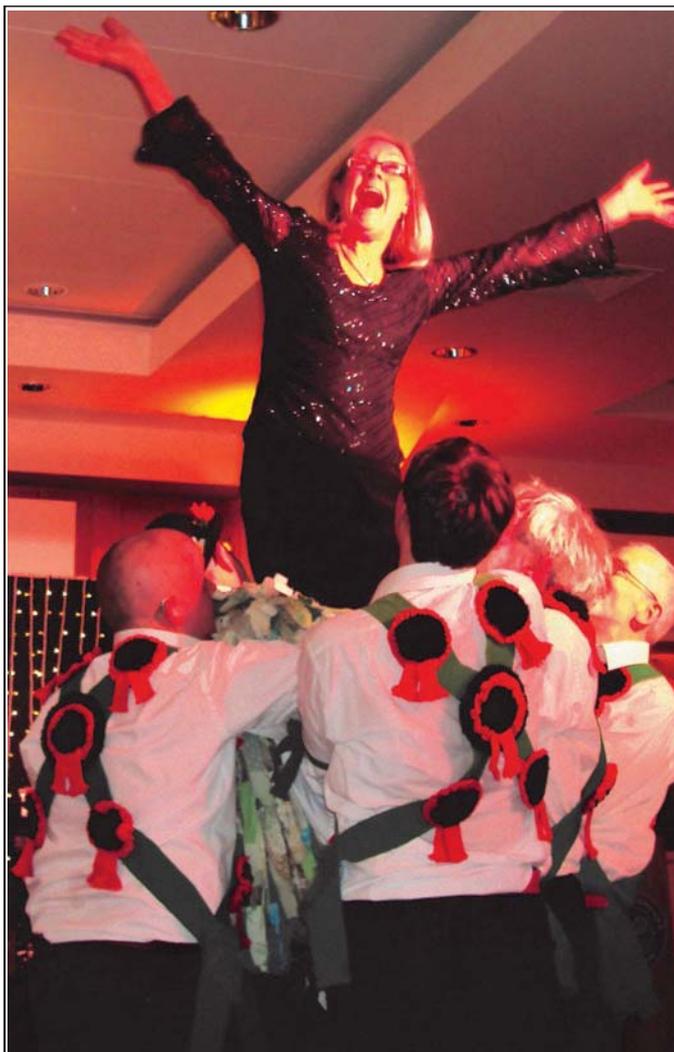


RENALITY

The NEWSLETTER of...

August 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



SMASHING TIME AT WIMBLEDON

ANDY MURRAY made history by winning the men's singles title at Wimbledon - the first win by a Briton for 77 years. But a few weeks earlier, the South West Thames Kidney Fund made a little bit of history too with a charity extravaganza at the home of tennis which raised £10,451. Anne Collard (above) got a little carried away by the Morris Men, as you can see.

FULL REPORT: Page 11



WALK ON THE WILD SIDE...

MARK DOCKRELL and Simon Butler certainly put their best feet forward for kidney research by walking from London to Brighton.

But after completing the gruelling overnight challenge both men might well have felt that they actually put their feet right in it by taking on such a daunting task.

Mark (top) and Simon (below) took more than 24 hours to walk the 100km course and both have the blisters and sore feet to prove it.

Mark said: "There were times when I felt like giving up. But, as you know, giving up is not the SWTIRR way."

This edition features many more heroic efforts by Renality readers.

FULL STORY: Page 15



Fantastic KPA Golf Day raises more than £3,500

The sixth annual golf day of the St Helier & Surrey Kidney Patients Association at Milford Golf Club was, quite possibly, the best yet. FULL REPORT: Page 3

In this issue:

Renal Unit News:

Clinical Director 7

SHSKPA News:

Golf Day 3

Chairman's Report 4

Donations 5

Holiday Dialysis 18

SWTIRR News:

HHD lunch 8/9

Institute Director's message 14

SWTKF News:

Hair we go 5

Chairman's message 6

Donations/Legacies 10

Wimbledon dinner 11

Tribute to Jean Shaw 12

Marathon efforts 13

100k walk 15

Brighton bike ride 16

Patient Feedback 19

Calendar winners 20

Lottery winners 20

Useful Contacts:

RENAL UNIT reception:

020 8296 2283,

020 8296 3100

SWTIRR & SWTKF,

Anne Collard, Administrator:

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

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



6th ANNUAL GOLF DAY RAISES OVER £3,500

What a fabulous day, warm, dry, well attended and profitable.

On Friday 21st June 75 golfers took to the fairways of Milford Golf Course to play what has become a fabulous annual event.

This year's event was a roaring success with a record turnout and a financial surplus of over £3,500, including Gift Aid.

The overall winner of the day was Tony Notaro with a magnificent 41 points (playing to 5 under his handicap).

Tony beat Terry Farmer, who also carded 41 points but lost on the count back system.

Martin Jeffrey took the Congu trophy with 39 points.

Other winners on the day were Simon Greenaway who won the Transplant cup and Sue Secrett the Donor Cup.

No dialysis patients played this year so Paul Connolly held on to his trophy.



Thanks must certainly go to everyone who attended but in particular to;

Paul Connolly, Carolyn Whitfield and Fay Eves for organising the event,

Di and Anna Spensley and Chelsea Eves for helping on the day.

And to Jim Rae for keeping track of our finances.

In addition my thanks must also go to the following:

Martin Dean of Becketts Barn Golf Society who promoted the event so well for us and did the score card calculations;

The many members of the Becketts Barn Golf Society and Littlehampton Golf Course who attended;

Ivor Connolly who handled our auction; Milford Golf Course, its members, Head Professional Simon and the Catering & Waitressing Staff for their welcome, hospitality and fabulous meal.

Everyone went out of their way to help and we've already booked next year's event, Friday 20th June 2014.

If you're a golfer or have golfing friends put it in your diary.

DAVE SPENSLEY, Chairman

Aldershot Cricket Club Sports Fun Day Grand Charity Draw Winners

- | | |
|----------------------------------|---------------------------------|
| 1st Prize £500 | SJ Moore, Alton |
| 2nd Prize £250 | M Guzman Rivero, Redhill |
| 3rd Prize £100 | N Cranstone, Tilehurst |
| 4th Prize £100 | M Kelly, Farnborough |

A huge thank-you to all who supported the event; a full report will appear in the next edition of Renality.

