital and the West Byfleet dialysis unit.

Paul has been facing his kidney problems with fortitude since first being diagnosed almost 20 years ago, despite the setbacks of two transplants which enjoyed limited success.

Now he says he is "50 and moving on" and counting his blessings one by one, although he still requires regular dialysis. Read the moving story of this First Gulf War veteran on Page 9.

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SWTIRR & SWTKF,

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020 8296 3698

SOUTH WEST THAMES

KIDNEY FUND,

Pat Godden, Secretary:

020 8777 7371

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, or by cheque to SWTKF, Renal Unit, St Helier Hospital, Wrythe Lane, Carshalton SM5 1AA

Create a **standing order**

Donate via **payroll giving**

Leave us a **legacy**

Enter our **car draw**

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**

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.

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.

We would like to thank Riverprint Ltd, Farnham for their help in producing this Newsletter.
9 Riverside Park, Farnham, Surrey GU9 7UG Tel: 01252 722771 Email: www.Riverprint.co.uk.

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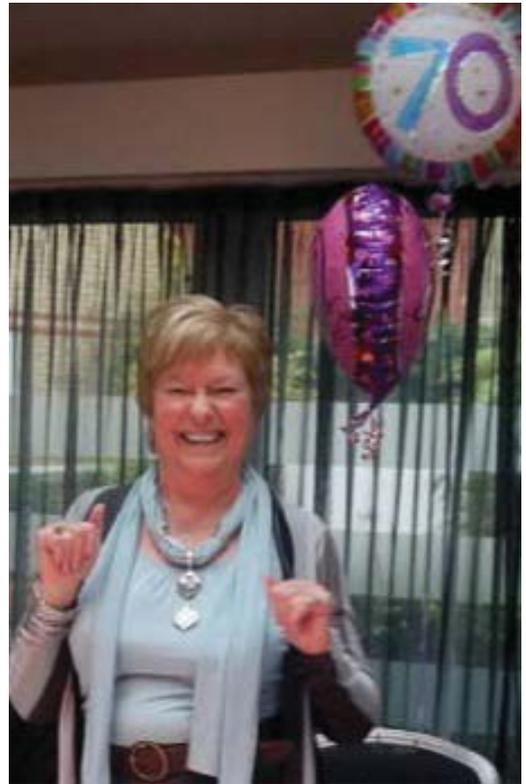
Celebrations for Anne and “Kenny the Kidney”

In November Anne Smith celebrated her 70th birthday, a day she had never expected to reach due to her Polycystic Kidney Disease.

But now, thanks to her kidney transplant three years before she felt so wonderful that, in her words, “the clock had been turned back 12 years”. So she decided to use her birthday to celebrate and thank “Kenny the Kidney”, along with 25 of her closest friends and family who had seen Anne through all the difficult years of poor health.

A delicious lunch was enjoyed in a hotel in Guildford and, as Anne had said she really didn’t want any presents, a collection was organised in aid of the South West Thames Kidney Fund instead.

At the end of the afternoon £266.25 (including gift aid) had been raised, as well as a monthly Standing Order for £50.



AND A BIRTHDAY BONUS FOR THE SWTKF FROM ELLA, 80

Mrs Ella Griffiths decided that the Kidney Fund should benefit from the gifts celebrating her 80th year. The birthday donations totalled an amazing £550 for kidney research!!

A belated Happy Birthday and Many Thanks Ella!

ALL THE FUN OF THE XMAS FAYRE

UK Border Agency staff brought the festive spirit to their Croydon Headquarters with a Christmas Fayre to raise money for the [South West Thames Kidney Fund](#).

During the previous weeks offices became would-be warehouses as people brought in unwanted items for sale and donated prizes.

On the day staff from throughout the building came to have a flutter on the tombola, lucky ducks and Play Your Cards Right games as well as to browse through the books, DVDs and bric-a-brac on sale, all donated by staff and their friends and family as well as Kidney Fund Christmas cards.

The biggest draw of all though was the cake stall which had a fantastic display of mouth-watering goodies for sale including festive treats such as mini Christmas cakes, sparkly Christmas Tree biscuits and Rudolph cup cakes.

The fayre raised £365 in all.



MANY REASONS

Peter Andrews, Clinical Director

I write on the first full day back to work after what seems to have been a very long and busy Christmas period. Long gone are the days when we were able to close one of our wards for a week. For most of the ward and dialysis staff, the needs of the service continue throughout the holiday period, with only Christmas and New Year's Day exempt. So I start by thanking them for all they have done while others (myself included) watched films and ate mince pies.

As we start a new year, it is an appropriate moment to look back at the highlights of the last 12 months.

We can be justly proud of much of what we have achieved. At Trust level, Epsom & St Helier was in the top 10% of NHS Trusts for SMR (standardised mortality rate). In simple terms, this means that your chance of not dying in our hospitals was among the best in the country. We passed a recent unannounced inspection by the Care Quality Commission with flying colours. And, perhaps most impressively, the Trust was the best in the country for 'excess bed days', meaning that we squeezed the maximum out of our assets and ran a very efficient ship. All these contributed to a marked and continuing reduction in the Trust annual deficit, and gives significant room for manoeuvre in the ongoing discussions regarding the Trust's long-term future.



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DIALYSIS CENTERS

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ATHENS - FALIRO | ATHENS - PALLINI | CRETE - HERAKLION | SERRES | KALAMATA | HALKIDA

TO BE PROUD...

