

RENALITY

The NEWSLETTER of...

May 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



GAME, SET & MASH...

FRIENDS of the South West Thames Kidney Fund enjoyed a fantastic night at the Wimbledon All England Lawn Tennis Club at the St George's Day dinner. "It was a great night," said spokesman Anne Collard. Full details and pictures from the event will be in the next issue of Renality...

Inside this issue, find out more about adorable Ella (right), the long-awaited addition to the household of Clinical Director Peter Andrews. Read his regular report on **Page 5**.



THE RECORD BREAKERS

YOUNG Emma Phillips shows how it should be done before her dad Nick joined Matt Dibb and 15 other volunteers who cycled round the clock for 24 hours to raise more than £8,500 for the SWTKF.

They covered a record-breaking 1,244 miles on static bikes—further than the distance from John O'Groats to Land's End. **FULL STORY: Pages 10 and 11**

WHEN THE GOING GETS TOUGH...

Stu takes on his hardest test yet

FITNESS instructor Stuart Levett is no stranger to the hardships of physical challenges.

But in June he will push himself to the limits in an incredible five-day solo event to raise funds for the South West Thames Kidney Fund and, also, the Shooting Stars Children's Hospice.

It takes place between Friday, June 7 and Tuesday, June 11. And what's more – the 11th is actually his birthday, too.

He said: "It is going to be without doubt the hardest challenge to date, but is in aid of two great charities/organisations. It would be great if you could support these two great charities/groups (and me!)." You can do that at:

uk.virginmoneygiving.com/team/stuart-levett

The challenge consists of the following epic distances:

DAY 1- 31 mile run, from Teddington to Liphook.

DAY 2- 31 mile run, from Liphook to Portsmouth.



Day 3- Kayak across the Solent to the Isle of Wight, 70 mile bike ride around the circumference of the the island, Kayaking back to Portsmouth.

DAY 4- 31 mile run, from Portsmouth to Liphook.

Day 5- 31 mile run from Liphook to Teddington.

Stuart added: "You can join me and my support crew (Martin, Gino and Celina) for small parts of the running sections (5km, 10km) either to or from Portsmouth to aid my motivation, just email me for details at info@foundryfitness.co.uk

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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. Riverside Park, Farnham, Surrey GU9 7UG Tel: 01252 722771 Email: www.Riverprint.co.uk

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MAD HATTERS HAT IT AGAIN



MARIE MOORE writes: It's that time again, however, this year we celebrated more than St Patrick's Day. As per usual I hosted supper in my home with lots of friends, who donated generously to SWTKF for the privilege. Dress code was 'Green Hats' – the more panto variety the better. So many turned up and those who couldn't sent a donation. That's what goodwill and good news does.

Last year following our supper, I explained that my husband Mike had been Dr Marsh's patient for 8 years and that I hoped to donate a kidney to him in the near future. Well, good news – we've done it!

It's been a roller-coaster 2 ½ years. We were a 'good' match, although not 'perfect' as we are not 'related' only married! We're not even the same blood group, I'm 'O' positive, Mike is completely different. We went through all the tests, ticking off the boxes along the way. I'm terrified of needles so I decided to do something constructive that would take my mind off it all. I chose GCSE Maths, as I hated Maths at school and never felt completely competent at them.

All the staff at St Helier were wonderful - no matter what part of the hospital we were in. As for the transplant team – what can I say? We are humbled by your dedication. We felt safe

and cared for throughout. It's been 6 months since 'our' transplant on Wednesday 19 September at St George's, Tooting. Mike's new kidney started working while he was on the operating table (I've put this down to all the porridge and mashed potato I was fed as a child).

I was home on the Friday and Mike the Sunday. We were a bit slow moving about at first, however, by 3 weeks I was walking 4 miles daily and by 6 weeks Mike had returned to spinning classes (stationary bikes) at our gym, while I stayed with pilates and aqua aerobics. Mike returned to work in December and cycles 75 – 100 km every weekend, not counting his spinning classes during the week.

We are still thanking people for all the support and goodwill we received. Kidney transplantation is so topical at the moment, it's good to spread the word. Everyone we know or knows of us has extended their good wishes and offers of help or prayer. In their way, they have been part of the greater kidney transplant 'team'.

Finally, we skipped the Irish dancing on the patio this year (weather!!) however, that didn't stop us raising £552.50, including gift aid. Due to his new Irish Kidney, Mike is our honorary Leprechaun and I passed GCSE Maths with 92%!!

SWTKF THANKS JOHN & JACKIE TREHARNE

John (a kidney patient at St. Helier) and Jackie Treharne have run the Wednesday Variety Market held at the St. Francis of Assisi Church Hall in West Wickham for the past six years. Over this time they have managed to raise in excess of £6000 for the Kidney Fund.