A message from your Chairman

By the time you read this it will be August already, Wimbledon will have come and gone and hopefully summer will have started and we will have had some sunshine!!!

It's been a relatively quiet few months so there's not too much to report on.



Epsom & St Helier Foundation Trust

The latest I've heard is that the Better Services, Better Value exercise that will undoubtedly decide the future of St Helier has been put on hold.

Hopefully this is great news for the renal unit as without an A & E department and HDU ward it's difficult to see how the renal unit could survive on the St Helier site.

With an ever expanding population we need more A & E units not less. So let's all hope for a great outcome for St Helier.

Golf Day

Friday 21st June 2013 saw the annual KPA golf day at Milford Golf course in Surrey and this is covered in a separate article. Seventy five golfers took part and the event should raise in excess of £3,500 including Gift Aid, a fabulous total.

Thanks must go to KPA Vice Chairman, Paul Connolly, his better half Carolyn Whitfield and to Fay Eves for organising this wonderful annual event and to Di and Anna Spensley and Chelsea Eves all of who helped on the day. Thanks also to Milford for a wonderful course and a lovely meal.

We've already booked next year's date Friday 20th June 2014

NKF Conference

This will be held at the Hinckley Island Hotel, Hinckley Leicester on Saturday 12th and Sunday 13th October and the KPA will pay the special package rate for KPA members.

Other News

KPA AGM:

This years AGM will be held on Wednesday 20th November at 7.30 p.m. in the Blue Room at the renal unit of St Helier.

Christmas Patient Luncheon:

This years luncheon will take place on Saturday 14th December between 12.00 and 2.00 p.m. and again this will also be held in the Blue Room

Best Wishes, Dave Spensley, Hon. Chairman

KPA Memorial Donations

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

Albert Avis

Kathreen D Hope

Eric Pither

John Charles Burch

A HAIR RAISING DAY AT NESCOT COLLEGE

The staff and students at Nescot in Epsom, Surrey were fantastic in March of this year when they managed to raise a total of OVER £1700 for our KPA, writes CAROLINE EVANS.



It all started with me over hearing a conversation about who would be their nominated charity this year.

Well, that gave me my opening line and the conversation soon got round to kidneys..!!!! It also tied in very nicely with World Kidney Day on 14th March.!!

I gave the students some inside info on the work of the KPA and they really wanted to help.

The group of Hairdressing students led by their tutor Michele and ably assisted by Rachel at Nescot really went above and beyond.

One student Abbe Fisher even offered to do a sponsored head shave and also donate her chopped off locks to a wig company who specialise in making wigs for cancer sufferers.

Abbe is pictured before (left) and after the hair raising experience (above) as a cheque for £1,431.98 was handed over to the KPA.

This group of teenagers worked hard obtaining donated goods for a raffle as well as finding volunteers to attend Nescot for a 'hair do' in exchange for a donation to the cause.

Even the 'Sugababes' Nimmy and myself went in to have a shampoo and set up, and I remain a Nescot convert!!

During term time, they offer a great range of hairdressing and beauty services at a fraction of the salon price, and models are always welcome!!

I was invited for the 'cheque handover', but post handover the final total went up even further !!

All in all, a wonderful experience, and the chance to see teenagers in a positive light for a change!!

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:

Wilberforce Lodge

Mrs I G Patel

Caroline Evans

Mr and Mrs P Steele

Helena Shiatis

D E Lewis

Halstead School

G M Davies

Dear Kidney Funders,

In the past few editions of Renality we have been stressing the importance of sporting events as a major source of sponsorship and funding for essential research in our Institute.

At a recent fundraising subcommittee we were analysing the breakdown of research income and were reminded that we receive very significant income from legacies left by well-wishers and supporters of kidney research in their Last Will and Testament.

The figures are quite surprising and make very heartening reading. In the last seven years the kidney fund has received £503,837.

Obviously this is a massive source of income and resource, but more importantly this is an amazing vote of confidence in Dr Mark Dockrell and the scientists who work under his supervision.

Over the last 10 years I have noticed that more and more National Charities solicit legacies from supporters in national newspaper advertisements.



I have always been very opposed to this on the grounds that soliciting for support is a delicate subject. It then struck me that this has many parallels to doctors seeking consent for organ donation from bereaved parents or family members. Without the gift of life to make organ transplantation possible many kidney patients would not fight to see another day and by analogy gifts covenanted will allow for research and development which will improve the lot of renal patients in the next-generation.

I am proposing to add a codicil to my own will to bequest a proportion of

my life's savings to ensure that the work that we are so involved in continues after we are gone.

Elsewhere in this edition of Renality you will have read of the death of Jean Shaw who worked with me as trusted secretary and PA over the last 30 years.

Jean was so calm and so peaceful and she brought happiness to all staff and patients with whom she came into contact.

We have sent our condolences to Derek and all of Jean's family.

On a happier note Pat Godden is retiring as honorary secretary of the South West Thames Kidney Fund at our next annual general meeting on 10 July. The work that Pat and her late husband Roy contributed to the fund is incalculable, and stretched over nearly thirty years. We wish Pat a long and happy retirement. I hope to be able to announce the appointment of her successor in the next edition of Renality.

With very best wishes,
Yours sincerely,

Michael Bending: Chairman

A rectangular advertisement for the Camberley Car Show. At the top left is the Camberley logo. The title 'Camberley CAR SHOW' is prominently displayed in the center. Below the title, a horizontal line separates it from a list of categories: 'Vintage - Classics - Customs - Rods - Motorbikes - Entertainment'. The main body of the ad features four images: a red classic convertible, a red classic coupe, a blue motorcycle, and a dark classic car with a flame paint job. A speech bubble with the text 'Bring your camera!' is positioned near the motorcycle. At the bottom, the location 'HIGH STREET & PARK STREET, CAMBERLEY' and the date 'Saturday 31st August 2013 (N.B. Weekend after August Bank Holiday) (10.00am - 4.00pm)' are listed. A small logo for the South West Thames Kidney Fund is in the top right corner. At the very bottom, a banner reads 'IN AID OF THE SOUTH WEST THAMES KIDNEY FUND'.

VROOM WITH A PHEW

Please mark **31st August 2013** (the Saturday AFTER the August bank holiday) in your diary for the '**Camberley Car Show**'.