Within the Renal Unit, we treated 4% more dialysis patients in 2012 with no increase in staff.

We continued to make a substantial contribution to the financial position and the senior management of the Trust. We achieved nearly £1 million in efficiencies and are on target for a further £0.5 million savings in 2013.

We are proud of the quality of care we deliver, and all available measures suggest that the above efficiencies have occurred without any reduction in the quality of the service delivered.

Indeed, a number of new initiatives have borne fruit this year. We have doubled the number of patients receiving home haemodialysis; reorganised the Consultant rotas to improve the availability of ward cover; introduced and expanded the local anaesthetic insertion of peritoneal dialysis catheters; contributed to the development of an Acute Kidney Injury network in Surrey; and expanded day care provision.

Other initiatives have included the appointment of another Consultant (our 13th) to improve services in West Surrey, continuing expansion of the transplantation programme, an increased emphasis on training and appraisal, and a strengthening of our relationship with colleagues at St George's Hospital.

We remain active in research. We have contributed to a number of clinical trials and national Clinical Guidelines, presented at numerous national and international meetings, and the work of the SWTIRR continues to attract attention.

Perhaps the most impressive observation is that we have achieved all of the above while keeping the wheels on the track in a highly unstable clinical, managerial and financial environment. I am deeply indebted to all my nursing, medical, paramedical, administrative and managerial colleagues for all that they do for you. It is a source of deep satisfaction that I go home at the end of a busy week knowing that I could not be more proud of my colleagues and the patient-centred culture that they have created.

St Helier is currently the 5th largest Renal Unit in the country – not bad for a DGH hospital with (frankly) a poor infrastructure. We have achieved this by never shutting our doors, and we will continue this policy.

One consequence is that our facilities are always in need of expansion. Our priority for 2013 is to try to improve some of the obvious problems with our outdated estate, if only to fix the leaking roofs and the sagging floors. We will also be investing in new beds (which we have to fund) and dialysis equipment, and are hoping to convert Beacon ward into a single bed isolation unit. This latter project depends, however, upon the building being structurally sound, which is by no means certain!

In the long term, we need another building. This may be as part of a redevelopment of St Helier, or at St George's, or in Surrey, or a combination of the three. The one certainty is that we cannot continue as we are, crippled by planning blight. 2013 may be the year in which we finally see agreement re the long term structure of renal services in SW London and Surrey. I certainly hope so, and will update you on progress as and when it occurs.

In the meantime, I wish you all a happy and healthy 2013.

P.S. My final Christmas present this year was the best: a book. "How boring", I hear you cry. Except that this one was entitled 'How to choose your Puppy'. Proof indeed that patience and perseverance can have its reward. Or, that if you nag for long enough, you sometimes get your way! More anon.



Peter Andrews



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 21st June 2013

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:

Paul Connolly

Hon. Vice Chairman

St Helier and Surrey KPA

5 Acorn Grove

Woking

Surrey GU22 9PB

Telephone: 07837 344 732

Email: connollypaul@hotmail.co.uk

**Cheques should be made payable
to St Helier and Surrey Kidney**

Patients Association

whose members thank you

for your support.



A message from your Chairman

I trust that you had an enjoyable Christmas and are looking forward to 2013.

Following re-election at the AGM in November, I have now started my seventh year as Chairman and the Committee and I will continue to work hard to benefit our members. A full list of your Committee members will be published in the next edition.

The KPA AGM was held on 21st November and was attended by 12 Committee Members and KPA members; it was disappointing to see only 2 KPA members attend! With the exception of Jim Rae, who stood down from the Committee, all of the Officers and Committee Members were re-elected. Also, 2 new Committee Members were elected and hopefully we have another patient interested in coming on Committee.

The St Helier and Surrey KPA Christmas Patient Lunch took place on December 8 and was attended by around 40 patients, carers and staff who all enjoyed a superb spread prepared by Pat Harris, the Committee's Secretary, ably assisted by Di Spensley and the other Committee Members. I would like to thank everyone for their help on the day.

It was a real shame to see so few patients attend but that's due to the fact that the renal unit is so successful and now has 8 Satellites and each has its own get together sponsored by the KPA. We also sponsor the St Helier patient get together. It was very different when the majority of patients dialysed at St Helier but I'd much rather patients get their treatment closer to home.

The Grand Christmas Draw took place during the lunch and details of prize winners are published separately.

The draw showed a surplus of circa £2,500 and my sincere thanks go to everyone who purchased tickets despite the uncertain economic climate and to Jim and Shirley Rae for organising the Draw, sorting counterfoils and banking the money, a job I know they both love doing !!!!!. I'll be looking for a volunteer to take on the task this year.

Golf Day

Following the success of our previous golf days we are holding another event playing the lovely Milford Golf

Course in Surrey. The event will be held on Friday 21st June 2013. 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.



Other Matters

The KPA Committee is still looking for new members and patient representatives for Kingston, Epsom and Sutton.

The present Committee has served for a number of years doing an excellent job but it would be lovely to have Committee members for every Satellite 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 generally on the first Wednesday of the month. It isn't essential that a Committee member attends every meeting as a report can be sent by email, letter or even a phone call.

We are also looking for volunteers to help on the servery counter at St Helier, if you are able to spare a morning or afternoon you would be helping the patients enormously, obviously without volunteers we can't open.

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

May I, on behalf of the Committee, wish you a happy and healthy 2013.