They have now decided the time is right to give their time and support to a different registered charity. We thank them most sincerely for their time and effort in raising this money for us and wish them continued success with the Market.

Pat Godden,

Hon. Secretary to the Kidney Fund.

No Decision about Me without Me

The renal unit has been one of 24 renal units to have been funded by NHS Kidney Care to take part in the 'Embedding the Renal Patient Decision Aids Project'.

The Patient Decision Aids (PDA) are tools aimed at helping patients make decisions about medical decisions in the context of their own circumstances.

There are 3 renal web based interactive tools together with a mobile phone app. and printed versions for those unable to use the internet.

They have been developed as part of the Shared Decision Making Programme. Shared Decision Making is essentially a conversation between the patient and the healthcare professional. The renal professional presents information and evidence about treatment options and the patient shares what is important to them about their care, their values and their preferences. This two way communication is at the heart of shared decision making, helping 'no decision about me without me' become a reality and not just another government slogan!

The project has been led by one of the Pre Dialysis consultants Dr Bhrigu Sood. Although the project is due to be completed at the end of March 2013, work will carry on to promote the PDAs and work with the Renal Registry in inspiring change, improving and evaluating patient involvement in treatment decision making.

The unit is also eagerly awaiting the delivery of a new information kiosk for patients to use when visiting the unit. This has been provided by Kidney Care as part of the project.

Why not take a look for yourself and visit the web site.

Go to <http://sdm.rightcare.nhs.uk/pda>

Look for the established renal failure aids as there are about 30 PDAs for various other medical conditions as well.



HOLIDAY ON LAKE GARDA - ITALY

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Don't Panic, Don't Panic! A Response to Mid Staffs

Peter Andrews, Clinical Director

Those of you who remember Dad's Army will recognise this phrase, uttered by an elderly man doing exactly that. I wish to start by pointing out that I am not (that) elderly. Nor am I about to panic!



Most of you will be aware that the Francis report was published in February 2013. This was a comprehensive analysis of the failings identified at the Mid Staffordshire Trust, where it is estimated that there were more than 1200 potentially preventable deaths from 2001-10.



The report made 290 recommendations and the executive summary alone ran to 190 pages. It will not surprise you to hear that it has prompted intense soul searching throughout the NHS.

It is important to state at the outset that we believe that the clinical services provided at St Helier are of a high standard, and that the Renal Unit stands as a beacon of excellence within a successful Trust. On all available measures, St Helier is one of the best hospitals in South London if you are unwell.

However, I would like to assure you that the clinicians and management at St Helier are not complacent and are reviewing the Francis report on a number of levels. Even in a well-run unit, there are always lessons to learn.

Space means that I cannot detail all the steps that have been taken in response, but so far these have included:

Reinforcement of the 'Consultant of the week' model to ensure that we provide Consultant-level care to all inpatients

Review of current practice compared to best practice in other UK renal units

Review of the availability of 'out-of-hours' services such as pharmacy, radiology, and social service input

Review of access to physiotherapy and occupational therapy

Above all, ensuring that our service remains patient-focused

Ensuring that we respond to feedback

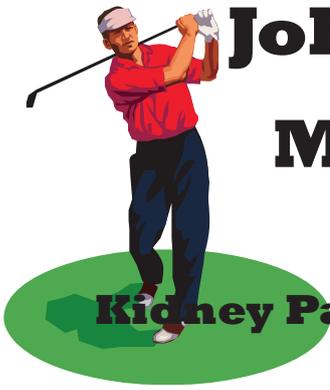
Picking up the last point, we welcome constructive feedback on our services – both good and bad. If you have any comments, please let us know. Speak to the ward nurses, or to any of your doctors. Or complete anonymised feedback. Or contact PALS. Or ask to speak to the Renal Matron, the duty Consultant, or a member of the Renal Management Team. If you have serious issues or feel that your comments have not been properly addressed, there are formal mechanisms to take your concerns further, and you can be advised of these.

How sad that this article has to focus on problems within the health service, when so much of what we do is so good. I was at a low ebb a couple of weeks ago, when the Francis report had just come out. But then I met a couple from America at a dinner party and spent an evening being reminded of how our NHS is the envy of the world, that visitors to this country cannot believe the quality of care provided (for free), and how much we get right. So let's not get things out of proportion. We live in an amazing country at a time when we can do so much. We are very fortunate.

And this leads me to the subject I know many of you are most interested in. By the time you read this, there will have been an addition to my family. We have decided to call her Ella. She is a 9-week-old golden retriever, one of a litter of ten, and is coming to her new home on 5th April 2013.

If I appear distracted over the next few weeks, please forgive me. I will have to get used again to the tyranny of the late night call of nature, the misbehaviour, and the incessant whining. Or maybe I will be better at training a dog than I was my teenage children!





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

Hopefully by the time you get to read this it will have warmed up and the sun will be shining.