Location High Street and Park Street, Camberley. Time: 10:00 am to 4:00 pm.

Enjoy the vehicles from all eras (from a Mini to a Routemaster London Bus), live music, street entertainment, childrens' face painting etc.

100% of all proceeds will benefit the South West Thames Kidney Fund and Kidney Research.

If you are unable to visit the event on the day, please show your support by visiting <http://www.justgiving.com/CamberleyCarShow> and making a donation!

For more information please visit www.camberleycarshow.co.uk.

Our thanks to Ken and Glenise Bonner for organising this amazing event.

PAWS FOR THOUGHT

Golden Retriever ELLA reports on her progress in the household of Clinical Director Peter Andrews...

I was surprised to be asked to contribute this article as I understood it was the responsibility of my pet. However, it appears that many more of you would like to hear from me, so here goes!

So far, I have generally good news to report. I have only been home for a couple of months but the training is going well. Right from the beginning, my pet has been fully house trained. He eats well and rarely begs. He exercises regularly and is kind and affectionate.

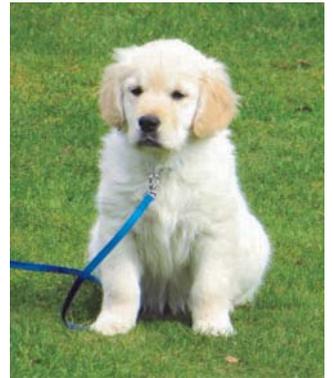
One early focus was to ensure that he provided appropriate food and water. In general, this has been fine, though I have noticed that he has increasingly devolved this task to other members of the household management team. In particular, he doesn't seem to be a morning person and I think I would starve if his (much hairier, much prettier) alpha female partner didn't get us both started in the morning.

More advanced training has started now that I have been fully vaccinated and can meet my friends on play dates. It is quite amusing to see how easily he is pleased when I sit down or lie down, and it's a good way of supplementing my meagre food rations. On occasion, I will fetch and bring him some toys, as he doesn't seem to have many of his own. He will often give me treats for doing this as well!

Sometimes he points at the ground and says 'stay', but I can't be bothered with that! It's much more fun to chase after birds, squirrels and - best of all - joggers. Last week, I even caught one and managed to bring her down!

There are some problems. Although the rest of my family are kind and look after me well, I do wish my pet could be home more often. He often disappears for virtually the whole day and looks very tired when he comes in. I try to cheer him up by rushing to the door, and this does seem to make him very happy. On the other paw, sometimes he gets cross when I jump up and he gets all furry, though to be fair this is a much bigger problem with the alpha female. She also spends an awful lot of time washing the floor, which makes it very slippery. I have to be careful with her. It's quite clear who is really in charge!

Overall, he's doing quite well, and I am very happy with progress. I aim to get him to slim down a bit over the next few months by taking him for progressively longer walks. He certainly needs it!



A Word in Edgeways...

Not too much to report from the Renal Unit this quarter.

The main concern is the ongoing 'Better Services Better Value' debate which in its current form proposes a major downgrade of the facilities at both Epsom and St Helier Hospitals.

This would have major implications for the safe operation of the renal unit.

At present, we do not know how this process will pan out. There is vigorous local opposition to the plans and – as ever – whether anything comes to fruition is likely to come down to a question of money and politics.

We are keeping close tabs on the discussions, and will work hard to secure the best possible outcome for the renal services.

But please don't imagine that this will be a quick process! It is unlikely that any changes will take place before 2016 at the earliest, not least because they would require major reconfiguration which would be unlikely to occur before the next election.

In practice, I have a sneaking feeling that my successor will still be writing of 'proposed redevelopments' in another 5 – even 10 – years' time.

In the interim, we worked hard to secure a very good settlement from this year's capital bidding process, and will be using this to upgrade and repair some of the existing renal infrastructure. In the short term, this will mean some disruption as we have to temporarily close wards while they are being upgraded.

We hope to start this work in the summer months (when bed pressures are less) and will try to keep any disruption to a minimum. Please bear with us as we try to improve our services!

It only leaves me to thank the KPA for its unswerving support and to wish it well for its 40th anniversary celebrations.

I hope next time to be able to claim back more column space and have the chance to update you in more detail!

Peter Andrews, Clinical Director



COME DINE WITH ME..

Home Haemodialysis patients get together for a meal at The Clink inside Highdown Prison

Home Haemodialysis (HHD) has become an important treatment choice and St. Helier currently has 23 people who are happily Haemodialysing in their own home.

Although there are certainly many significant benefits, some people miss the company of the others.

So, the HHD patient and carer forum was formed.

Our first meeting was in the rather unusual surroundings of Highdown Prison, at the much acclaimed Clink Restaurant, which is located within the prison.

For many renal patients eating-out poses a number of problems, mostly around the question of what can I safely eat?

When dishes have complex and hidden ingredients it can be hard to know what is suitable on an unfamiliar menu.

Our dietician Caroline Lawson took on the challenge and met with Head Chef Al Crisci of the Clink.

Caroline worked very hard to provide a lovely diverse three course menu that was entirely suitable for everyone.

We met on 26th March. Because the restaurant is deep within the prison walls we all had to pass through the rigors of security.

For most of us it was the first time we had been on 'the inside' and it was a fascinating experience.

Potentially though this could be a little daunting if you had something to hide; and it was noted that Dr Peter Andrews was unable to attend at the last moment!



But then again, how did these 4 get in? (Our team of Renal Technicians below. Only joking boys!)

It was great to have so many of us together (45) at the launch of our HHD Forum, a lovely opportunity to catch up and share stories. The pictures you see here show what a great time we all had.

Our plan is to meet once or twice

a year and the next meeting is a family game of Rounders on July 28th.

If you are interested in knowing more about Home Haemodialysis then please call us on 0208 296 4702

Debbie, Karen and Clair

HHD nurses



WITHIN THESE WALLS



Menu.

