RENALITY

The NEWSLETTER of... *November 2015*

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



YOUR TURN TO BE A MUDDY MARVEL

LIKE the queens of breakfast television Kate Garraway and Susannah Reid (left) YOU can take part in the Tough Mudder challenge thanks to the South West Thames Kidney Fund.

The hosts of Good Morning Britain, Kate and Susanna, joined the merry mudlarks along with X Factor's Sam Bailey and Liberty X singer Michelle Heaton in September. Now you can get down and dirty, too.

We have 10 places available for next year's event which involves taking part in a team over a 10-12 mile obstacle course. Full details are on Page 13

It's that time of year once again



We have a really nice selection of Christmas cards this year. There are limited numbers on some of the cards, so first come first served! All proceeds will go to support the South West Thames Institute for Renal Research!

Cards are £3 per pack of 10 same design cards. Postage will be additional. But the cards will be available to buy at St Helier Renal Reception and on the Tea Stall in the St Helier outpatient waiting room. To order your cards please email christmascards@kidneyfund.org.uk or phone 0208 296 3698.



...AND WE BID OUR FOND FAREWELLS TO PETER SIMPSON & ANNE COLLARD

Full story: Pages 8 and 9

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RENAL UNIT reception:

020 8296 2283,

020 8296 3100

SWTIRR & SWTKF:

020 8296 3698

SOUTH WEST THAMES

KIDNEY FUND,

info@kidneyfund.org.uk

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 020 8296 3698.

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

Create a **standing order**

Donate via payroll giving

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

Shop 'til you drop and Give as You Live!

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

Sell an item on ebay

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

Buy our **Christmas Cards**

Donate shares

Donate your tax refund

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

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

follow us at www.twitter.com/renalresearch

RENALITY

is now available on CD, PDF form & large print

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

We thank Graham Morrow who produces the electronic version.

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

07970 675087 or

email: steve_purcell@btinternet.com

REMEMBER...

our website addresses are:

South West Thames Kidney Fund:

www.kidneyfund.org.uk

South West Thames Institute for Renal Research:

www.swtirr.org.uk

St Helier & Surrey Kidney

Patient Association

www.shskpa.org

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

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

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

BUNBURY CRICKETERS RAISE OVER £20,000



Back in August, The Bunbury Celebrity Charity Cricket Team played in Purley for the first time to raise money for the Kidney Fund. The Bunburys were formed by Dr David English CBE 29 years ago after he retired from managing Eric Clapton and The Bee Gees, and over the past 29 years they have raised over £17million for a wide range of good causes.

Around 400 people packed into the marquee on the sunny day to join the Bunbury Celebrities including former England Cricket Captain Adam Hollioake, Harry Potter actor James Phelps and ex England and Crystal Palace footballer John Salako.

The day was an amazing success, with over £20,000 being raised on the day with help from Wates Group, who were the main event sponsors.

The event was inspired by an idea from Renal patient and Bunbury Nick Ford while he was being treated for kidney failure at St Helier in September of last year, and a chance meeting with Nurse Sarah Bowen on Secombe Ward meant that Nick was put in touch with the Kidney Fund while he was having a blood transfusion!

Thanks Sarah for your prompt action!! Big thanks also to Anne Collard and Maggie Porter for all your work and to everyone else who contributed to the success of the day!!

ZERO TOLERANCE

For Violence and Aggression towards our HD staff

Alison Jones, General Manager, Renal Unit, writes:

We understand that for many reasons sometimes you may not feel well or are frustrated by your transport waits or waits to get on the machine and this can affect your mood.

However we have been concerned at a rise in violent and aggressive behaviour towards our Ambulance and HD staff. Please ask to see a senior member of staff or matron if you feel things are getting on top of you, or ask to be referred to our counsellor, Celia Eggleling. We will do everything we can to help you through things.

Nevertheless we won't tolerate persistent aggressive behaviour and certainly not violence towards any of our staff, and will take measures to protect our staff (and other patients who are affected by this conduct), and will look at alternative ways of providing dialysis to any patient who will not comply with this reasonable request.

Thank you, Alison Jones

The Pursuit of Excellence

Peter Andrews, Clinical Director

"We are what we repeatedly do. Excellence, then, is not an act, but a habit." Aristotle

With the eagerly anticipated visit of the Care Quality Commission (CQC) scheduled for the beginning of November, the last few months have seen a huge effort to showcase the quality of the services we are providing.

For those not familiar, the CQC is the regulatory body which inspects NHS facilities and services. Inspections occur at least every three years and are widely reported.

A poor report may have consequences including immediate shutting down of inadequate services and the sacking of the senior management teams, so it certainly concentrates the mind; while a good report is a validation of all the hard work that goes on behind the scenes.

Hospitals are judged by five main criteria:

- Are the services safe?
- Are they effective?
- Are they caring?
- Are they responsive to peoples' need?
- Are they well-led?

By the time you read this, we may already know the answers to these questions (if we didn't already!). More likely, the full report will come out in the New Year.