This is a generally quiet time of year for the KPA but here are a couple of dates for your diaries...



Sunday 14th July KPA's 40th Anniversary Celebration

St Helier & Surrey Kidney Patients Association is 40 years old in June 2013 and we're having an afternoon tea party at Epsom racecourse to celebrate.

The event will be in the Downs View Suite between 3 and 6 p.m. and admission will be by ticket only as we have to limit numbers to 100 due to the room's size. Attendees will be allowed to bring one guest so book early to avoid disappointment.

Tickets can be obtained by contacting Jackie Moss on 020 8668 7435 or by email j.moss149@btinternet.com

Please contact before Friday 14th June. A poster on the event is included within this edition.

Friday 21st June, 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 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.

Purchase of Equipment

Since the last Renality we've purchased the following items

- Bedside Tables for the renal wards at St Helier
- Bedside chairs for the renal and PD wards at St Helier.
- Overlay Mattresses for St Helier and its Satellites.
- Profiling beds for St Helier and Mayday Satellite
- Televisions for the PD training rooms
- Television for the Patient transport waiting room at St Helier.

This has only been possible due to the generous donations that we receive from patients, their families and friends, together with what we make on our Grand Draw at Christmas and our Golf Day so as always thanks to everybody who supports us and helps us to improve patients' lives.

Other Matters

The KPA Committee has 3 new members but we still don't have patient representatives for Kingston, Epsom and Sutton. and 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. That's about it for my report; I'm off to cut the grass.

Best Wishes, Dave Spensley, Hon Chairman

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

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
Mr and Mrs Banton
T E Bond
The Charities Trust
Halstead Girls Prep School

Mr Andrew Poynter
National Grid PLC
J Hollis
J R Rodway
Abbe Fisher and Nescott College

KPA Memorial Donations

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

Kathleen Hope
Eric Thomas Walpole
Devathassam Paul
Christine Leadley

Clive Bradshaw
Cedric Henderson
Mary Laurie Thornton
Francis Yoxall

St Helier & Surrey KPA Committee members - 2012/2013

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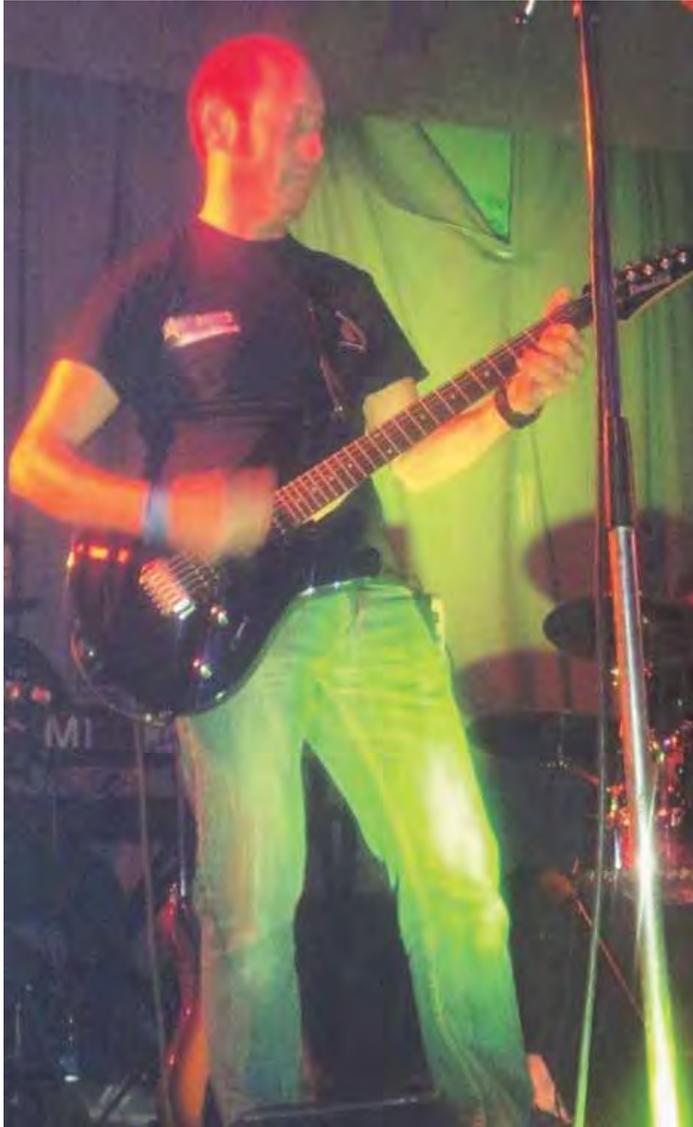
Satellite Liaison – Farnham

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Renal Social Worker/Amenity Sub.Committee

Celia Eggeling
Renal Unit, St. Helier Hospital
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email: Celia.Eggeling@esth.nhs.uk

JOHN O'GROATS TO LAND'S END



CYCLING kidney patient Matt Dibb set the wheels in motion to raise money for the South West Thames Kidney Fund – with astonishing success.