Starter:

Vanilla scented English Goats Cheese with compressed Pears
Boiled Butternut Squash & Chilli
Tortellini with diced Feta Cheese in Broth
Salad Bar

Main:

Slow cooked Breast of Lamb with lemon, olive and caper tapenade, Pea and Mint Croquettes and Boiled Creamed Cabbage
Rock Salmon in white wine & fresh tomatoes with Saffron and Seasonal Greens Risotto
Blanched Broccoli Buds and Ricotta Pancake Cannelloni baked in fresh tomato with grilled cheese topping

Pudding:

Homemade Vanilla Ice Cream
Ricotta and Blood Orange Cheesecake
Cheese Board/English Apple Trio



HARD WORK RAISES 'BEER' MONEY

ALLAN BEER and his family have been raising funds for the last three years with their stall at the Ashted Village Day.

Allan reports: Well what a weekend that was, tiring, great fun and the weather was on our side.

Our Stall at the Ashted Village Day attracted plenty of interest as usual. The day started for us at 8.30am when we started to set up our pitch with people in and around the Stall from 11.30am onwards.

Again we ran a 'Good as New Stall' with all the items being donated by family and friends. In addition we had plants for sale that my sister-in-law Jill had supplied and homemade Cards that were donated by my niece Jayne.

Eight of us ran the stall: myself, Sally my wife, my brother-in-law Roy and his wife Anne, Barbara, Sally's sister and her husband Barry and my brother-in-law Dave and his wife Jill

(who donated the plants). It was a long day, arriving back home just before 7.00pm but well worth it. The weather was hot and sunny and we all had great fun. In total we raised £320.28

The following day the Sunday we held a Charity Cream Tea in our garden. The weather was not so kind but it was well supported with around 50 family and friends turning up.

There was a small charge to get in and we held 3 small quizzes to raise additional money. We had Jewellery and Cards left from the Saturday so we put them out to sell as well.

The event ran from 2.00pm to around 7.00pm. Again a great day, a good way to support a worthwhile charity and catch up with family and friends. We had on the day a £50.00 donation from Rosa and Keith Edwards and Sally, myself, and Sally's two sisters Barbara and Eileen donated the food and drink for the day. We raised on the day £360.50 and overall £680.78.

THE SWTKF are grateful for the following Donations

Thanks and many congratulations to **Roy and Lesley Down** for the donation in respect of their Golden Wedding anniversary. Thanks to John and Deborah Wills for their donation to the Kidney Fund of £564.04.

In memory of:

Geoffrey Cathie

Eric Pither

John Charles Burch

Anantrai Bhatt (Mrs Manjula Bhatt wrote: My husband Anantrai Bhatt was in the Renal Unit in December last year. He had diabetes, heart problems and impaired kidneys. He was having EPO injections prescribed by Dr Mike Bending and survived for many years with the help of this injection. I am very grateful to Dr Bending. My husband was in hospital for about 3 weeks and was well looked after by Dr de Silva, Dr Jonathan and other members of the team. His last wish was not to have flowers but donations to the Kidney Fund. I am donating £300 to buy a Mini Lab Roller in memory of my husband Anantrai Bhatt and will try my best to support the South West Thames Kidney Fund.

...and three donations were made in memory of **Vipin Patel** by his daughter Heeral - one of them for his birthday, and one in the name of his new granddaughter Amber Patel born on 7th May 2013.

We were also very grateful for the legacies we have received from **Mrs Dorothy Calow** and **Mrs Alice Joan Adams**.

Wimbledon St George's Day Event: £10,451 Raised in our Fight Against the Dragon of Kidney Disease

I believe we can honestly say that a 'Good Time was Had by All' at our Wimbledon St George's Day event on the 13th April, writes ANNE COLLARD.

It was an evening of bubbles, raffles, magic, recitations, morris men, feasting, drinking, hilarious speeches, sing songs, flag waving, auction and dancing and was an excellent celebration of our Patron Saint George's Day and 15th Anniversary of our Renal Research Institute.

The evening's festivities were opened by Dr Mike Bending, Chairman of the South West Thames Kidney Fund, the Master of Ceremonies was Richard Sammons, Chairman of the South West Thames Institute for Renal Research and my fantastic co-planners for the event were the ever supportive Maggie Porter and Kathryn Harrison.

Joanna Bending - we applaud your brilliant poetry readings and fantastic rendition of the 'renalised' speech from Shakespeare's Henry V.

Mark Dockrell - it has been suggested that you have a future waiting for you as a stand up comic. Your speech (right) was excellent entertainment.

Please everyone make your donations now to the South West Thames Kidney Fund so that Mark doesn't have to go off and pursue a new career! In addition to his science and comic skills he is also the budding poet responsible for the very amusing 'renalisation' of the Henry V speech!

Michael Hore - our successful auction



was due to your outstanding auctioneering skills - which brought in £3,582.

Peter Scarlett - you are a magician par excellence. Thank you so much for your time and the amazing magic you contributed to our event!

Cheryl Gibson - you offered to help with the floral arrangements on the tables and with the help of your sister you ended up doing the lot. The result was lovely. Thanks very much to you both.

We are so grateful to the following for their many and varied contributions to the success of a really good event:

Accuvison; Mrs June Arnold; Mrs Judy Ashworth; Mrs Lindsay Blazey; Joan Boore; Les Burton; Hayleyanne Fitzgerald; Chris Foster; Cheryl Gibson; Pat Godden; Ian Harrison; Carol

Makanjuola; Claire Martin; Jean Masson; Medical Access; Robin Mulcahy; Joanne Reed; Alexia Ross-Lewin; Jo Russell; Michael Sealey; Kate Shipton; Paul Steele (Eddingtons); Sylvia Watt; the Greensleeves Morris Men and the band Taboo.

And last, but definitely not least,
A HUGE THANK YOU TO ALL OUR GUESTS.



In loving memory of Jean Shaw

4th April 1941 to 12th June 2013

Jean Shaw worked as a secretary on the renal unit at St Helier Hospital for 20 years and was so well-known to all staff and so many patients. Two years ago, on 12 June 2011 Jean was diagnosed as having lung cancer and after a very brave and courageous fight she died on 12 June 2013. She continued to work until six days before her death in St Raphael's Hospice.

She started her secretarial career as a legal secretary and told many amusing stories of working for a very demanding solicitor who insisted that every word be spelt accurately and this early training held her in very good stead for her career in the NHS.

As a young mother Jean fostered many babies together with husband Derek and own three children but when she returned to secretarial work she was fortuitously sent to the Royal Marsden Hospital for three days and she ended up there for 15 months. Following a period in the chest clinic at the old Cumberland Hospital she was recruited to the renal service, and spent the rest of her working life with us.