In the meantime, the CQC visit provides an opportunity to list some of the other checks and controls that hold us to account, all of which are designed to ensure that services are consistent and of the highest possible quality:

- London Peer Review of Renal Services
- London Quality Standards
- Unit and National Protocols and Guidelines
- Unit Information Sheets and Consent Protocols
- Key Performance Indicators
- UK Renal Registry Reports (dealing dialysis and transplantation)
- NHSBT / ODT Reports (dealing with organ donation and transplantation)
- Serious Incident Reports
- Incident (Datix) Reports
- Internal Audits of services (e.g. OPD and cancer waits, time to transplant waiting list)
- Complaints and Commendations
- National Guidelines (Renal Association, British Transplantation Society)
- International Guidelines (KDOQI)

- Performance, Risk, and Clinical Assurance
 Panel meetings
- Infection Control meetings, HD and PD reviews, Transplant and Access MDT meetings
- Individual Peer Review, incorporating 360 degree and patient feedback
- 'Quality Directorate' overseeing quality throughout the Trust
- Appraisal and Revalidation, including GMC and GNC review of medical and nursing staff
- Financial Performance Reviews
- Human Resource and Sickness Reviews
- Legal frameworks

Phew! If you think that sounds a lot, you are right. There is – rightly – a huge emphasis on quality, and I hope this shows through in all that we do.

I would particularly like to highlight two areas other than the CQC that are influencing our current practice.

First, as you are aware, there is a huge drive to ensure that acute services are provided to a high standard across the working week and at weekends.

The London Quality Standards (LQS) cover the provision of acute medical and surgical services and are a major driver of improved services within the M25.

Partly in response to this, we are well advanced at St Helier in providing 24-hour seamless care on every day of the year, and lead London in many of the quality standards such as waiting times in A&E.

The other area to highlight is the London Peer Review of Renal Services. More renal-specific than the LQS, this is an initiative in which the seven major London Renal Units have agreed to conduct reviews of each other's services, share best practice, and help ensure that all are providing the best possible care to all patients.

This is a self-generated initiative which is being closely monitored by NHS England and may provide a model which will be widely adopted across specialities. As in many things, Renal leads the way!

So I hope that you are reassured by the above, irrespective of the ruminations of the CQC. Measurement is important, ongoing, and we come out well.

But sometimes I wonder if, in the effort to document everything, we risk losing touch with the really important things: holding the hand of a sick or loved one; telling people they are appreciated; smiling; enjoying; remembering what a privilege it is to share other people's lives.

The most important things can't actually be measured.

"The trouble with not having a goal is that you can spend your time running up and down the field and never score" Bill Copeland

The Pursuit of Rabbits

The further adventures of ELSA

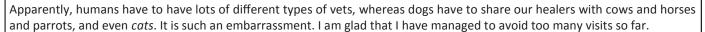
This has been quite a busy few months. The new kennel complex is progressing well, although there are no roof or stairs yet, so opportunities for inspection have been limited.

The space allocated for me appears to be satisfactory, although I'm a bit suspicious about its proximity to the washing machine. I *refuse* to go in! And the TV would be much more entertaining...

At home, the matriarch has been bossing us around as usual, and still makes the floor slippery by washing it at least twice a day. However, I think she has finally fallen for me and, to be fair, she is a very reliable hunter-gatherer.

Meanwhile, the senior pup has decamped to the far north to study Politics and Economics. I miss him. And the junior

pup has decided to become a human vet. This has made the pack leader very happy!



Although, on the positive side, you are always offered a biscuit if you don't mind having your temperature measured. Which reminds me: why do humans always put the thermometer in their mouth? Yuk!!



SIGN UP FOR A PDF - MAKE SURE YOU ALWAYS GET YOUR COPY OF "RENALITY"! DID YOU KNOW ...

- If your appointments at the Renal Unit drop to 2 or less per year, you will be removed from the 'RENALITY' mailing list and will no longer receive the newsletter.
- You can receive a PDF of 'RENALITY' by email just email Graham.Morrow@kidneyfund.org.uk and he will add you to PDF distribution list.

Receiving a PDF will not stop you receiving the postal copy if you are on the mailing list. You can receive both, and share the PDF with family and friends.

However, if you are happy to receive your news online rather than receiving a copy through the post email anne.collard@kidneyfund.org.uk and we will remove you from the mailing list.

Recognise kidney failure for the purposes of PIP and ESA

KAREN THEOBALD writes:

Many kidney failure patients are being turned down for Personal Independence Payment as they do not easily fit into the regulations.

They are also being put in the Work Related group when claiming Employment Support Allowance instead of the support group as they do not fit into a category easily.

There is a petition at https://petition.parliament.uk/petitions/104849

Please forward it to everyone in your mailing list you know, or any other ways you can think of promoting it.

SHSKPA NEWS

8th ANNUAL CONFERENCE ON HOME DIALYSIS

24 – 25th September 2015 By PAUL CONNOLLY

This annual conference is designed for doctors, nursing and industry staff to share best practice. As a patient it was most encouraging to see this.

There were a few patients there who also shared the platform and spoke; listened to by all the delegates.

There were a few reasons why I wanted to attend this conference and as Vice Chair of the St Helier and Surrey KPA, I wanted to report back on the latest thinking and technologies at the renal units around the country.

I can honestly say at St Helier we are up there with the best as far as home haemodialysis is concerned.



It was great to see Dr Ginny Quan our HHD consultant and Clair Laidlaw one of our HHD nurses (above) there; listening and sharing best practice with their peers.

All the dialysis manufacturers were there with the latest machines on their trade stands. I feel we are still doing well with the machines we use at St Helier and in our satellite units, being the Fresenius 5008.

Having been on dialysis nearly 17 years, with five of them at home, I surprised myself in understanding a lot of the speakers, even though a few of the Consultant presentations did go straight over my head!

As I look back on the conference two key things stood out for me. Firstly, a talk by Fiona Loud on Dialysis patient's perspective, choice, participation and dignity.

The second was the overall low up-take on home haemodialysis across the country. Having dialysis at home for a few years now, I found it hard to understand why more patients would not want to engage.