Best Wishes, **Dave Spensley, Hon Chairman**

KPA Memorial Donations

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

R Harris & J Panayiotidiin in memory of their Dad

Kathleen Mary Abbott

Luke Peter Paul Finn

Richard Blunden

Frank John Shelley

Anthony Dalman

Cedric Henderson

SHSKPA NEWS



MY FIRST TRANSPLANT GAMES – by Martin O’Halloran

Well, where do I start? I was lucky enough to have a transplant in July 2011. That’s when I heard about the Games. I was always into sport having played professional football at a young age, and was still involved in football when I became ill.

I was so excited leading up to the Games and could not wait, as I was feeling so strong and fit after my transplant - I was not disappointed when I got to the Games. The atmosphere was fantastic; meeting some amazing people who had had multiple organs transplanted and they also were excited, even though they had already experienced the Games before!

My team made me very welcome and I even led the team at the opening ceremony which made me very proud and happy to be there competing. I did not win any medals this time, but can’t wait for next year.

I would dearly recommend any patient of any age to take part – you will never stop once you start – promise you that!!!!

16 YEARS AND COUNTING – by Angie Morrow

As a very proud mum and a supporter of the Team for the past 16 years I thought it time I put pen to paper and say what a fantastic 5 days we spend at the Games each year. We have the opportunity to visit different universities and cities, but the most wonderful part is meeting the dear friends we have made over the years.

We see children from 2 years to adults over 80 taking part and having fun; we come home exhausted, but always feel privileged to have seen such brave people taking part.

Why not come along and support YOUR team, they so deserve it; or why not join the team if you have been fortunate enough to receive a transplant?

On the calendar for 2013 are [Apr 6th-7th Racquets event to be held in Oxford](#) and **The British Games will be held in Sheffield, 15th–18th August -- a great opportunity for athletes and non-athletes alike to experience the warmth and friendship of all who attend the Games.**

On behalf of the team, a huge **THANK YOU** to SHAK for their financial support and to the SHAK committee and our supporters for their encouragement, we really do appreciate it.

If you are interested in taking part and wish to be on the mailing list, please contact Graham Morrow on 01252 325230 or make contact via a SHSKPA (SHAK) committee member.

ST HELIER & SURREY KPA CHRISTMAS DRAW

Following the Grand Christmas Draw at the Patient Lunch on 8th December 2012, we are pleased to announce the winners were as follows:

| | Winner | Total Prize Won |
|--------------|----------------|-----------------|
| First Place | Mr. J Hollis | £500.00 |
| Second Place | Mrs. M Kemp | £200.00 |
| Third Place | Pauline Searle | £100.00 |
| Fourth Place | Mr. J Carter | £50.00 |
| Fifth Place | Karen Canavan | £50.00 |

We would like to congratulate all winners and thank all of you who, despite the current economic climate, purchased the draw tickets.

FIFTY AND MOVING ON

Diagnosed with renal disease at 31 years of age, with the prospect of dialysis in the not too distant future and having not long been back from the first Gulf War, life could not get any better!!

Then as the illness takes hold my partner at the time decides to leave me with a heavy mortgage.

As the body got weaker the outlook became darker and darker. As Bob Dylan once wrote “When you think you’ve lost everything you find out that you can lose a little more.”

How do you pick yourself up after all this, as the old hymn goes, count your blessings and name them one by one.

One of the first blessings was being under doctors that know their stuff and you feel they endeavour to give you their best. Another blessing is being in a system where I have choices on the type of care and not just the cheapest, and I can go on.

At the age of 37 I began haemodialysis at St Helier and after a few sessions I was in a state of euphoria, as I felt the best I had felt for a number of years on non-dialysis days. But this wore off as the permanence of dialysis took hold of my life.

After two transplants that gave me short times away from the machine, this is the time to take stock and concentrate on every blessing. Life is different now but there is still life. I have learnt to accept help from others and not feel bad.

We just had a fantastic party to celebrate my 50 years of a



great life despite renal failure and it gave me space to thank some of the great nursing staff at St Helier and West Byfleet (above) with some flowers.

With these times of austerity and cutting back we are still getting a good service from our NHS at St Helier.

As I close I would say to all patients, if you feel something is not right let the lead nurse know or your Doctor, I have done this a few times in the past and things are resolved straight away. I feel as well, where credit is due please give credit, not just to nursing staff but our carers at home and families. THANKS is a little word but does mean a lot.

PAUL CONNOLLY

Hon Vice chairman SHSKPA

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

S Shafiq

Mrs S Hilderley

Mr Paintall

Mr Keith Hubbard

Andrew Poynter

Dani Christmas

The Charities Trust

Jackie Moss

M Beckles

Queen Katherine School (Year 9)

Roger Mann

KPA Legacies

St Helier and Surrey KPA is very grateful to have received the following legacy:

Muriel Rose Badrick

The South West Thames Kidney Fund



our 2013 London Marathon Runners

Our eight team members will train for months through all weathers while raising sponsorship for Kidney Research.

They really deserve our support

Please help them reach this year's target of

£25,000

Our team:

Clockwise from top: Stuart McSweeney, Jan Schuster, Simon Williams, Peter Ttoui, Nicky Slater, Craig Fletcher, Charles Harvey and Sophie Blaker.



**PLEASE SUPPORT
YOUR TEAM**

sponsor online
by visiting

www.justgiving.com/kidneyfund2013



take a sponsor form and
ask your friend, family and colleagues
to support our team

Registered charity No. 800952

The 2013 London Marathon takes place on April 21st

OUR MARATHON MEN & WOMEN

Stuart McSweeney

One of my sisters and my wife, Kirsty and Keri McSweeney, ran the London Marathon this year for the South West Thames Kidney Fund. We travelled to London on the day to cheer them on and it was such an incredible atmosphere that I felt inspired to apply for a Marathon place.