Jean had a particular talent for making people laugh and it was a lesson in diplomacy to hear her chatting away on the telephone to a patient who might well have been very frightened or very anxious or quite angry. Within minutes all anxiety was blown away and all was smiles and laughter.

Jean's Funeral and Memorial service was held at the North East Surrey Crematorium on 28 June. Eulogies were read by Jean's son David and by Mike Bending with whom she worked for so many years. The service was led by the Rev Chris Lee who had known Jean as a patient and as a great friend over many years

Jean was a shining example of friendship to all who worked on the renal service. She will be sadly missed and we send our sincere condolences to Derek and Jackie and Lisa and David.

MIKE BENDING

In Memory of Pynee Sanjivi

Pynee Sanjivi died on Wednesday 12th June. Pynee was the Chairman of the Croydon Branch of the Kidney Fund for a number of years and produced the Croydon Branch Kidney Fund magazine.

He had not been well for some considerable time, apparently he had lost a lot of weight, he had a recent fall and needed an operation, which he had but had a heart attack soon afterwards.

Pynee will be remembered for all the work he put in to the Branch and his stalls at the Croydon Mela.

Donations in memory of Pynee can be made to the Kidney Fund.

Pat Godden

£10,500 raised from the 2013 London Marathon

Yes another London Marathon is over! This year's team started off eight strong but the numbers dropped slowly due to training injuries (could it have been something to do with the year...?) and we ended up with only four able to take part in the run.

They all completed – well done to them, and here are their stories. Many thanks to all our Renality readers for their generous support of the team!

NICKY SLATER

I managed a very respectable 4.59 in the end, which means I didn't walk and that was my main aim. I had pain from mile 11 but managed to jog slowly on and then had loads in the tank to speed up in the last mile to bring me home under 5.

I was bawling my eyes out as I crossed the line and I know my Dad was with me every step of the way.

Despite the pain I really enjoyed it, thanks for giving me the opportunity of running for you. Here I am (right) having a post-race refreshment!

SIMON WILLIAMS

A huge thank you to everyone for their generous marathon support and to the South West Thames Kidney Fund for the opportunity. After what seemed a long winter of training the sun came out to make it a really special day. I'd gone out quietly hoping to beat my younger self (I last ran London in 2008) but having made a good start my legs started to stiffen going into Docklands. By the time I emerged from Canary Wharf with the positive psychology of heading in the direction of Westminster the legs had seized up and the run turned into more of a shuffle.

I kept going with the help of numerous shouts of support until the Cannon Street tunnel on the embankment when I had to walk. Annoyingly that was more painful than running so I gritted teeth and shuffled another run to the finish. Unfortunately I ended up 4 mins slower than 'younger me' finishing in 3hr 20min but the atmosphere and achievement made it nonetheless special.

JAN SCHUSTER

This being my third marathon I thought it would be great if I could improve slightly on my last marathon time. I felt that my training had all gone to plan and I had managed to stay injury free. Never in my wildest dreams did I expect to knock 12 minutes off my previous marathon and 21 minutes off my previous London Marathon to finish in 4 hours and 2 minutes.

It was a beautiful day and the support was absolutely amazing all the way around. I was fortunate to see my twin sister and brother-in-law just past Tower Bridge. My running club man the water station at mile 13 so there was lots of support there. As you come back that way on the opposite side of the road, I knew that I would see them again at 22 miles which really kept me going. The last 4 miles are incredibly hard as legs were feeling very tired and shoulders were aching. I knew at that stage I was heading for a personal best and therefore that also kept me spurred on mentally and physically.

The last mile is amazing due to the support and the cheering of the crowd. When I reached the finished it is a feeling of real achievement and elation. Having your photo taken with your medal makes all the hard work very worthwhile and I am delighted that I have been able to raise my sponsorship for the South West Thames Kidney Fund. My next goal is to run a marathon in sub 4 hours and therefore I have arranged to run the Brighton Marathon in April 2014

CHARLES HARVEY

I made it round, managing to run to 14 miles before my knee and ankle started giving a bit of a problem. By 17 miles I was down to a walk. For the last 2 miles I managed a Herr Flick style limp waddle and made it over the finish line in under 5 hours. Thanks to the South West Thames Kidney Fund for the opportunity to take part!

Congratulations to everyone for getting around safely!!



When work gives you a BUZZ...

MARK DOCKRELL
Institute Director

Greetings Loyal Renality readers.

Well, we may have had the wettest dullest spring in years but SWTIRR has been buzzing with activity – even more than usual... preparing papers for publication, developing a new test to screen drugs and pollutants to see if they are damaging to the kidney, submitting papers to conferences, meeting with prospective business partners, having discussions about patenting some of our discoveries and going on foolhardy long sponsored walks – that Anne Collard has a lot to answer for.

But I would like to start with some news from the labs.

From time to time I like to tell you about some of the talented people I have the pleasure of working with at the Institute and I have previously mentioned the Kidney Fund Young Scientist PhD Research Fellow, Buzz.

About three years ago I was interviewing candidates for the fellowship and they came from far and wide, one lady came all the way from Italy but in the end we chose a home grown talent.

Buzz was a quiet self-composed young man who was just completing a Masters of Research at St George's, he interviewed well and he had glowing references.

However, the project I had planned was going to be a real test for him; we don't do easy things at SWTIRR, we take on ideas that others might shy away from.

I wanted Buzz to study a very interesting signalling molecule called Erk5. Our previous work had suggested that Erk5 may have a role in kidney disease but it had never been studied in a very important and curious cell in the kidney called the podocyte.



This was to be Buzz's challenge. I have written before about how Buzz battled through difficult times of no results and investigating dead ends but the reason I'm writing about him again is that Buzz is coming to the end of his time at the Institute.

Now he must start the formidable task of pulling together all the work of the last three years, make sense of it and write his PhD thesis.

Buzz has used his natural dogged determination combined with some newly sharpened tools of insightful thinking to dissect many of the varied aspects of diabetic kidney disease and identify how they regulate Erk5 in the podocyte, a mammoth task in itself but more than that he has developed new tools to see how Erk5 then goes on to regulate the behaviour of the podocyte.