I would like to encourage suitable patients to sit down with their partners or carers and write down the pros and cons of home haemodialysis. We have great training that will take as long as it takes and patient safety always comes first. No one will be let home until they are compliant with the machine and the safety around it.

As far as needling goes I would encourage you to maybe start to watch the professionals in the unit when attending your dialysis session. I used to turn away but decided I needed to get my head around how I could possibly do this myself. I started to watch the professionals, asking questions and after a while had the great courage to have a go myself.

The first time I needled myself was at the West Byfleet Satellite Unit and I cried!! Not in pain but in happiness as I knew what a great difference this could make to my dialysis dependent life.

In conclusion the pros and cons of home haemodialysis may come in another article but if anyone needs a patient's point of few on any aspect of home HD please email me on connollypaul@hotmail.co.uk and I will try my best to help.

I also occasionally attend the Patient Education Programme days held at St Helier for pre-dialysis patients. These sessions are held to discuss treatment options for the future when dialysis becomes necessary. The home haemodialysis team are also willing to answer any questions you may have so please feel free to contact the team on 020 8296 4531.

KPA MEMORIAL DONATIONS

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

- Peter John Tearall
- Sylvia Charsley
- Myrna Gertrude Geraldine Quayle
- R Austin

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
- Michael Dale
- Denise Emmerson
- Wheatsheaf Public House, Ewell

A message from your Chairman

I am nearing the end of my ninth year as Chairman and I am more than happy to continue for another year. I hope that the patients and the renal unit staff are pleased with the work that the KPA's Committee has done on your behalf over the last year.

On a personal note I would like to thank all of the Committee members, all of our Volunteers including those on the Servery together with the Renal Unit staff all of whom provide invaluable support to the KPA throughout the year.

We have over 770 members so we're kept pretty busy dealing with the many and varied requests which we receive from both patients and the renal unit.

As in previous years I thought it would be good to show how we have distributed our funds during the past year. These include:

- A Profiling bed for Farnham and another for Kingston
- 2 Evolution Dialysis chairs for St Helier
- 4 TVs for St Helier with aerial and power installations.
- Wheelchair Weighing Scale for St Helier
- Bariatric Dialysis chair for St Helier
- 6 x 24Hr Ambulatory Blood Pressure Monitors
- TABs fall monitor system for St Helier
- 70 Renal Overlays for St Helier and its Satellites
- £5000 towards an Icepod isolation unit at St Helier
- Furniture & TV for Beacon Day Room at St Helier
- Enhancement of the HD waiting area at St Helier
- Wheelchairs for Mayday.
- Renal bedside folders and shared care pamphlets
- Home therapy DVDs
- Patient seating for the phlebotomy area at St Helier
- Financial assistance with Holiday Allowances, Travel Benefits and Amenity payments to a higher level than any previous year.
- Financial support of the participants in the St Helier Team at the Transplant Games
- Supporting of a number of buffet lunches and PEP's

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

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

If you feel that you are unable to purchase them can I please ask you to return them to the address printed on the tickets as we had requests for additional books last Dave Spensley, Hon Chairman

year? As there is no longer a St Helier patient lunch, the draw will be made at the renal unit on Wednesday 9th

December during our Committee meeting; we will be asking the renal and dialysis patients to draw the winning tickets.

Wheatsheaf **Public House**



reported in last edition the Wheatsheaf

held a Fun in the Pub day and raised a magnificent total of £3,300 which they presented to me (see photo below) Once again thanks to the Management, Staff and Patrons of the Wheatsheaf. This donation will go a long way to supporting renal patients.



Lee Hull, Wheatsheaf Manager with Dave Spensley

Committee/Patient Representatives

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

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

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

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

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

Best Wishes

A Fond Farewell to Peter Simpson

Almost 30 years ago Peter and Margaret Simpson volunteered to help the St Helier Kidney Patients Association. SHAK raised funds for patients who needed help with transport, equipment and holidays etc.

They raised (and SHSKPA continue to raise) many thousands of pounds. Shortly after a new group was formed called the South West Thames Kidney Fund, this new group was raising money to build a research laboratory to be built at the rear of St Helier Hospital renal unit.



Peter and Margaret were involved in both groups and needless to say the Research Institute was built after a lot of work and dedication.

The SWT Kidney Fund (Frimley Park and Guildford Branch) and SHAK was where Graham and I joined 24yrs ago and we met Peter and Margaret and a very motivated group of folk. Over the next years our small group raised many thousands all due to the dedication, determination and drive steered by Peter and Margaret.

Sadly Margaret passed away last year, but she will never be forgotten and now Peter has decided to retire and move to join his family in Wales. We will miss him terribly but we will be forever grateful to them both.

Graham and I have been working alongside them both for these past years and it's been fun, exhausting but very rewarding. I am so glad that my family and I have been able to dedicate the time and seen what has been achieved.

Now it's time for Peter to relax and look back with pride at what they both did for the SWT Kidney Fund and SHAK.

THANK YOU TO BOTH PETER AND MARGARET - YOU HAVE BEEN AMAZING.

Angie Morrow (Angie is pictured above with husband Graham and, sitting, Peter Simpson)

SWTKF Chairman Dr Michael Bending writes...

Dear Kidney Research Fundraisers,

Earlier this year the Kidney Fund commissioned a review of our fundraising operations.

We approached "Comptons", an organisation responsible for the highly successful fundraising efforts of St Christopher's Hospice.

This week they have delivered and presented their report which highlights the difficulties of funding basic scientific research on an isolated District General Hospital site.