Seeing the support for the runners, the general feel-good feeling and taking in the atmosphere was brilliant with the Olympics only a few months away. I have really enjoyed taking part in events for the South West Thames Kidney Fund such as organ recitals and doing the Bristol 10k twice and I look forward to taking part in some more events such as a mini series of organ recitals all on one day in local churches! The work the South West Thames Kidney Fund provided for my dad, Derek McSweeney, has been incredible and I feel it is only right to be able to help support the Kidney Fund to be able to provide such care and support.



Nicky Slater – In Loving Memory of Chas Howe

I first ran the London Marathon in 2010 when I wanted to do something to make a difference for my 40th Birthday - I raised £3,000 for the British Heart Foundation in the process. I chose to support the BHF as my father had suffered with high blood pressure and heart problems since 1987.

I am choosing to run again in 2013 as I sadly lost my Dad in June 2012. As a result of his heart and blood pressure problems, he developed chronic kidney disease and suffered with diminishing kidney function for many years. Watching carefully what he ate and taking a mountain of pills each day he made regular visits to Guy's Hospital to try to keep the problem at bay. As with many kidney disease patients, in the end it was the build up of fluid that resulted in the loss of use of his legs and ultimately causing his heart to fail. Always one for the "little guys", when he died we chose to have donations to SW Thames Kidney Fund, a smaller, lesser known charity than one of the big players. He would have been pleased that the £700 we raised would make a big difference to the charity that received it.



I promised at the funeral that I would run a marathon in 2013 in memory of him and that's exactly what I intend to do. I'm pleased it will be London, it really is the best marathon in the world and so close to home too as I'm gonna need all the support you can get!

This one's for you Dad, we all miss you terribly.

Sarah Blaker

Although I enjoy running, I only started in my forties and am not a natural athlete. To me, the idea of running a marathon compares to that of climbing Everest. The London Marathon is the best-known marathon in the world, and if I am going to try and undertake the challenge once in my life, I would like it to be this one.

I want to run for the South West Thames Kidney fund as it is a charity that is very close to my heart. From a young age I watched my stepfather suffer from polycystic kidney disease. He eventually ended up on dialysis before dying far too young in his early sixties. My two younger brothers have also been diagnosed with polycystic kidneys, which may in time lead to kidney failure. I want them to have a more hopeful future than my step-dad, and consequently want to raise money for a charity that is aimed at improving and extending the lives of people suffering from kidney disease.

Charles Harvey

I have always wanted to run a marathon. Well, I have always told my family, friends and colleagues it would be a great thing to do knowing full well that I wouldn't enter. So why do I find myself in the position where I have a place and there is a realisation that I have to run over 3 times as far as I have ever run before. Quite simply I had a realisation that time doesn't stop, slow down or wait for you, its time to get on and do all those things on the many lists I have written.

The personal challenge coupled with raising money for charity is a fantastic incentive to push myself outside my comfort zone and achieve something worthwhile.

Jan Schuster

I was born and brought up in London. Right from a young child I always wanted to be a nurse and achieved my ambition when I qualified as a RGN almost 30 years ago. Following this I trained and worked as a midwife 8-9 years and since 1994 I have specialised in Occupational Health. Being a twin makes you more competitive and, at the age of 49, I ran my first marathon in 2011. This year I have chosen to run for SW Thames Kidney Fund following a good school friend I have known since I was seven, very courageously donating a kidney to her husband. They have both since made a good recovery. I would like others to benefit from the research into the prevention and cure of kidney disease.

MORE OF OUR MARATHON RUNNERS ON P12

LAST CALL to reserve your place at the South West Thames Kidney Fund's Gala Celebration of 2013!



- Location:** Wimbledon's lovely All England Lawn Tennis Club
- Date:** 13th April 2013
- Time:** 7:00 to 11:30pm +
- Parking:** No problem – there's room for all
- Purpose:** to have loads of fun, food, wine and dancing while celebrating St George's Day and the 15th Anniversary of the South West Thames Institute for Renal Research
- Cost:** £70 per person
- Result:** More funding enabling a better understanding of how to stop the kidney failing
- When to book:** As soon possible as places are limited.
- How to book:** Turn to the back cover where you will find a reservation form



We hope to see you there!!



OUR MARATHON RUNNERS

Simon Williams

This will be my second time running for the SWT Kidney Fund and my 3rd Marathon. Some years ago my father was diagnosed with kidney cancer eventually leading to surgery and one being removed.

Thankfully the remaining kidney is still going strong but it highlighted the importance of this specialist field of medical practice and personalised the fund raising efforts. I'm very grateful for another opportunity to help raise additional funds (albeit ask me that again at mile 19) and hope I'll be able to get friends and associates to dig that bit deeper to support this important work.

As a side note I have foolishly accepted a wager from another Kidney Fund runner 6 years my junior as to who will beat who. The loser will be making a further contribution to the fund so I guess you could argue its 'win-win' (apart from the 10 years of daily ridicule that would follow coming 2nd!)

Peter Ttoui

My mum had a kidney transplant a while ago and running the London Marathon for the South West Thames Kidney Fund is a way for me to give something back.