In the final months of his time in the lab he has made some wonderful discoveries, of course it is the irony of a PhD that you spend a lot of time doing the tedious ground work only to get to the really exciting work just as the curtain is closing. I hope to build on the work Buzz has done to advance our understanding of diabetic kidney disease. We should be



proud of the contribution he has made and wish him the best for the future – but first he has to write that thesis.

Of course as one chapter comes to an end there are always new ideas bursting forth. For some time at the Institute I've had the good fortune of working with Sarah Yates.

Sarah has taken on so many different tasks that it would be impossible for me to list them, another quiet unassuming member of the team whose contributions are ever present.

One of the projects Sarah has been working on has been developing a screening test to try and identify substances that are harmful to the kidney. This is really very exciting work and I'll tell you more about it in a future edition of Renality but I thought I would just quickly mention one little bit.

Sarah has been setting up a test where she exposes human kidney cells in the lab to a range of agents including, drugs and pollutants and trying to establish whether we can detect the damage they do. Her preliminary results have shown that she can do exactly this; we hope that this work will establish a new test that can be used to help prevent kidney damage in the future. Watch this space.

So what about that sponsored walk? You can see how I managed on the opposite page but I can tell you now, it wasn't a walk in the park!

100k WALK WAS REALLY A FEET OF ENDURANCE

SIMON BUTLER writes...

As you may be aware, I am a keen supporter of the South West Thames Kidney Fund and if there's a challenge thrown in then so much the better.

This year I decided 26.2 miles (a marathon) was not enough of a personal trial so I signed myself up for the London to Brighton challenge.

The challenge requires entrants to trek from London to Brighton over all sorts of terrain and all within 30 hours.

We set off from Richmond Old Deer Park in the early hours of the morning on Saturday 25th May. We walked and occasionally ran the 100kms (about 62 miles) to Brighton arriving some 28 hours later.

The course had us walking through the day and night covering a variety of obstacles including the odd hill, a few muddy slopes, several wobbly bridges, a fallen tree, and what felt like 100 stiles.

In order to fully earn the sponsorship money which many of you kindly pledged I even completed a few extra kilometres to make sure. When darkness fell I realised I was missing my head torch and had not seen it since the last checkpoint. Since a large proportion of the night would be spent trekking through woods I left my colleagues and jogged back to the last check point to try and find the torch.

Alas, despite checking the places I had been, and scouring my back pack yet again, I could not find it.

I decided, as a final resort, to ask the organisers if such a torch had been handed in. To my disappointment they hadn't had any lost property handed in but kindly pointed out that if I was stuck for light I could always use the device around my neck...

I then jogged back to re-join my colleagues to restart the night session, failing to mention my slight oversight.

It was around mid-day Sunday when the finish line in Brighton came into view. Having crossed the line I felt a combination of relief and joy, as in 28 hours 28 minutes I had covered a solid 100km, seen some fantastic scenery, met some great people and collected several blisters as souvenirs.

Without a doubt this was my hardest challenge to date, my feet are only just returning to normal, but it was worth it. For those of you interested in the challenge next year search London2Brighton challenge online and I hope to see you at the start line in 2014.

And here's how Research Institute Director Mark Dockrell suffered, too...

Well against my better judgement but goaded on by Anne I decided to walk from London to Brighton to raise money for the Kidney Fund.

Friends I can tell you it was hard. We walked all day and all night, there were times when, with more blister than foot in my shoe and my poor old legs screaming at me to stop, I very nearly did.

After 80km at 2.30 in the morning I was ready to give up, but as you know giving up is not the SWTIRR way.

If we give up just because it's hard we'll never find a cure for kidney disease, so I went on. By 7 am I had reached the finish line and thanks to the generosity of my sponsors I raised £1500 pounds for our research.

Well after all; funding allows research and research will lead to a cure.



BIKE RIDE 'FREEDOM'

CORRINE FRANCIS writes...

Please know I had the best challenge taking part in a Team from work in the London to Brighton cycle ride that took place last Sunday, 16/06/13.

However, this was a personal challenge for me, as I am now currently 17 month post kidney transplant; after being into my 11th year on renal dialysis; 5 years on Peritoneal Dialysis and the start of 6 years on Haemodialysis.

For me, it was like a cycle ride to relative freedom; knowing how much it is to be pinned down for many years, having to be supported to live life through 'technical' support!

I totally enjoyed the whole of the 54 miles it took to get to Brighton; even when it took forever to get out of Clapham and having to stop a good few times due to so many enthused and happy cyclists! All credit to **every-one** that took part in the event.

I completed my 'freedom cycle ride' challenge in 6 hrs on the button; possibly could have done it a lot sooner, if not for the above, but all was good; shared my chocolate; spoke with fellow cyclists; enjoyed the views. I actually rode through the finish- line with an unknown puncture; on what I called my 'ghetto' bike (bought for £60 from Gum-tree and cleaned up) 'pimped' with two new tyres and a very good new gel seat!

It was a brilliant experience and I can say I virtually 'bounced' the whole way!

I trained good and hard for the cycle ride; completing back to back Spin Classes (2hrs); riding out and about up to 30 miles; going swimming and to the gym; walking my dog Tyler; and playing badminton with my youngest son.

All the above I could do was because of gaining a Kidney; that was transplanted by very clever, skilful and dedicated persons; from our valuable nurses to Surgeon. And with all those in mind it brings about why I also decided to do the challenge; to give some-thing back. Therefore without those involved from the above to those in Research, I may not be here today.

I am a very proud mother of four beautiful grown children; two precious adorable grand-children; happy to call myself a Jehovah's Witness; who is trying to work hard for a living; and hopefully contributing more fully to society!

I completed my 'freedom ride' with well trained relative fit body and mind; lots of heartfelt prayers for those who could not join me due to being 'held up' on renal dialysis; and moreover, with sincere thanks and gratitude to the most loving and kind person who donated their kidney to me....that has enabled me to live on and truly enjoy life within this system of things!

Please see link for any further possible donations to the 'South West Thames Kidney Fund' that supports Kidney (Renal) Research <http://www.justgiving.com/Corrine-Francis>

Big Thank You

Ride London-Surrey Event

We mentioned in the May issue of Renality that the Kidney Fund has been allocated 5 places for the Ride London-Surrey 100 event to take place on Sunday 4th August 2013.