Originally this was a great benefit to the Institute because we were free of University and Medical School restraints. Now, however, research interests on the Renal Unit have evolved significantly, with a new intake of keen young Nephrologists.

This presents an exciting opportunity to broaden the research profile of the fund.



It is hoped that this will recruit a more inclusive era of integrating laboratory and clinical research. The object of the exercise, as always, is to improve the out-come of treatment for the benefit of Kidney patients, now, and in the future.

It will not reduce the work Mark Dockrell has been doing which last year resulted in a £150,000 grant from Kidney Research UK or his plans to recruit a new scientist for the diabetic kidney disease research. My hope is that it will

strengthen his efforts to get more external funding.

This new initiative is made possible by the appointment of Dr David Makanjoula as the new vice-chair of the fund and the co-operation of the Trust R&D lead Dr Pauline Swift.

We will be discussing these developments in full at our AGM next week, 23rd October.

We will let you know the outcome of these initiatives in the next edition of Renality.

Whatever the new direction we are forever indebted to our supporters over the last 30 years that has made the commissioning and building and operation of The Institute for Renal Research at St Helier Hospital such a success.

Personal best wishes Dr Michael Bending

Anne Collard says farewell after 12 years as Administrator of the Renal Institute

Very sadly, my job as Administrator of SWTIRR is no longer to be funded by the Hospital Trust and is now considered by the Trust to be redundant. The reason is that the position does not "directly contribute to Renal and the Trust's work" so I will be leaving in November.

I have been very lucky to have come to know so many fantastic people in the past 12 years.

I have thoroughly enjoyed working with all the amazing scientists/researchers at the Institute; the wonderful people who are involved with the Kidney Fund; and the friends I have made along the way.

I have also been very touched by the generosity of the really kind and often very busy people who volunteer their time; respond to requests by bringing in prizes for

events; join in or initiate fundraising events; sponsor or donate towards events and generally support the Fund in any way they can. The Institute could not survive without your support and I shall miss you all.

A few weeks ago I was invited to a farewell party for Peter Simpson who (with his wife Margaret) was deeply involved with both the Renal Unit charities - the St Helier Kidney Patient Association and the Kidney Fund. I am pictured with Peter here.

You may have read in the newsletter of May 2014 that Peter's much loved wife Margaret had died, and so Peter is now moving to

Wales to be near his daughter. He and Margaret made a massive contribution to the Kidney Fund (and to the KPA) and Peter was my mentor in the early days. He will be sorely missed by us all.

My duties in the renal unit have been many and diverse. Through my work in the day to day administration of the Institute I kept the books balanced and the bills paid and maintained education and research accounts for the renal nurses and consultants, but I also developed skills like website design.

This was interesting and enabled me to not only maintain and develop the Renal Unit and SWTIRR web site but launch the Kidney Fund site too. Getting the government stamp for "Trustworthy information" for the website was difficult but worth it in the end.

People have to know that what we put there is accurate and impartial and that's what the Information Standard "kite mark" is for.

Organising the World Kidney Day events brought its challenges but in the end definitely worth it as I firmly believe in the importance of educating the general public about kidney health. Dealing with the hospital IT and works department hasn't always been fun; I don't think I'll miss that.

A lot of you know me for the events and fundraising I've been involved in which have been very satisfying and often great fun.

There were two huge Renal Symposiums led by the Renal Unit which were attended by people from all over the country; two Fire Walks; a reception at the House of Lords; events at the Globe Theatre, Epsom Race Course, Wimbledon All England Tennis Club; annual Dragon Boat Challenges, marathons and cycle events; and so much more.

Over the course of 13 years our London Marathon teams

raised over £314,000! Of course, from 2005 to 2007 our intrepid consultants Dr Mike Bending and Dr Jonathan Kwan led our marathon team and boy did they get some support!

And last but not least I will really miss working with Dr Mark Dockrell who works his socks off for many many hours each day supervising all the scientists and Institute staff, writing grants, thinking up new research projects, joining in and doing his own fundraising events to keep the Institute afloat and generally supporting us all.

He gets my vote for the ABCD (Above and Beyond the Call of Duty) award!

It would be fantastic if you would show Mark your support and appreciation for his dedication and incredibly hard work.

The Kidney Fund supports the research at the Institute and it is only through continued donations and fundraising efforts that the work will be able to continue. If you haven't joined the Kidney Fund research supporter email group it's not too late.

By joining the group you will get to hear about Kidney Fund and Institute activities, upcoming events, volunteer opportunities etc. You will not be bombarded with emails, and can ask to be removed from the group at any time, but we do need your permission to add you. Please email info@kidneyfund.org.uk and ask to be added to the group!

Don't forget! FUNDING > RESEARCH > CURE

Anne

www.kidneyfund.org.uk/donate

Dr Phanish on the magnetic pull of St Helier and the challenges he found working in India

In February 2014 I wrote in the Renality about my 1 year sabbatical in India ending with a note saying 'I may or may not come back, time will tell'. Here we are, I am back. Clearly, St Helier is a strong magnet.

There were many challenges from the day we arrived in India. It wasn't an easy task to cope with soaring temperatures (up to 48°C), massive crowds and non-stop phone calls. It was an achievement to drive through the city and when I reached the

hospital in one piece with an intact car I had surprised myself.

I worked in a busy transplant centre in India (Gurgaon, New Delhi) where we did around 200 transplants per year. It was a private establishment where patients had to pay for their treatment, many of them 'out of their pockets' and some through private medical insurance.