A team of 17 volunteers pedalled round the clock and covered a distance greater than that from Land's End to John O'Groats, raising more than £8,000 in the process.

They also created an unofficial world record by smashing their target of 1,000 miles to ride **1,244 miles** at an average of over 16mph, non-stop over 24 hours, on a static bike.

Their efforts were accompanied by live bands adding a rock festival atmosphere making Dibbfest 2013 an amazing event.

Matt said: "We sold out on ticket sales over both nights, and had hundreds of people come and go over the whole weekend.

"We raised awareness of the importance of exercise, having healthy kidneys, and of kidney disease in general, and raised over **£8000** in total for South West Thames Kidney Fund!

"And for 2 days and nights we brought a whole community together for a great time and a deserved cause."

"Friendships were forged and reinforced, generosity was shared by the bucket load. People went through unimaginable levels of pain – all for a damn good cause.

"The fallout afterwards was everywhere. Sore legs, bums, heads and utter exhaustion. But it's also safe to say that not one person involved in DibbFest 2013 holds a single regret for the efforts they put in and have nothing other than happy memories to take away.

"DibbFest was always about involving everyone who wanted to be involved and having a damn good time.

"I am truly humbled to have a bunch of mates who are prepared to drag themselves out of their beds in the middle of the night and push themselves physically beyond the limit – and then come back and do it all over again. And again."

Matt, 42, a father of three, was diagnosed with focal segmental glomerulosclerosis [FSGS] – chronic kidney disease - in

The Kidney Fund has been allocated 5 Golden Bond places for the Ride London 100 to take place on Sunday 4 August 2013

Celebrating the legacy for cycling created by the London 2012 Olympic and Paralympic Games, Prudential RideLondon-Surrey 100 will start in the new Queen Elizabeth Olympic Park, then follow a 100-mile route on closed roads through the capital and into Surrey's stunning countryside. With leg-testing climbs and a route recently made famous by the world's best cyclists, it will be a truly spectacular event for all involved and will finish on The Mall in Central London.

The route of the Prudential RideLondon-Surrey 100 is perfect for both club and recreational cyclists. Slower cyclists can enjoy a challenging ride while faster riders will relish the opportunity to pit themselves against the country's top amateurs. As well as the personal challenge of completing the route, participants' involvement will also benefit good causes – the Prudential RideLondon-Surrey 100 aims to be the largest charity fundraising cycle event in the world. If you're a keen cyclist and interested in one of these places please contact Anne on 0208 296 3698 or email anne.collard@kidneyfund.org.uk.

In return for a Golden Bond place at the Prudential RideLondon-Surrey 100 on Sunday 4 August, you will be asked to raise money for South West Thames Kidney Fund.

The deadline for rider registrations is May 15.



WITHOUT LEAVING SURREY...

1991. He said: "Eight months ago I had a call from my doctor. They had the blood test results back and it wasn't looking great.

My kidney function had been about 70 per cent of a normal kidney's function, now it's dropped to between 30 and 35. When it goes down to 10 or 15 per cent I'll go on dialysis and the transplant list.

"My doctor said that the fitter and healthier and leaner I am going towards surgery and transplant, the better the chances for me having a good recovery post-transplant as well.

"So I'm balancing what I can reasonably expect from my body with being as fit as possible.

"I'm doing a two or three-hour ride every Sunday morning with my ride mates and I'm turbo-training at least two or three times a week.

"I'm absolutely going to keep cycling after surgery, too."

DibbFest took place in at The Chichester Hall in Witley in March. DibbFest wishes to thank...



Howdo Research, Beyond Mountain Bikes, Geared Up Cycles, Ace Security, Alifabs, UK Hide, Gunwharf Quays and Land Securities. Donations can still be made at: www.dibbfest.com

mesogeios⁺

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Fax +30 2810 371 570 www.mesogeios.gr

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Tel 01508 816009

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

WHERE ARE ALL YOU COMPETITORS FOR THE TRANSPLANT GAMES?