Craig Fletcher

When I was younger I ran for my School and an Athletic club. After many years of laziness I began running again at the beginning of this year and realised how much I missed it. To help motivate myself and keep the running up I thought I should set myself a goal, this was when I thought of the London Marathon.

I mentioned this to my wife Emma and she suggested that I should talk to her Dad (Richard Sammons) and see if there was any way I could combine running the marathon and helping to raise money for the SWTKF. We have helped to raise money for the charity in the past not only because of Emma's Dad but because her Mum (Carol Sammons) has been a renal patient for many years.

Having attended various fundraisers and hearing about the research that the charity helps to fund, running the marathon seemed like the perfect way to help raise money for the SWTKF.

BEAT THAT

Chris Fey ran in 'Run to the Beat', London's Music Half Marathon, on 28th October 2012, raising funds for Kidney Research. **Many thanks Chris!** The 13 mile Docklands course passes multiple stages featuring London's best music talent en route with the main stage located at the start and finish point! If you would like to find about next year's Run to the Beat event visit <http://www.runtothebeat.co.uk/> and click on 'Register Your Interest' and they will let you know the date of the 2013 run as soon as it is announced.



Pub Quiz adds To Tiger's feat

Claire Tyne, whose father Brian received a kidney transplant from his elder daughter Kerry in March 2011, has been busy fundraising for the SWT Kidney Fund.

£300 was raised after a very successful Charity Pub Quiz evening at the Waggon & Horses, Surbiton on December 6th 2012.

Many thanks to all those there for their kind generosity.

The New Year brings even more fundraising opportunities, with Claire and colleagues at MAA Architects in training for the Property Triathlon at Dorney Lake, Windsor in May.

Claire is also a keen open water swimmer and will be taking part in various open water events during the summer months. All monies raised by sponsorship of 'Tyne's Tiger Kidney' events will go directly to the South West Thames Kidney Fund.



SWTKF LOTTERY WINNERS

| | | | |
|------------|--------|-----------|---------|
| 12/10/2012 | 101151 | Belmont | £101.00 |
| 19/10/2012 | 101189 | New Haw | £101.00 |
| 26/10/2012 | 101124 | Farnboro' | £100.50 |
| 02/11/2012 | 101078 | Fleet | £100.50 |
| 09/11/2012 | 101004 | Camberley | £101.00 |
| 16/11/2012 | 101025 | Caterham | £101.00 |
| 23/11/2012 | 101185 | Camberley | £100.00 |
| 30/11/2012 | 101041 | Purley | £99.00 |
| 07/12/2012 | 101120 | Farnboro' | £101.50 |
| 14/12/2012 | 101199 | Purley | £102.00 |
| 21/12/2012 | 101047 | Ash | £102.00 |
| 28/12/2012 | 101018 | Guildford | £102.00 |
| 04/01/2013 | 101104 | Camberley | £101.50 |
| 11/01/2013 | 101133 | Belmont | £101.50 |

BUSY TIME FOR BRANCH

The SWTKF Guildford & Frimley Park Branch had a very successful December.

Our Xmas Draw raised £540 and the main prizes were won by Ken Bonner, Camberley, £200; Jennie Repton, Blackwater, £100; and Mrs H Smellie, Chobham, £50.

Our Christmas Fayre in Ash and the Tombola at Farnham Hospital netted £599.40 and Dennis Amy sold out of his marmalade and preserves at the Godalming Fair (right) raising a fantastic £1,317! Thank you to all who supported us that month and throughout the year.



FANCY AN ADVENTURE IN 2013?

You will have read, in previous issues of Renality, about people climbing Kilimanjaro, cycling from London to Paris, Skydiving, running marathons etc. – but have you ever thought about how wonderful it would be to have your own adventure?

You could do a Charity Challenge:

- Trek though the Sumatran Jungle
- Trek to the Geographic North Pole
- Cycle Vietnam from Hanoi to Ho Chi Minh City
- Discover the Great Wall of China by Bike or Trek
- Trek through the Andes
- Trek to Machu Picchu
- Trek Transylvania
- Trek to Everest Base Camp
- Trek to the Home of the Dalai Lama
- Take part in the Rajasthan Tiger Challenge
- Trek in the Indian Himalayas
- Take part in the South Pole Challenge
- Trek the Sahara Desert



And the list above is just a small sample of what you COULD do.

Closer to home, examples of what you can do are: 100km London to Brighton Challenge (walk or run);

50k or 100k Thames Path Challenge (walk or run);

and, of course the London to Brighton Cycle ride or the London to Paris Cycle ride.

There are charity challenges suitable for everyone of all ages, challenges for over 50's and 'Miss Adventures' just for women.

If anything tickles your fancy or if there is something you have always wanted to do but didn't know how to go about doing it, email me anne.collard@kidneyfund.org.uk and/or phone me on 0208 296 3698 and I will do everything I can to help. You can also visit www.charitychallenge.com where you will find all the challenges they offer.

DIBBFEST 2013: Bikes & Bands

Keep the weekend of next March 15th to 17th free to visit 'DIBBFEST 2013', based at the Chichester Hall in Witley, where a team of 6 local men will be cycling non-stop from 19:00 on Friday evening until 19:00 on Sunday evening on a static turbo-training bike.

They will be aiming to cover between 750 and 1,000 miles and will each be spending a total of 8 hours in the saddle during the course of the weekend.

While being entertained with music, stalls, games etc., you will be able to cheer on Mat Dibb and the team (some of whom are pictured practising) as they raise funds for Kidney Research!