Cost of the treatment and affordability was an important consideration. It was heartbreaking when those who couldn't afford treatment had to be sent off to hospitals with inadequate facilities. However, it was also obvious that many Indians from diverse backgrounds could afford more than what I had seen few years ago which is a reflection of the country's growing economy and the fact that families save for health and education.

Patients and their families took on the entire responsibility of getting necessary investigations done, chasing the results, bringing them to their doctors and even nursing their relatives during the ward stay. Every patient had a relative or a friend to stay with them when they were admitted and social situation was not a consideration that would ever delay discharge. Once the medical problem was dealt with, patients were out of the hospital.

It was a shock to my colleagues in India when I told them that we often provided transport to bring patients to hospital. Completely different world to what I was used to here.

I wished on many occasions for an 'NHS' that would allow me to treat everyone irrespective of who they are and their financial status. It makes it very obvious as to how lucky we are to have an NHS that provides 'free at the point of care' treatment. While I acknowledge there are problems with NHS, it is a great healthcare system to have.

Transplantation was predominantly living donor transplantation as deceased donor transplantation is still in its infancy in most of India.

As dialysis is expensive and not widely available in rural areas Dr. M.K. Phanish



of the country early transplantation is the only choice for the majority of patients with end-stage kidney disease.

The pressure on family members (directly or indirectly) to donate a kidney was 'palpable' especially on women.

The hospital I worked did not allow any illegal transplants and donor safety was given due consideration. It was pleasing to see that Indian legislation has banned illegal transplants (buying a kidney for

money) and most of the centres barring a minority in India have stopped doing such transplants.

Undirected altruistic donation was not allowed (as chance of coercion or money exchanging hands is high) and proving a relationship was the most important part of transplant co-ordinator's job.

The transplant surgery and subsequent management was of high standards in the centre I worked. We even had surgeons from the UK visiting our centre in India to learn new techniques.

That takes me nicely to something I observed immediately when I started working there. Individually, most of the Indian doctors were good, hard working and practised good quality medicine but there was little emphasis on team working, policies and protocols, governance and risk management.

This is something I worked on, implementing some policies and protocols, developing a team spirit, emphasising on success of the unit and reducing variability in patient care so that there is some uniformity in the standards of care given to the patients, values that I had learnt in the UK over years.

In addition, I helped in establishing a piece of laboratory kit to detect antibodies against HLA antigens that are of crucial importance in organ transplantation.

It is great to see all the patients and colleagues again here at St Helier and in Croydon. When I left here I was sad and happy for different reasons and I feel the same on my return.

Life moves on and commitment to high quality patient care will always be a priority. The focus over next few years will be transplant services and the SW Thames Institute for Renal Research

I wish you all a Merry Christmas. My youngest daughter wants a West Highland Terrier puppy for Christmas. I am not sure if I can cope with it on top of our three kids!

WOULD YOU LIKE TO EDIT RENALITY...

Our current Editor of Renality, Steve Purcell, is looking to hand over the compilation of our quarterly magazine due to changes in his full-time employment. He says: "You don't need to be a computer wizard, but obviously being comfortable using a computer is a huge advantage. It is very rewarding but you will need to be able to devote several hours to the task over several days once every three months. I will give all the help required to anyone who feels they would like to have a crack."

If you are interested and would like to know more email Steve at steve_purcell@btinternet.com

Something's been bugging me..

By MARK DOCKRELL **Institute Director**

Greetings Renality Readers-

You might have noticed that I use the plural - readers. Yes, despite the fact that I received not a single postcard or telephone call in reply to my requests in my last newsletter, it appears that there are a few of out there. So, I'd better crack

It is a little odd writing these pieces for you. You will read this around the end of October or beginning of November but I am sitting here writing it at the beginning of October. We're still in the throws of the Rugby World Cup. Unfortunately, England have already bowed out but, at least for another 48 hours, me and my fellow Jocks still believe, we still have hope. Of course John Cleese famously said "it's not the despair, I can handle despair, it's the hope I can't stand". Well, Mr Cleese, I think this is where you and I part company. I love hope. Not blind hope, like Scotland winning the Rugby, or the football for that matter, but hope built on evidence, hope fuelled by seeing what has been achieved and looking forward excitedly knowing how much more that can still be done.

Over the past few years, there has been a lot of press, a lot of concern about antibiotics, or the lack of them. We had headlines like "Prepare for a world without antibiotics". My goodness the people of the press do love being Jeremiahs don't they? Talk about prophets of doom. They all seemed to think we would be thrown back to the Victorian era. One of the biggest issues is the development of antibiotic resistance; the antibiotics we have would no longer be effective on new strains of bacteria. Well, firstly way back in 1928 Alexander Fleming discovered penicillin; is there any reason to think that we can't discover or even invent new antibiotics? Yes there needs to be invest-