We can now announce that all our places have been filled and would like to send our very best wishes for a safe and speedy 100 mile cycle to our five intrepid cyclists:

Justin Dunn; Harvey James; Luke Morris; Richard Bowen and Matthew Hopkins (CEO of the Trust).

The very best of luck and many thanks to all of them. We will update you with their progress and stories in the August/September issue of Renality.

WELL DONE, DENNIS

Our congratulations and thanks to Mr Dennis Court who completed the Shepperton Round Table 10K Thames Walk on the 10th May and raised £252 for the South West Thames Kidney Fund.

This was no mean feat - Dennis is 77, due to start dialysis shortly, and in October 2011 he had a stroke. He has been working hard doing three hour gym sessions, three times weekly to speed his recovery. In Dennis's words:

'I took a big step forward and entered the Shepperton Round Table 10k Thames Walk... Having competed in 3 London Marathons in my early days '82, '83 and '84 - best time 2 hours 27 minutes - my 2 hours 5 minutes for the 6 mile walk seemed slow, but I was just as pleased'

In addition to achieving his 10k walk Dennis is keeping his fingers crossed that he will be back on the golf course again soon. I'm crossing my fingers too! (Anne Collard)

SNACKS ON DIALYSIS

A question for all patients

Managers of the Renal Unit would like to know:

Would you be prepared to bring in your own snack (other than biscuits provided by the unit) or ask your nursing home to prepare you one for when you are on dialysis ?

Please either email Sara Jobson sara.jobson@esth.nhs.uk or put a note in the boxes provided on the units

Renal Patient View: Frustrating delays on blood test results

Linda Wichall lives in North East Hants and had her kidney transplant in 2011. She writes:

I read with interest the letter in February's Renality regarding the problems experienced by Steve Purcell in getting blood taken at his local GP.

Fortunately, I've been lucky enough to have received excellent care from my local GP practice, which has been happy to take blood for testing.

My problem relates to what happens to the test results after processing by Frimley Park Hospital.

I guess that most kidney patients are familiar with Renal Patient View (RPV), the system designed to give patients speedy access over the internet to their blood results. When blood tests are conducted at St Helier, the data is made available to my consultant and also up-loaded to RPV, normally within 24 hours.

Until about nine months ago, results from tests conducted by Frimley Park were also available on RPV though, understandably, they took a day or so longer to appear. However, from August 2012 data from Frimley Park started to take 3-5 weeks before appearing, or was not posted to RPV at all. The situation further deteriorated at the end of 2012, since when virtually none of my results from Frimley Park have made it on to RPV.

In my view Renal Patient View is an excellent system, when working properly. It provides an up-to-date set of results from the blood tests taken between the 2-3 month visits to see my consultant, which allows me to monitor my progress and to check on any changes compared to previous results. However, virtually all benefits are negated if blood results are lost or unduly delayed.

Numerous unsatisfactory answers have been given by staff at both St Helier and Frimley Park as to why the system is not working as it should, but none that I have spoken to appears to know what the problem is, whether it can be fixed and, if so, when. I'm confused and disillusioned. Am I the only one, or have other patients suffered similar frustrations?

To have your say on this or any other issue email steve_purcell@btinternet.com or write to Anne Collard c/o Renal Unit, St Helier Hospital, Wrythe Lane, Carshalton SM5 1AA



TIME TO THINK ABOUT CHRISTMAS CARDS

IT might still be summer but it's time to remind you all that there's another major event looming after Wimbledon. Yes, that's right, Christmas is a-coming and the cards are laying flat. But now's the time to think ahead and order your special SWTKF cards and help raise funds for our vital research!! Ask about them at the Renal Unit and look out for full details in the next issue of Renality.

HOLIDAY DIALYSIS

What you should know

Thinking of going on holiday or need to dialyse away from home for a short while?

The Trust wishes to support as many people as possible to experience the freedom of going on holiday, and for this reason, we employ a Dialysis Away from Base Coordinator to support you in arranging this.

So, what should you do?



BEFORE YOU BOOK

1. Check with your consultant that you are fit to travel.
2. Source the unit closest to where you want to stay. You can use either of the sites below for guidance to help you find the nearest unit.

For the UK: www.renal.org/unit/

For outside the UK: www.globaldialysis.com

If you are staying with a friend or relative, you can ask them to help you look for local units.

2. Secure your dialysis dates with the unit of your choice. Please note that if they do not have availability for the time you have requested, you may have to find the next closest unit to where you are staying.
3. Once you have secured your dates, contact Lindsey Blazey our Dialysis Away from Base Coordinator on 020 8296 3454 or email Lindsey.Blazey@esth.nhs.uk
You must pass on contact details of the unit, such as contact name, telephone and fax numbers and email so that Lindsey can contact them directly.
5. Lindsey will then liaise with both your home and chosen away from base unit to get your paperwork prepared for your holiday.

DO NOT BOOK YOUR HOLIDAY/ FLIGHTS UNTIL YOUR DIALYSIS HAS BEEN CONFIRMED.

Additional Information

Insurance

If travelling to a European country, please ensure your European Health Insurance Card (EHIC) is up to date as most units will ask to see it prior to your arrival. If you do not have one, please visit <http://www.nhs.uk/NHSEngland/Healthcareabroad/EHIC/Pages/about-the-ehic.aspx> or phone 0845 606 2030 to apply .

Do I have to pay for dialysis?

Not if you dialyse in the UK or Europe (countries in the European Union) or some countries where we have special arrangements like Australia and Barbados.

If you wish to travel abroad to countries outside the EU and we don't have special arrangements such as South Asia and the USA (check with Lindsey for others) **you will be responsible for dialysis costs** if you travel to these places. This also applies to cruise ships.

Please note that we require a minimum of 6 weeks' notice in order to complete the necessary paperwork.

If you have any queries regarding the above, please do not hesitate to contact Lindsey.

A letter from ALISON JONES, General Manager, Renal

Re: Holiday Dialysis Arrangements

Dear Patient

The Holiday Co-ordinator requires an absolute minimum of 6 weeks notice, whether you have booked holiday dialysis yourself or require the holiday co-ordinator to help you with this. Due to the number of patients we now have, the Holiday Co-ordinator will no longer take bookings where the required notice of 6 weeks minimum has not been given. This request to patients is supported by the Management Team.