For further information and to learn about Mat and his team go to www.dibbfest.com and to sponsor this epic static bike ride, visit www.virginmoneygiving.com/matdibb.

DibbFest tickets are now on sale here: <http://www.wegotickets.com/f/5651>

Or via our website, www.dibbfest.com



KIDNEY FUND CALENDAR PHOTOGRAPHY COMPETITION FOR RENAL PATIENTS!

You've got until the end of May to help us create a Kidney Fund calendar featuring photos each month taken by our Renality readers. Scott Brawn, a photographer who is one of our readers, suggested the idea and has agreed to be one of the judges. He has allowed us to use a couple of his images on our example calendar.



If you have a photo that you have always thought was particularly good and you might like to share, please send it for consideration. For those of you that enjoy snapping away, you have just under a year to take the 'perfect' picture to submit for consideration for the calendar.

Main points of the competition:

1. The categories for entries are:
 - How Dialysis / Transplant Changed my Life
 - It's a Wonderful World / Life
 - Time Out / Holidays
 - Miscellaneous
2. Entrants must only enter photos taken by themselves. All submissions must be in digital format. Prints may be scanned to create a digital format
3. Digital entries should be emailed to Anne.Collard@kidneyfund.org.uk.
The subject or body of the email must state the competition entry category (point 1); your title for the photo and, if appropriate, the location.
4. 12 photos will be selected from the above categories
5. Deadline for photo submission is 31st May 2013
6. Winners will be announced in the July/August 2013 issue of Renality
7. The 2014 calendar will be available for purchase soon after printing – in September/October 2013

Terms and conditions for entry:

Entrants must be patients and/or immediate family of patients of the South West Thames Renal & Transplantation Unit which includes St Helier Hospital Renal Unit and its satellites. The competition is not open to professional photographers. Owners of any photo submitted in the competition grant their permission for the photo to be used in a South West Thames Kidney Fund calendar if selected by the judges.

If you would like to see more of Scott's work, email Anne.Collard@kidneyfund.org.uk for details

South West Thames Kidney Fund donations

In memory of:

Francis Fenech-Soler

Alan Kemp

Patricia Olive Day

Frank 'Frankie Baby' Yoxall

Bernard Samuel Gray

Stephen Paul Brown

John Leslie Twist

Jim Leahy

Leslie Piper

Geoffrey Charles Newman

Mr Keith Gordon Hodson.

And our gratitude goes to:

The members of **St Johns, Tenby** for the £100 collected during their church meetings during 2012.

The Bishopsgate Lodge No. 2396. The fundraising efforts on the part of their Masonic Lodge in London resulted in a £750 donation to our research.

The brethren of **Acorn Lodge 5320** for their donation of £200.

To all those individuals, families and others who have made donations to the Fund. To those who bought and sold the 2012/2013 Car Draw tickets especially **Gaylene Maisey** who sold £200 worth of tickets resulting in estimated income of £600, and to those who supported our Christmas Card sales bringing in a profit of over £600 this year. **Thank you all!**

AN INSPIRING FUND-RAISER

Hi Kidney Research Funders,

Tucked away in a corner of one of last year's editions of Renality was yet another story of inspiring fund raising by a Kidney Fund member.

The full story only came to the full light of day, because his employer is considering him for a Volunteering Award. When you read the story I think you will agree that he deserves to win !!!

John Wills' remarkable contribution (with a little help from his wife) to his rather special community.

Kidney failure is rare. You would never believe this reading the average Sunday paper, but then remarkable stories of man being kept alive by machine or transplanted organ captures the public's imagination with wonder and incredulity.

Kidney failure is often of unknown cause, and often strikes down young people. There is a very high mortality. If the diagnosis is made promptly and if the equipment and know-how is available some patients survive to live another day.

This happened to John Wills at the young age of 16. He was admitted to the Royal London Hospital and for two weeks he was dependent on an artificial Kidney machine (dialysis) for survival.

At the same time he was receiving toxic drugs to suppress the Wegners granuloma which was destroying his kidneys. His survival also depended on plasma-phoresis to clear the antibodies that were attacking his own kidneys.

This treatment was only developed to any extent in the 1970's only just in time to benefit John.

Imagine the stress that John and his family went through at that time. Despite missing so much schooling John secured a job with "The Pru" and has enjoyed employment for nearly 30 years with the same company. How many people can boast that under the age of fifty in this day and age?

The acute renal failure in teenage years



left chronic progressive scarring in his kidneys and John was monitored on a six monthly basis. For many years he faced the likelihood of permanent dialysis at some time in the future unless a scarce kidney transplant could be found.

Enter the new Mrs Wills, who announced on their honeymoon that she was considering being a kidney donor for her new husband. John had obviously chosen a rather special bride.

Despite increasing tiredness and nausea, and muscle cramps and weight loss John continued to struggle to work hiding most of his symptoms from his colleagues. By the time his kidney function had fallen to 10% of normal his doctors on the Kidney Unit blew the whistle and arranged the pre-emptive, live unrelated kidney transplant from his wife, Deborah. Mr and Mrs Wills were both back at



work within two months of the surgery, and it was then that John determined to make a difference to the lives of Kidney patients to come after him.

Research is the only way to improve the treatment outcome for patients in the future and fellow patients from John's kidney unit had collected enough (over £1million) to build a purpose built Research Institute (South West Thames Institute for Renal Research [www.swtirr.org.uk]).

For 15 years the Institute has been focussed on ways of slowing the progression of kidney scarring and already the research is generating more and more interest from other leading Institutions, particularly in the United States.