FUNDING



RESEARCH



CURE

ment and effort but with research they will do it. Secondly, antibiotic resistance is partly due to overuse. The way I was 1y different – as John Cleese used to say. brought up was that if you have something special then you don't use it every day. I don't wear my Sunday best shoes everyday and, hey, who would guess, they last longer. Yes, this philosophy you know that I'm talking about cardiomeans that my clothes last a lot longer vascular disease! Of course we have and as some of you may have noticed a known about cardiovascular disease for a fashion icon I am not. By the same token long time, in fact my PhD work 20 years if we use antibiotics less and in a more ago was on exactly that subject and there focussed manner there will be less re- are many therapies and life style changes sistance. Of course, many doctors don't that can reduce our risk of cardiovascular deliberately over-prescribe, they do it disk. Despite this it still remains an enorbecause they have to act quickly and it mous problem among patients with kidcan take a couple of days to identify the ney disease. We know that there are what type of bacteria and know what antibiotic are called traditional risk factors like is appropriate. So, the earlier we detect smoking and obesity and people with an infection and identify it the better it chronic kidney disease may respond very will be for everyone. Nowhere is this differently to these factors. But in addimore true than in PD patients who might develop an infection and get peritonitis. The Institute does have some expertise in microbiology; in fact the Institute is currently saving the Renal Unit and the Hospital a lot of money by doing the tests on dialysis water rather than spending large amounts of money on an outside company to test the water for bacteria. We don't really have the expertise to develop completely new bacterial tests, but we know people who do. So, the Institute is currently working with a couple of partners to do exactly that. We recently submitted



some grant applications for these projects. I'll let you know how we get on.

And now for something complete-At the end of my piece in the last edition of Renality I mentioned research into a condition that kills more renal patients than kidney failure. I imagine most of tion we now know that there are nontraditional risk factors that people with kidney disease have as well. This is the basis of some of the research that we are planning with some of our consultants who have an interest in high blood pressure and also with colleagues from St George's and Darent Valley Hospital. So, watch this space for some new exciting research results.

Through research we will find a cure!

Funding - Research - Cure



What a weekend! - Newcastle-Gateshead 2015

Transplant recipients from across the UK gathered in Newcastle to take part in the annual Games which aim to highlight the continuing need for organ donation.

This year we welcomed Jonathan Douglas-Green to our fold and he joined Louise Cook, Moray Laing, Craig Morrow, Martin O'Halloran and Kevin Trimming to make up the St Helier team supported by Catherine Cook, Angie Morrow and Stephen Whitcombe.

On Thursday night, hundreds of athletes and spectators took part in the Games' launch in Newcastle city centre as transplant teams from across the UK paraded along Blackett Street, Northumberland Street and Northumberland Road.

As St Helier and the other teams assembled at the City Hall the Transplant Flag was handed over from the Manchester Team to those from Newcastle's Freeman Hospital.

The Donor Family Flame was then lit in recognition and celebration of those who have given the gift of life and the Games oath was taken.

Over the weekend, Gateshead International Stadium hosted athletics and archery.

Friday saw the first full day of competition for the Games which included Table Tennis at Gateshead College, fishing in Leazes Park and Golf at Close House.

On Saturday, hundreds of runners gathered on the <u>Newcastle-Gateshead quayside</u> for one of the event's highlights - The Donor Run.

Hundreds of athletes have done their bit to boost the NHS Organ Donor Register after Gateshead and Newcastle's Transplant Games. The Newcastle Chronicle set a target of getting 10,000 onto the Register, but the North East public came forward in massive numbers and agreed to become donors.

The Games got underway on the day the Newcastle Chronicle campaign to boost the number of lifesavers in the region smashed its target. Figures revealed 23,063 people are now signed the NHS Organ Donor Register since it launched its "Become a Donor" campaign.

A host of celebrities were backing the Games, including

TV stars Ant and Dec, Newcastle United legend Alan Shearer, <u>and TV's Jeremy Kyle</u>, who attended the gala dinner at Gateshead Sage.

The team representing SHSKPA and St Helier competed in 14 events (Archery, Snooker, Volleyball, Fishing, Golf, Ten Pin Bowling, Table Tennis, Darts, Badminton, Swimming, Ball Throw, Shot Put, Discus and Javelin) winning medals in 11 of them.

Once again each Team member returned home with at least one medal and the final tally was 6 Gold, 3 Silver and 4 bronze medals and everyone returned home with a smile, a medal and looking forward to 2016 Games in Liverpool.

As well as a lot of fun, it has also been quite an emotional weekend as all the athletes have been thinking about their donors and the difference they have made to their lives

And here's what some of those taking part had to say:

Martin O'Halloran: "These were my fourth games and i enjoyed them like they were my first. I made new friends again as I always do and I will never stop been inspired by amazing people, can't wait for Liverpool to meet up with all my team mates and compete for medals again and enjoy a fantastic weekend."

Catherine Cook: "Once again we had a wonderful time at this year's BTG. It was great to see so many medals being won by the team. It was great to catch up with old friends and make new friends. One of the highlights for us was the Donor run along the Quayside, it was exhausting for me but great fun. Feeling very proud of this team a lovely weekend and great results."

Angie Morrow: "Another great time was had at The Transplant Games this year in Newcastle. The weather was kind and the facilities very good.

Each year we meet old friends and make new friends, it's such a memorable time. Being a supporter of the St

TRANSPLANT GAMES 2015

Helier team for the past 18yrs has been a rewarding journey and a time I always enjoy. Next year we are off to Liverpool, another interesting city, why don't you come along and take part or support our St Helier team who represent the hospital, they are a great group of people who enjoy taking part and meeting up with the other Transplant patients from other hospitals. A time you will never forget."

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

The next British Games will be held in Liverpool, 28^{th} – 31^{st} July 2016 and will be a great opportunity for athletes and non-athletes alike to experience the warmth and friendship of all who attend the Games.

We already have two new recruits for Liverpool so if you are interested in taking part and wish to be on the mailing list, please contact me on 01252 325230 or make contact via a SHAK committee member.

You may already have received your "Gift of Life" - why not help promote awareness into the need for more organ donors and ensure someone else can receive this precious Gift!

Graham Morrow, Team Manager (graham.morrow@ntlworld.com)



England football legend and TV presenter Alan Shearer helps to get the show on the road for the 2015 Transplant Games held in Gateshead.