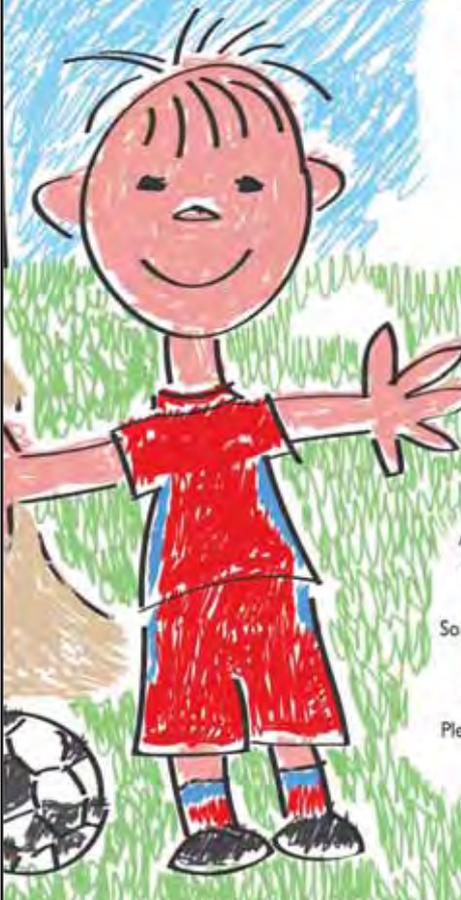
The response to emails and letters to 33 people who have previously indicated an interest in receiving information relating to the British Transplant Games has disappointingly resulted in only 15 replies, writes GRAHAM MORROW.

I have received replies from 5 who have indicated they will participate in this year's Games by competing or supporting and 9 who have said they don't wish to or cannot participate this year.

Registration for the Games is on line at www.gmsportal.net-btg and closes 31st May. At the time of writing, only six competitors and two supporters have registered.

Don't miss this opportunity to say thank-you to the donor families or see how transplants have changed the lives of the recipients.

If you need additional information, help with registering or wish to be removed from my database you can contact me on graham.morrow@ntlworld.com or 0795 125 7788.



SPORTS FUN DAY

at Aldershot Cricket Club

Guildford Rd, Aldershot GU12 4BP

Aldershot Cricket Club are hosting a **SPORTS FUN DAY** to raise funds for



on **Sunday 7th July**

A large variety of sports will be available to watch and give you the chance to discover check your hidden talents.

So please come along with your friends and join in.

Much of the funds will be raised by a draw. Please help by selling and returning your tickets. It can make such a difference!

THE SWTKF would like to thank the following for their support of our research:

Messrs Kingston Smith LLP for their donation of £500

The Redstone Redhill Rotary club for their donation of £250

The Waitrose Fleet shopping community for putting their green tags in the Kidney Fund box and raising £550 for kidney research.

The Martin Way Methodist Church in Merton Park for donating £500, representing half the proceeds from the recent panto performed by church members.

Two of the cast members are children of a church member who has recently benefited from a kidney transplant which has transformed her life.

MAGNIFICENT EFFORTS

Dear Kidney Research Funders,
Only April and it has been an amazing year for the Fund and for Kidney Research in South West Thames.

Most of the recent events have been so strenuous that it makes you feel like going to lie down for a little snooze.

We reported John Wills's amazing efforts in the last issue of Renality, and then in March, Mat Dibb with support from wife Haley and three children set up an amazing static cycle challenge in the the Village Hall in Witley, supported by many of his cycling friends.

In forty-eight hours they broke an unofficial record by cycling at more than 26 miles an hour. That is 48 consecutive marathons !!!

As I type away, the indefatigable Anne Collard is putting the final touches to our St George's Day Extravaganza at the All England Lawn Tennis Club at Wimbledon on 13th April. That will be a most enjoyable event for the cause and we are looking forward to meeting many supporters there.

Dr Mark Dockrell has received a gentle reprimand from our Parent University, St George's because he has exceeded, by one, the official



maximum number of PhD students that he is allowed to supervise at any one time (his students at this highest level now stand at seven). Can you imagine an employer objecting that one of their staff is working too hard?

Mrs Thatcher, once a research Chemist, would not have been very impressed. Well done Mark, we are supporting you all the way!

Finally the most momentous event for the Kidney Fund is the retirement of Hon Secretary, **Pat Godden** (right) at the time of our AGM on the 10th July.

Pat was associated with the Fund from its earliest conception in the 1980's. For more than 25 years Pat has worked as a tireless Hon Secretary to the Fund.

In the 1990's she was supported by husband Roy Godden OBE.

Without those two and five or six others our magnificent Research Institute would never have come to fruition. More recently in the calmer 21st Century, Pat was so helped by her dear friend Ron who was always there as support.

We are planning something of a party to replace the AGM on the 10th July and this will be your last official chance to come and thank Pat for everything she has done for all of us, over 25 years, patients, nurses, secretaries, researchers, trustees.

Without the continuity provided by Pat we would never have kept the show on the road.

Well done Pat,

**Mike Bending, Chairman,
South West Thames Kidney Fund**



WOULD YOU LIKE TO HELP RAISE FUNDS

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.

A DATE FOR YOUR DIARY IN ASHTEAD

Here's one very typical fundraiser, showing just how you can set about helping the South West Thames Kidney Fund.

Allan Beer reports that he is now working now towards the 2013 Ashtead Village Day which this year in on Saturday 8th June, where he has raised funds for several years.