With a life-long love of cycling John set out to train for the London to Paris sponsored bike ride to be completed in May 2012. What an amazing feat for a kidney transplant recipient.

John completed the 301 miles in 4 days, much to the relief of Deborah and the rest of his family. John's contribution of sponsorship, £ 3,302.50, will make an enormous difference to one of the ongoing research projects. Even more importantly it will be a stimulus to other patients and staff to contribute to victory over their own illness.

RESEARCH is so important for the brighter future of all kidney patients. Obviously only a few can manage this sort of feat of physical endurance..... but if each one reading this edition could run a coffee morning, say, to raise £ 5 -10 the boost would be magnificent. Fundraising efforts do more than priming research with much needed funds. They also lift the profile of kidney failure in local communities and inspire others to join in. If you would like further inspiration for other ideas ask the guru, Anne Collard on: 0208 296 3698.

Michael Bending, Chairman: South West Thames Kidney Fund

HERE COMES THE SCIENCE...

MARK DOCKRELL
Institute Director
Greetings for 2013

I realise it will be February before you receive your copy of Renality and perhaps even late February before you've looked at everything else and finally decide "here comes the science", as Jennifer Aniston used to say when trying to sell you shampoo.

But as I write this memories of Christmas and New Year are still stretching my belt just that little bit too far (and I still have Burns night to look forward to).

For many families Christmas is a stable almost unchanging aspect of our busy lives; we give it a sense of permanence by having many of the same rituals and often the same food each year.

I read something that suggested we've been eating mince pies at Christmas for hundreds of years; in fact a custom from the middle ages says that if you eat a mince pie on every day from Christmas to Twelfth Night you will have happiness for the next 12 months – the amount I ate I should be happy for sometime to come.

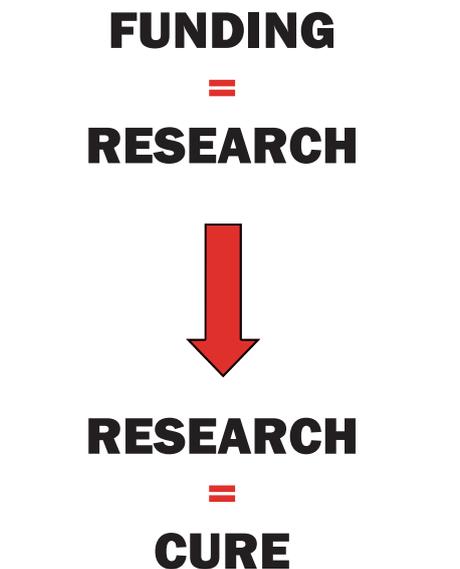
We think that some things are just there and always have been and we don't consider them to be changing.

As you know I have a reputation for making tenuous links but this idea of a stable entity was also quite common in biology.

Before I moved into kidney research I studied vascular biology; what regulates veins and arteries contracting or dilating and the implications for this in high blood pressure and heart attacks.

For decades we used to think of the endothelium, the thin layer of cells between the blood and the blood vessel walls as just a lining, like the lining of a jacket protecting the important material. Then, back in the 1980s a scientist called Robert Furchgott accidentally discovered that the endothelium was an important "organ" in its own right mediating how the blood vessel responded. This massively changed vascular biology and Professor Furchgott got the Nobel Prize.

A similar change happened some time ago in our understanding of the kidney.



As you all know probably better than most, a key component of the kidney is the filtering unit called the glomerulus where blood is filtered.

Some of the contents of the blood pass through the blood vessel endothelium across the basement membrane and between the little cells on the kidney side called the podocytes. (Podocyte is Latin for cell with foot; the podocytes appear to have foot like structures attached to basement membrane.)

We used to think of the basement membrane between the endothelium and the podocytes as basically a tight mesh that the cells sat on. Yet we knew that in some conditions the thickness of this membrane could change and that was associated with different renal diseases.

It turns out that the glomerular basement membrane is not a stable inert mesh but a highly dynamic system that is constantly being renewed and remodeled by the very cells that sit on it; the endothelial cells and the podocytes.

Here, at the institute, we were fascinated by the idea that podocytes were partly responsible for the make up and structure of the membrane they were sitting on; as I said, we know that the thickness of the membrane changes in renal disease including diabetic nephropathy and we also know that the podocyte are markedly



changed in renal diseases including diabetic nephropathy. So, we have been studying how the podocytes might contribute to changes in the membrane and whether we can prevent them.

Much of this work is being carried out by a bright PhD student, Tarun, who got in touch with me in 2010 and asked whether he could come and study here at the Institute.

Tarun didn't expect us to provide the money for him but with my help he wanted to apply for a scholarship that would pay his expenses.

After a lot of hard work and chasing around trying to get the scholarship, get his visa and all the other paperwork Tarun packed his bag, got on a plane to Heathrow to come and perform this very exciting research.

As you might imagine from a young man with such determination his work his going well.

Tarun came to study here because over the years the Kidney Fund has helped build an internationally renowned center for kidney research, the South West Thames Institute for Renal Research.

With your help and support we can continue to build on this success, attract more bright researchers and find new treatments to improve the lives of people suffering from kidney disease and find a cure to stop kidneys failing.

Mark Dockrell

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

PLEASE NOTE: The rates quoted above are current for 2013

WHY MY BLOOD TEST IS NOW SUCH A TRIAL

STEVE PURCELL, who had a kidney transplant at St George's Hospital in 2009, lives in North West Surrey. He writes:

I have just returned from the regular and mundane task of providing a specimen of blood ahead of my two-monthly check-up with the consultant.