COME AND JOIN THE TOUGH MUDDERS

THINK ABOUT THIS!!

Tough Mudder is a team-oriented 10-12 mile (18-20 km) obstacle course designed to test physical strength and mental grit.

Tough Mudder puts camaraderie over finisher rankings and is not a timed race but a team challenge that allows participants to experience exhilarating, yet safe, world-class obstacles they won't find anywhere else. Tough Mudder is more than a fitness challenge, it's a set of values lived out on the course, and in everyday life.

The Mudder Pledge

- I understand that Tough Mudder is not a race but a challenge
- I put teamwork and camaraderie before my course time
- I do not whine kids whine
- I help my fellow mudders complete the course
- I overcome all fears

"The idea of Tough Mudder is not to win ... but to have a story to tell"- New York Times

So how do you feel about testing YOUR Physical Strength and Mental Grit? The Kidney Fund has 10 places available for 2016 Tough Mudder events (details not available at the moment).

We will ask anyone that takes part in this charity challenge for us to pay a non-refundable deposit of £50 to secure their place and raise a minimum of £250 in sponsorship.

Let us know at <u>toughmudder@kidneyfund.org.uk</u> if you or any of your friends, family, colleagues are interested in an amazing team challenge!





SWTKF NEWS

GOLDEN YEARS Pauline and Colin **Attridge write:**

This was our Golden Wedding Celebration in Addlestone on September 26th.

My husband has been on CAPD for three years and we decided to ask family and friends for donations to The South West Kidney Fund instead of presents.

We feel that Research into Kidney Disease is vital for the future as more and more people seem to be suffering from Kidney Problems. We collected £700 for the fund.



NEW DIALYSIS UNIT IN FARNBOROUGH

The official opening of the new Farnborough dialysis unit will be on Thursday November the 19th at 3.30.

It will be opened jointly between Sir Andrew Morris, CEO of Frimley Park Hospital and Daniel Elkeles, our CEO.

In the next edition of Renality we will bring you a full report and photos of the new unit.

2016 Gold Bond Marathon places available

We are delighted that we have several Gold Bond places available for the 2016 London Marathon.

If you were unsuccessful in your bid for a balloted place (or missed the ballot) and would like to discuss one of our Gold Bond places, please contact us as soon as possible at londonmarathon@kidneyfund.org.uk.

In return for a Gold Bond place we ask our runners to commit to raise a minimum of £1,500 (excluding gift aid).

Ballot entries for 2016 will be announced in October. If you are successful and have your

own place, please do consider joining our team and raising whatever sponsorship you can.

We would love to have you on the team.



to you all!

Would you believe that since 2003 the Kidney Fund London Marathon teams have raised £314,203.29 in sponsorship!

This is an incredible feat and we are so grateful to all those runners who have worked so hard for us for the past 13 years.

We would also like to thank their individual sponsors, and all our Renality readers who have been so generous in their sponsorship of the team – watch out for the 2016 sponsor form in the January issue!







SWTKF NEWS

JEAN'S OVER THE MOON TO RAISE £3,600

JEAN MOONEY writes:

Dear Friends, Sponsors and Supporters,

My participation in the last trek in the series of five x100km walks, in aid of the South West Thames Kidney Fund took place this weekend (12/13.09.15) along the Thames Path from Richmond to Henley.

In view of the debacle of the 4th walk (Hackney to

Cambridge, with its brief and unplanned sojourn in Addenbrooke's Hospital) my family had banned me from taking part as a walker in the Thames Path Challenge, so, instead, I participated as a volunteer helper.

Ironically, as the picture above shows, it was the only one of the 2015 walks that I was able to wear the Fund's tee-shirt as I came at long last to a finishing line!

I wanted to say thank you to you all, once again, for your marvellous, inspiring and generous support: an amazing 105 donors gave a grand total of £3571.43, which has been rounded up to £3600.00, for the South West Thames Kidney Fund.

I confess that it was somewhat tongue in cheek when I suggested that a figure of £5000 should be the fund-raising aim, and did not, in all honesty, dare to hope for anything more than a couple of grand., at best...but, as ever, you have surpassed all expectations. Muchas gracias. That money will provide a sizeable chunk of the purchase price of the new, super-duper autoclave urgently needed by the South West Thames Institute for Renal Research .

The 2015 walking series did not quite turn out as I anticipated, hoped or expected (understatement!). But, teasing a minor triumph (OK, perhaps by sleight of hand) from the jaws of impending disaster, and due to my propensity for completing each walk on the 'never never', I did actually manage to cover an overall distance of 500+km in long walks since the early May Bank Holiday to date (the dog is very fit now).

So I can kid myself, at least, that I did 'do the distance', and the 24hr stint as a volunteer over that weekend, lets me I now feel that I have also 'done the time'.

Thank you all, so much for your unfailing support of my escapades.

Kindest regards, Jean Mooney

WHO ARE THE LUCKY WINNERS IN OUR LOTTERY

Lottery winners since last edition:-

24/07/2015 101052 Streatham £157.50

31/07/2015 101119 Croydon £158.50

07/08/2015 101271 Shamley Green £158.50

14/08/2015 101204 Farnborough £158.00

21/08/2015 101216 Farnham £159.50

28/08/2015 101181 Morden £158.50

04/09/2015 101195 Worcester Park £159.00

11/09/2015 101106 Warlingham £160.50

18/09/2015 101088 Woking £160.50

25/09/2015 101092 Croydon £161.00

02/10/2015 101105 Horley £161.50

09/10/2015 101176 Cheam £162.00



Lucky Bags in aid of Kidney Disease Research

The "LUCKY BAGS" theme has continued again this year by Kate Shipton, Pam Hibbett, Gordon Carter and Mr & Mrs Marshall.