SW THAMES KIDNEY FUND



www.kidneyfund.org.uk

Supporting the S.W. Thames Institute for Renal Research
St. Helier Hospital, Wrythe Lane, Carshalton, Surrey SM5 1AA

Patron: Lord Rogers of Riverside

Chairman: Dr. Michael Bending, M.A. M.Sc F.R.C.P.

Please reply to:

NOTICE of the ANNUAL GENERAL MEETING

of the

South West Thames Kidney Fund and the Institute for Renal Research

to be held in the

Institute for Renal Research Conference Room

St Helier Hospital, Carshalton

on

Wednesday 10th July 2013 at 2.00 p.m.

Dr Michael Bending, the Chairman of the S W T Kidney Fund invites you to attend the above meetings.

Come and hear about the progress of the Kidney Fund since its inception in 1998, 15 years ago this year and the wonderful things the Institute is achieving with their research into Renal failure and Diabetes.

As well as the usual AGM business, the Committee is proposing to amend the name of the Kidney Fund and make amendments to the Constitution which will require approval by members.

If you would like to nominate yourself, or anyone else, to serve on the committee, please send your nominations to the Hon. Secretary, Pat Godden, 478 Wickham Road Croydon CR0 8DJ by midnight on Friday 28th June 2013. All nominations must be proposed and seconded and permission of the nominee must be obtained. In the event of more nominees than vacancies a ballot will be held.

Light refreshments will be served.



Let's Get Quizzical!

The Barley Mow pub on Horseferry Road was once again packed with teams of Civil Servants from across Whitehall as Ian and Kathryn Harrison ran their latest quiz night there.

Kathryn, who works for UK Border Agency said that she ended up turning people away such is the popularity of the quiz nights she and her husband Ian have been running there for the last two years.

"We started running the quiz nights with teams of people who were colleagues and friends," said Kathryn. "But now I am getting contacted by people I don't know who have heard about them and want to enter a team.

"This event proved to be particularly popular and we were full soon after I advertised it. It's a shame to have to turn people away but we filled the room to its maximum capacity."

Ian and Kathryn set the quiz questions themselves and as they admit to having totally opposite interests they are able to come up with a good mix.

"Anything to do with science and technology is strictly his field," said Kathryn, "whereas I concentrate on the music and literature type questions. Something that has proved to be really popular is our 'interactive feature' which we now do.

"This time we had a Nature Trail where each team had to identify different types of seeds and berries. It was great fun watching people trying to work out what they were."

The quiz raised £562 for the South West Thames Kidney Fund and an additional donation of £130 from colleague Julia Dolby for selling cakes in her office brought the grand total to £692.

Kathryn donated a kidney to Ian nearly 3 years ago.

THE SWTKF are grateful for the following Donations

In memory of:

Irene Margaret

Stanley Best

George Strang

Eric Ayling

Smith Bernard

Carmel Ennis

Jack Lesley Roots

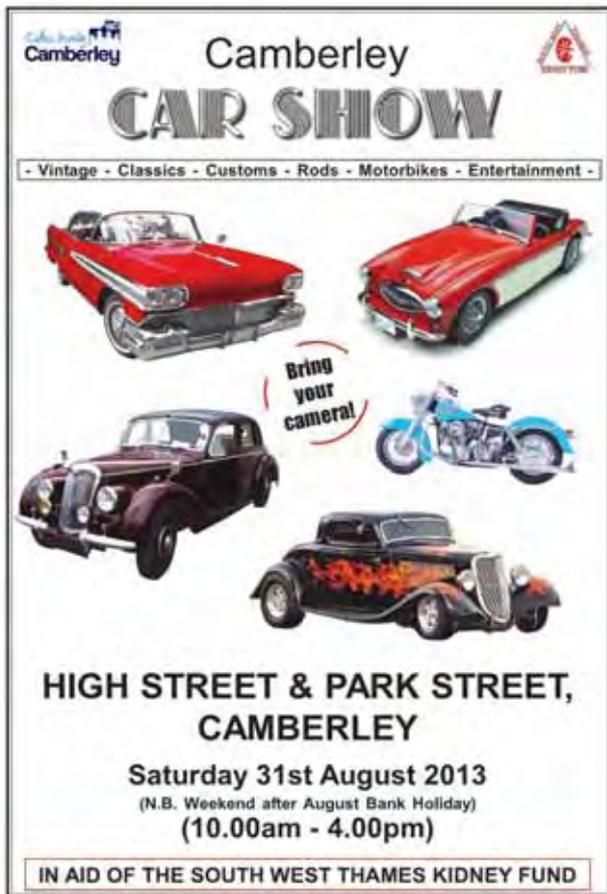
Cynthia Gladys Bath

S Gray

Douglas Cox

Anthony George Bruce

CLASSIC CARS RAISE CASH IN CAMBERLEY



The Camberley Classic Car Show returns this year to the High Street and Park Street in Camberley on Saturday 31st August 2013 from (10am-4pm), in aid of South West Thames Kidney Fund.