But what sets this test apart is the fact that my local GP surgery has now refused to carry out blood tests requested by consultants.

So, what used to involve a five-minute bike ride to the surgery and, maybe, a 5 or 10 minute wait to see the nursing assistant has taken up most of the morning.

Instead, today's test required a 15-mile round trip by car to St Peter's Hospital at Chertsey, a £3 car parking charge and an hour and 25 minutes wait to have the test.

In all, it has taken two and a quarter hours and involved adding to the general merriment of rush-hour traffic. And, of course, I am also taking my tacrolimus more than three hours later than usual.

This improvement in my service from the NHS was both a "safety and a workload issue for primary care" according to my local Medical Practice. When I asked the surgery to reconsider, the Practice Manager wrote to tell me:

"When you see a hospital consultant, our budget is charged for each visit. Within these charges is an element to cover required tests, such as blood tests. This means that if we were to carry



out the test, not only would we be doing the hospital's work, we would still be paying the hospital as if they did it."

No doubt this makes sense to those who have to oversee the impenetrable budget jungle within the NHS.

But in an era of ever-greater centralisation meaning longer and longer journeys for patients unfortunate enough not to live within a stone's throw of the "centre of excellence", it makes no sense at all.

I am fortunate that I am fit – thanks to my kidney transplant in November 2009 – and mobile with my own transport. Many patients are not so lucky. They are the ones I am worried about should this cost-cutting measure start to spread.

LET US KNOW WHAT YOU THINK

We really would like to hear your views on this or any other subject relating to your condition and the treatment you receive. Patient feedback is important. So tell us about your experiences, good or bad. But please keep your correspondence brief. We will publish a selection of your letters but we can not guarantee to publish them all.

If you have access to email, send your comments to steve_purcell@btinternet.com

Otherwise write to Renality c/o Anne Collard, Renal Unit, St Helier Hospital, Wrythe Lane, Carshalton SM5 1AA.

CAN YOU HELP WITH OUR AUCTION?

If you have any contacts that might be able to help us with auction items for our Wimbledon do (booking form on Back Page) could you please contact me. Ideas are sports memorabilia, a short break/week in a holiday cottage/apartment/b&b/hotel, anything travel related, paintings, jewellery - ANYTHING appealing you can think of.

If you have someone/a company you would like to approach and need a 'request' letter, let me know and I will forward one that you can use. Let me know and thanks! Anne.collard@kidneyfund.org.uk





Join us at our **ST GEORGE'S DAY CELEBRATION** at
Wimbledon All England Lawn Tennis Club
 on Saturday, 13th April 2013
 and *Fight the Dragon of Kidney Disease!*

Enjoy a delicious 'English feast' in the Courtside Restaurant,
 plus a variety of Entertainments, an Auction, Raffles & More.

In addition all dinner guests have the chance to experience
 an hour to browse in the Tennis Museum;
 tea in the Terrace Restaurant;
 an Official 1.5 hour Blue Badge Guided Tour of AELTC

| | | |
|---------------------------------------|------------------------|-------------------|
| Reception, Dinner, Entertainment etc: | 7:00pm until 11:30pm + | £70.00 per person |
| Guided Tour and Museum (2.5 hours): | 4:00pm until 07:00pm | £21.50 per person |
| Tea: | 5:00pm until 05:30pm | £ 5.00 per person |
| Guided Tour only (1.5 hours): | 5:30pm until 07:00pm | £13.50 per person |



PLEASE JOIN US FOR A WONDERFUL AND A VERY WORTHWHILE EXPERIENCE!

Yes, I will fight the Dragon of Kidney Disease alongside the South West Thames Kidney Fund!

I wish to reserve _____ place(s) for dinner @ £ 70.00 per person £ _____ (total dinner cost)

I would also like to reserve the following (please note, this tour etc. may only be reserved with a dinner reservation):

_____ place(s) for a museum visit and tour @ £21.50 per person £ _____ (total museum & tour cost)

_____ place(s) for the tour only @ £13.50 per person £ _____ (total tour only cost)

_____ place(s) for tea @ £ 5.00 per person £ _____ (total cost for tea)

Total enclosed (cheque made out to South West Thames Kidney Fund): £ _____ (thank you!)

Guest Information (please put contact person first): If you would like more than 4 places please contact Anne below

(1) Title: _____ First _____ Last: _____

(2) Title: _____ First _____ Last: _____

(3) Title: _____ First _____ Last: _____

(4) Title: _____ First _____ Last: _____

Contact person's address: _____

Post Code: _____ Home phone: _____ Mobile phone: _____

Email: _____

*I am unable to attend this event, but wish to join the South West Thames Kidney Fund in the fight against kidney disease. Please find enclosed my donation of £ _____ on which gift aid may _____ may not _____ be reclaimed. Your name: _____ Address: _____
 Post code: _____ email: _____*

_____ *Please add me to the Kidney Research Supporter Email Group. I understand I can ask to be removed at any time.*

Please return this form and your cheque made out to the 'South West Thames Kidney Fund' (charity no. 800952)
 to: Anne Collard, South West Thames Kidney Fund
 Renal Unit, St Helier Hospital, Wrythe Lane, Carshalton SM5 1AA
Any questions? Please phone Anne on 020 8296 3698 or email: aeltc@kidneyfund.org.uk