All the people that help are, in their own way, connected to kidney/diabetes issues.

This band of dedicated followers and helpers manned the stalls at Rowledge Village Fayre and Tilford Village Fete where an overwhelming response resulted in achieving the sum of £1,050 for the South West Thames Kidney Fund. The success of the project has been to a great extent due to the generosity of people and businesses giving superb prizes and donations, all of which were gratefully received.

Next year here we come!

Note from Kidney Fund: If you are planning an event to raise money for us, do contact us in good time beforehand and we will do our best to supply you with Kidney Fund leaflets, balloons etc.

MAGIC MOTORS











CAMBERLEY CAR SHOW RAISES OVER £6,600

Saturday August 22nd saw the return of the Camberley Car Show, our fourth year and the biggest and best show to-date, raising £6,602.00 for the Kidney Fund

Over 200 rare and classic vehicles, of many makes and eras, were on static display in and around the town's main streets, with some other exceptional attractions including: The 'BLOODHOUND' Super-Sonic Land Speed Record Attempt full size show car...

Jody Scheckter's iconic Tyrrell P34 6-wheel F1 racing car from the 1970'sP

Chris Evans' Chitty Chitty Bang Bang

Edd China's amazing 'Outspan Orange' on wheels - with Edd (from TV's Wheeler Dealers) spending a considerable amount of time at the two SWTKF gazebos, meeting and greeting people and signing autographs.



In addition, there were various street entertainers, roving musicians, free face-painting for children and of course, being a town centre location, lots of shops, restaurants, coffee bars and pubs on hand so a real free fun day out. The 2016 Event is already being planned and the date has been set as Saturday 3rd September so make a diary note now and come along. For more information, see - www.camberleycarshow.co.uk

We are extremely grateful to the many volunteers who helped out on the day in many ways, making the day a great success. These of course include many of our family and friends as well as a number of kidney patients and their partners/relatives, including Martin and Cynthia Banton, Chris and Clare Barrett (and Chris's parents), Angie Morrow (and son Craig), Jackie Magness (and Mum), Annie yuk ying Tse, Alexia & amp; Christopher Ross-Lewin and Allan Prince (and Jackie) so thanks to all! As in our three previous years all money raised by the event has been donated to the South West Thames Kidney Fund.



The Kidney Fund is very grateful for the donations in memory of:

Joyce Sanford M Thorp Harry Richard Townshend Bowen

Eberhard Reichelt Hannah Scutt Kevin John Whybrow

Marie Johanna Leiser Sylvia Grieg Peter John Beams

June Owen Thelma Tracey Hodson Millicent Davis

Chris Palin Sylvia Charsley Gordon Thomas O'Brien

Jill Mary Lawson Mary Hoye Betty Howard

Shelton Hoilett

We are also very grateful to:

- Waitrose Raynes Park for the £520 received from their Community Matters Collection
- The very kind lottery winners who have made a donation because they won on the Kidney Fund Lottery (we certainly don't expect this, but we really do appreciate it!)
- The pupils of Ewell Castle Senior School for their support they raised £318.63 for the Kidney Fund!
- All the lovely people who couldn't attend our Bunbury Celebrity Fundraiser but made a donation instead.
- All those that donated towards our Bunbury Fundraiser raffle. I am always stunned at the quantity of really nice items you donate in response to requests you are all totally amazing!
- Afton Chemical who donated a further £300 in respect of Collette & Mark Jones Charity Quiz night reported in the May issue of Renality
- Maureen Ayling who, as President of Middlesex Bowling Association, has so far raised £1,220.00!
- Our Vitality British 10K team who between them raised a total of £2,273.87 for our research
- Saskia Kavanagh who held a bake sale at her school, Woodlea School in Woldingham, Surrey to raise money for research. Saskia donted the funds she raised in memory of her grandfather Frank Leonard.
- Castle Green Bowling Club whose annual charity day resulted in a donation of £202.00 to the Kidney Fund
- Lizzie Webster and the Sutton College Saxophones who collected donations at their summer concert, and split the proceeds between the church where they played and the Kidney Fund.
- June and Vic Arnold who have supplied us with some fantastic amusing and creative handmade items for our raffles and events. We really appreciate your support!
- All those who have scrapped their old cars via GiveaCar (details inside front cover of Renality) and raised funds for us.
- And to all those people who have made donations, done fundraisers, supported the Kidney Fund and research in any way ... we are very very grateful to you all.

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 newly constructed ramp with decking to enable all patients to enjoy its facilities.

The Holiday Home 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 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)

2010 Patient Rates

March	£150
April	£150
May	£150
June	£200
July	£200
August	£200
September	£190
October	£180

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 purchased our holiday home with generous donations in 2008. We are now into our second season. Please look after it so that we can enjoy it for many more years. It has been newly furnished with crockery, cooking utensils, duvets, a new TV and DVD player.



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SOUTH WEST
THAMES
KIDNEY
FUND

£1
per entry
per week

50%
to the
winning
number

Funding
Research
Cure

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

Title: Initials;	Surname:				
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Please note that to save on	postage we prefer to comm	nunicate by email or	telephone. P	lease tick h	ere if you require a lette
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If you have any questions or would like more information, please phone Anne on 020 8296 3698 or email lottery@kidneyfund.org.uk

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