This is only the second time we have held the event. Last year we had 42 'classic' vehicles in Park Street only. This year, with two streets, we are hoping to have around 120 vehicles of many types and eras from a Mini to a Routemaster London Bus.

We'll have a good selection of various makes and types and in addition to the vehicles we are hoping to have some 'Street Entertainers' and a 'Childrens Competition' so that there is something for everyone.

So, please come along to this fantastic classic car show and give your support to the South West Thames Kidney Fund.

Following the success of the 2012 Car Show at which we raised £450.00 for the fund, Collectively Camberley generously donated a further £200.00 by cheque which, like the money collected at the show, was forwarded to the fund through the Guildford & Frimley Park Branch.

AND HOT RODS HELP, TOO

Surrey Street Rodders, a Surrey and Hampshire based Custom Car Club, has donated £500 to the South West Thames Kidney Fund.

The club was established in 1974 and the Surrey Street Rodders 'Wheels Day' has become established as an annual meeting for Custom Cars, Street Rods and American vehicles.

Over the years it has grown to become one of the biggest car shows, if not the biggest, in the UK. The venue has changed over the years mainly due to the increase in size of the event and it is now held at Rushmoor Arena, Aldershot, every Good Friday and now attracts thousands of both exhibitors and visitors.

Surrey Street Rodders is run as a non-profit making organisation and the monies collected from the entrance fees and stall-holder site fees at their annual event, raises thousands of pounds which is generously distributed to selected local charities.

If you would like to know more or to get involved, you can contact the club chairman Harold Martin at South Cranmere, Drift Road, Whitehill, Bordon, Hants .



Be a SWEATY KIDNEY SCIENTIST for a day! *(no lab experience or boating/swimming skills necessary)*

Raise: £250 in sponsorship

Date: all day Sunday 21st July 2013

Place: River Thames, Canbury Gardens, Kingston Upon Thames

Result: Absolutely loads of fun, a great feeling of satisfaction, and a huge benefit to the future of kidney research.

There will be approximately 50 teams taking part. We need 17 people to fill our Dragon Boat (16 paddlers and 1 drummer). Each team takes part in three heats and, if placed high enough in the heats, the final.

Before the teams are allowed in the boat they are given safety instructions, a life vest & a paddle. If you, or anyone you know, would like to be part of this wonderful annual event please contact Anne on 0208 296 3698 or email anne.collard@kidneyfund.org.uk

We will also have a charity stall at the event

If you are interested in organising the stall this year, or are interested in helping on the day please contact Anne (details above)

Again, it's a really fun and satisfying day.

If anyone has items (unwanted gifts, sweets, toys, anything!) they can donate for tombola and other prizes we would be most grateful.



FOR EVERYONE! Make a note in your diary and come to Canbury Gardens, Kingston on Thames on the 21st July 2013 for a really good day out. There are activities for children, a pub, stalls to buy food, and plenty of area for family picnics by the river. We hope to see you there!

NB: Excessively heavy rains last year caused the July event to be cancelled.

In the unlikely event that we have heavy rains again, please check this website before you go

<http://kingstonrotaryclub.org.uk/dragon-boat-challenge>

Organ donations on the increase

Organ donation has increased by 50% in the last five years according to new figures published in April.

In the last 12 months alone 1,200 people helped transform 3,100 lives - but doctors say more work still needs to be done

The rise is largely due to a new network of special nurses who discuss organ donation with bereaved families.

There are 7,300 patients on the transplant waiting list – 6,000 hoping for new kidneys. And three Brits a day die waiting for an organ.

Meanwhile the numbers of families refusing to grant consent remains among the highest in Europe.

“This is an outstanding achievement that few thought possible at the time this ambition was set,” said Bill Fullagar, chairman of NHSBT.

“It is the result of the hard work and dedication of staff in hospitals and communities across the country.



“We must also share our heartfelt thanks with every family who, at a great time of sadness, supported their loved one’s wish to donate their organs and transform the lives of up to nine other people.”

The increase in donated organs has led to a 30.5% boost in the number of people

receiving a life-saving or enhancing organ transplant in the last five years.

Professor Anthony Warrens, professor of renal transplantation surgery at Barts Health NHS Trust and the Royal London Hospital and president of the British Transplantation Society, praised the NHSBT for the increase in organ donors.

He said: “There can be few greater achievements than to have given life to those who were on the verge of death - but that is the reality of this achievement.

“Data show that an individual who donates his or her organs after death gives the recipients an aggregate of an additional 56 years of life.

"And despite the sadness of the moment, this usually becomes a major comfort to bereaved families as time passes.”

Dr Paul Murphy, NHSBT’s national lead for organ donation, called the 50% increase a “landmark event in donation and transplantation for the UK”.