Patients are advised not to make a definite booking for their holiday accommodation/travel until you have received confirmation from either the Holiday Co-ordinator or you have personally received confirmation that dialysis treatment is definitely booked for you at a holiday dialysis centre.

These web sites will help you to find the nearest Unit to where you want to stay:

For the UK: www.renal.org/unit

For outside the UK www.globaldialysis.com

In the past we have provided dialysers free for patients to take on holiday with them. However, this is no longer the case.

If patients specifically request to take dialysers with them on holiday they will now be required to pay the current cost of £10.00 per dialyser. **Please be aware that some units actually request them, so you will be asked to pay the required amount.** The Renal Unit will need to raise an invoice in advance so that payment can be received before the dialysers are provided (we will need at least two weeks notice for dialysers). Payment can be made by cash or credit card.

It is the patient's responsibility to obtain permission from your Consultant to have a planned holiday.

Please be aware that any cruises that offer dialysis on-board are classed as "private" and therefore the patient has to pay for the dialysis treatment, even if the cruise is in or around Europe. The EHIC card is not accepted for payment of dialysis treatment on a cruise liner.

The Unit Policy is that patients who dialyse outside the UK will require a period of isolation on their return. This may also mean that you will not be able to immediately dialyse at your normal dialysis unit or time due to the limited isolation facilities in the individual units. Please discuss with your Consultant/Dialysis Unit Manager. The isolation period could be up to eight weeks.

Patients who are on the Transplant Waiting List – you should inform the transplant sisters' when you are going to be away.

- If you are holidaying in the UK the transplant team will require additional contact numbers so that you can remain active on the transplant list
- If holidaying anywhere outside the UK, you will be suspended from the active list until you return. You are responsible for contacting the transplant team on your return to the UK.
- When returning from outside the UK, a risk assessment will be undertaken (which could mean you cannot be re-activated for up to two month's).

There is no limit imposed on the number of sessions you are allowed to have for dialysis away from home, but it is recommended that patients do not dialyse away from home for a single period longer than 3 months.

Yours sincerely

Alison Jones

General Manager – Renal

KIDNEY FUND CALENDAR COMPETITION WINNERS

I would like to thank all entrants who sent in their photos, the standard of images we received was very high which made it all the more difficult for the 3 judges to choose the winning images. Thank you to the co-judges Nick Lewis and Vip DeSilva for all their help in choosing those 12 final images. Thank you also to Anne Collard who has worked tirelessly to put the competition together and arranged for the calendars to be printed with the winning images. I hope all the Renality readers will show their support of the great work, effort and artistry put into the resulting calendar by reserving one (details below) or purchasing one when they are on sale. I am sure they will be perfect as gifts for Christmas and birthdays as well as treats for yourselves in your own homes. I know I will be buying one. Thanks again to all who took part and were involved in the production of the calendar. *Scott Brawn*

The winners (in no particular order) are:

It's a Wonderful World/Life

November Mist: **Lynda Morris** Happy Eater: **Val Straw** Autumn Moon Over New Quay Harbour: **Tom Thorpe**
Spring Blossom in the Morning Sun: **Sue Beesley** Reflections: **Charles Moss**
Forever Autumn: **Louise Lynott** January Robin from my Kitchen Window: **Lynda Morris**

Miscellaneous

Bee in Clover: **Tom Thorpe** Dawn Over Spirit Lake: **Bruce Burgess**

Time Out/Holidays

Autumn at Frimley Park: **Jo Thorpe** Sunset at Bosham: **Lynda Rowell** Sails in the Sunset: **Val Straw**

Our congratulations to you all!

How to order your 2014 Kidney Fund Calendar:

The calendar will be produced as an A3 13-leaf hanging wall calendar and we estimate it will sell for approximately £8.00 plus postage and packing. We will also produce a smaller, possibly desk sized version but details have not yet been decided.

Please either email Anne.collard@kidneyfund.org.uk or phone Anne on 0208 296 3698 if you would like to reserve your beautiful 2014 Kidney Fund calendar now!

Our thanks to Scott Brawn for coming up with the calendar idea and agreeing to judge the competition. Scott is a professional photographer and one of our Renality readers. If you would like more information on Scott's work contact Anne and she will give you the details.

We are looking for corporate sponsorship for our calendar. Please let us know if you are interested.

WIN THE LOTTERY

If you join The Kidney Fund lottery you will have a chance to win in excess of £100 every week.

AND The Fund wins the same amount EVERY WEEK!!!!!!

This is what we call a WIN WIN situation - **BUT** you can only be a part of it if you join!

All it takes is £1 per week. One you join you will be given your unique lottery number.

All lottery numbers are entered into the weekly draw. The owner of the winning number will receive 50% of the weekly entry money and the Kidney Fund will receive the other 50%.

It's that simple! **BUT** you can only win if you join! See recent winners, right!

To enter either email lottery@kidneyfund.org.uk phone 0208 296 3698, or visit www.kidneyfund.org.uk/lottery where you can download a form.

GOOD LUCK!!

18/01/2013	101021	Shepperton	£101.50
25/01/2013	101069	Addlestone	£103.50
01/02/2013	101168	West Molesey	£103.50
08/02/2013	101039	Frimley	£103.00
15/02/2013	101065	Cheam	£103.00
22/02/2013	101079	Walton on Thames	£103.00
01/03/2013	101017	Surbiton	£103.00
08/03/2013	101121	Addiscombe	£107.00
15/03/2013	101167	Epsom	£107.00
22/03/2013	101027	Wallington	£107.00
29/03/2013	101142	Farnborough	£107.00
05/04/2013	101034	Streatham	£107.00
12/04/2013	101162	Farnborough	£107.00
19/04/2013	101019	Shepperton	£108.00
26/04/2013	101183	Guildford	£108.00
03/05/2013	101111	Farnborough	£108.00
10/05/2013	101154	Cheam	£108.00
17/05/2013	101107	Kingston	£108.00
24/05/2013	101040	Guildford	£108.00
31/05/2013	101080	Fleet	£108.00
07/06/2013	101202	Epsom	£108.00
14/06/2013	101184	Carshalton	£105.50
21/06/2013	101180	Whyteleafe	£105.50
28/06/2013	101197	Worcester Park	£104.00