SPRING HAS SPRUNG SO... GET SNAPPING

This is your last chance to help us create a Kidney Fund calendar featuring photos taken by our Renality readers. So be inspired by the change in the weather and let us have your entries by the end of May.

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.

email Anne.Collard@kidneyfund.org.uk for more details



Spring has sprung...

Aren't we lucky with our weather? Some poor blighters have such predictable temperature patterns; snow in winter, warms up in spring and hot in summer.

We, fortunately, enjoy the spice of life; it's not a wonder we Brits have a reputation for talking about the weather – you never know what it's going to be like from day to day.

I think sometimes the researchers in the Institute feel likewise. They come in enthusiastically to treat their kidney cells to do an experiment and then they get results they did not expect and possible didn't want.

It is both a thrill and a challenge of research that you don't know what the outcome of an experiment is going to be, you never know what's round the corner. If we knew what the outcome was we wouldn't need to do the experiment.

So, when things don't work the way you expected you have to do a bit of head-scratching, a little more reading and a little more thinking before you can make sense of your results. Then, perhaps, just perhaps, you have found out something completely new, something unexpected, something not in any text book and it could be important!

March was quite a busy months for us, in addition to the usual work we had two conferences.

The first was the joint meeting of the British Transplant Society and the Renal Association in Bournemouth – if anyone invites you to Bournemouth for a break in wet and windy March, take a rain check. The weather wasn't great but the meeting was. We learnt a great deal and got some good feedback on our own work.

One of the people from the Institute presenting was the SWT Kidney Fund Young Scientist, Irbaz, or Buzz as he's known in the lab.

Buzz has been studying a specific enzyme and how it is regulated in kidney cells exposed to a diabetic environment to mimic diabetic kidney disease.

It must be said that Buzz's work has not

FUNDING
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CURE

been plain sailing; this little enzyme is difficult to work with and has never been studied in podocytes before. (Remember, podocytes are the cells in the kidney that control filtration and get damaged in diabetes.)

On this occasion, Buzz had worked hard, done a lot of head scratching and made some interesting discoveries, and when he presented his work he blew the audience away.

Bristol is probably the main centre in the UK for research into podocytes and after Buzz talked about his work he got an invitation to go through to Bristol to do some specialised experiments with them. We're hoping this will open new collaborations where we can share expertise.

The second conference was the 25th meeting of the European Renal Cell Study Group, a conference that brings together a select group of top renal researchers from around Europe.

This year the meeting was in Oxford – and it snowed. In Italy we sat on the terraces and sipped espresso, in Oxford we stayed inside and shivered, but once again the science was good.

This time Subash was giving a talk from the Institute. Subash is the South West



Thames Kidney Fund Clinical Research Fellow, and was talking about his project which we're doing in collaboration with King's College London and Isis Pharmaceuticals in the US.

Subash, like Buzz, has had some "unexpected results" but he gave a good talk and it was well received.

Research isn't easy, you have many set backs and you get a lot of "unexpected" results but it is only through research that we will make the advances we need to improve the therapies for Kidney disease.

The work that Buzz and Subash are doing will help us understand diseased kidneys and move us towards better treatment. Without the kidney Fund and your support we would not be able to do this work.

So just before I sign off, one more little plug; for those of you who may have missed it, I'm doing a sponsored walk.

I'm walking **100 km** for the South West Thames Kidney Fund because we need a cure for kidney disease!

If you have few bob to spare and you'd like to sponsor me you can post it directly to Anne Collard at the South West Thames Institute for Renal Research, St Helier Hospital, please mark your envelope or letter "Marks Mad Challenge" or go on line at <http://www.justgiving.com/mark-dockrell1>.

Thank you and remember:

Funding = Research

Research = Cure

THE HAWTHORN LESLIE 3837 PRESERVATION SOCIETY PROUDLY PRESENTS:- THE BIG CHARITY FUNDRAISING SHOW, JUNE 23rd 2013, 11-00 am to 5-00 pm, IN THE MOLE BARN AT THE LEATHERHEAD LEISURE CENTRE.

If you would like to have a stall to raise funds for the South West Thames Kidney Fund, contact Brian Davis, 63, Cannon Grove, Fetcham, Surrey, KT22 9LP. Email address brian.davis1947@btinternet.com The Hawthorn Leslie 3837 is a steam locomotive, lovingly restored and preserved by steam enthusiasts.

*St Helier and Surrey Kidney
Patient's Association
40th Anniversary
Tea Party*

*Sunday 14th July 2013
Down View Suite
Epsom Racecourse*

Admission is Strictly by Ticket Only

*Tickets are available by contacting
Jackie Moss*

Telephone 020 8668 7435

Email: jmoss@btinternet.com

By Friday 14th June

Dress Code—Smart casual