

RENALITY

The NEWSLETTER of...

May 2011

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

Both shy.... And retiring!



PETER and MARGARET SIMPSON have worked tirelessly for the benefit of fellow patients in the South West Thames Renal Service for around two decades - founding the Renality newsletter in the 1990s.

Now, 15 years beyond retirement age, they are stepping back to give themselves a little bit more time to enjoy their lovely garden .

SWTKF chairman Michael Bending said: "Right from the start they threw themselves into supporting other patients, and Renal Research. Their contribution to the NHS in SWThames and Surrey goes far beyond Renal Medicine in their role on Patient focused groups. What a contribution those two have made in what might otherwise been a blissful slipper and pipe retirement! FULL STORY: P 17



IT'S 30 YEARS SINCE JOAN, 89, GAVE JOHN HIS 'NEW' KIDNEY...

In 1980, Lily Joan Loughran donated a kidney to her eldest son, John, under the care of St Helier Renal Unit. At the time, Joan was 60 years of age and her son, a young man of 24 years.

Since then, both Joan and John have enjoyed remarkably good health and have enjoyed life to the full.

In March, all their family celebrated the 30th Anniversary of John's transplant by going out for a meal. It is a remarkable achievement. But the celebrations will not stop. Joan will be celebrating her 90th birthday in May. She is an amazing woman of great strength and character and is much loved and highly regarded by her friends and family.

The family have always supported the Renal Unit and the Patient Association and as part of the celebration, Joan has donated £500 saved from her pension to St Helier and Surrey KPA. We hope both she and John continue to enjoy life and remain in good health. *Peter and Margaret Simpson.*



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Pat Godden, Secretary:

020 8777 7371

ST HELIER & SURREY KPA

Dave Spensley, Chairman

01483 426276

Jim Rae, Treasurer:

01403 242601

Your new Editor:

I have been given the honour of producing this and future editions of Renality as the founding editors, Peter and Margaret Simpson, have decided to take a well-earned rest.

Inside this issue, Peter and Margaret have written about how Renality came to be and chart the progress of the newsletter from a black and white folded sheet of two or four pages to the full-colour magazine we have today.

I would like to take this opportunity to thank Peter and Margaret on behalf of everyone who contributes towards Renality and the thousands of renal patients and staff who receive it.

I had a live donor transplant myself more than 18 months ago and came to appreciate this quarterly newsletter during my time on dialysis, keeping me up to date with all the latest news.

Steve Purcell (steve_purcell@btinternet.com)

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: Peter or Margaret Simpson on

01252 792196 or email: mps@mpsimpson.demon.co.uk

REMEMBER...

our website addresses are:

South West Thames Kidney Fund:

www.kidneyfund.org.uk

South West Thames Institute for Renal Research:

www.swtirr.org.uk

St Helier & Surrey Kidney Patient Association

www.shskpa.org

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

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

We would like to thank Riverprint Ltd, Farnham for their help in producing this Newsletter. 9 Riverside Park, Farnham, Surrey GU9 7UG Tel: 01252 722771 Fax: 08707 702781 Email: www.Riverprint.co.uk.

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THE South West Thames Kidney Fund, the Institute for Renal Research and St Helier's Renal Unit marked World Kidney Day 2011 by getting out into the community, setting up a stall in the St Nicholas Centre in Sutton and making people think about their kidneys.

Volunteers raise awareness on World Kidney Day

The main theme of World Kidney Day is 'Kidney Awareness' - an excellent opportunity to make people aware of their kidneys, their importance to our general health, how they work, and what can damage them. So we spread out our stall with leaflets covering everything from kidney disease and diabetes to healthy eating and the increased prevalence of kidney disease in the Indo-Asian communities.

We discussed kidney health with interested passers by handing out relevant literature to anyone who wanted to know more. We had set an internet-active computer to encourage people to join the organ donor register as this had been a big success last year in Croydon; this year people preferred to take the literature with them to read at home before hopefully signing up.

As there is such a strong link between raised blood pressure and renal disease renal Unit nurses



Nimmy Logeswaren & Tracy Norton-Smith set up their blood pressure stations and offered free blood pressure checks.

Over 70 people took advantage of the offer and had their pressure checked. Many people had what might be considered raised blood pressure, though the nurses did point out that a shopping centre might not be the ideal place for a health check; a few had blood pressure readings that were so far out of the normal range

they were 'strongly advised' to see their GP as soon as possible. This might turn out to have been a life saving trip to the shops for a few.

It was a good day - sharing information on kidney health with people, and helping them become aware of the importance of monitoring blood pressure, diabetes and their links with kidney failure. Over £100 was raised for renal research.

Thank you to all who contributed towards such a successful day: Nimmy and Tracy for their blood pressure checks and their chats with people; Kathleen Black and her granddaughter Danielle, Gillian Hynd, Margaret Porter, Peter Charsley, Pat Godden and Ron Hobdell who gave up their time to rattle cans throughout the day; and to the staff from the Institute: Dr Mark Dockrell, Anne Collard & Sarah Yates.

World Kidney Day, March 10

LET'S MAKE THE GOLF DAY GREAT

THE fourth John Edward Foxwell Memorial Golf Day at Mannings Heath GC will be held on June 17.

Apart from this year's two Prize Draws, the Golf Day is now the KPA's single largest fundraiser, so making the day work is in all our interests. This year 50% of the net surplus will be allocated to the "No Place Like Home" appeal – so let us make the day really successful!

Patients, carers, friends, employers or local businesses can still help. We still

need: One sponsor for the last of the four Par 3's. Prizes for the raffle table (about 12). These do not have to be big, a bottle of wine, box of chocolates – even those unopened presents that you have put to the back of THAT cupboard.

Volunteers to help on the day with small tasks such as selling raffle tickets, helping with the Putting Competition or helping out at Golfer Registration time – 3 or 4 more would be great. Lastly, 95 other golfers! I am determined to play



Signed Tony Jacklin montage

this year, the first time in 4 years – so if you know any golfers it's a great day out for just £40, including a post round one course meal. Harry "I want your money" Hotz has volunteered to run the very important Auction for us. Here are the Auction Items and their donors. We are

accepting **BIDS NOW** – but all items will only finally be "sold" on the day.

HOEBRIDGE GOLF CENTRE, ROUND FOR 4.

ROOKWOOD GC, ROUND FOR 4.

IFIELD GC, ROUND FOR 2.

CHOBHAM GC, ROUND FOR 4.

SANDOWN RACECOURSE, TWO PREMIER ENCLOSURE BADGES.

TONY JACKLIN SIGNED MONTAGE.

FARNHAM GC, ROUND FOR 4.

NORTH DOWNS GC, RD FOR 4.

SURREY DOWNS GC, RD FOR 4.

KUONI TRAVEL LTD, £200 KUONI HOLIDAY VOUCHER.

SURREY NATIONAL GC, ROUND FOR 3.

LA BARBE (Reigate), MEAL FOR 2.

HOGS BACK BREWERY TOUR FOR 2.

SAVILL COURT HOTEL & SPA (Windsor Great Park), 1 night B&B for 2.

MITCHAM GC, ROUND FOR 4.

GUILDFORD GC, ROUND FOR 1

WINDLESHAM GC, ROUND FOR 4

DENBIES WINE ESTATE, WINE TASTING TOUR FOR 2

HARLEQUINS RFC, SIGNED RUGBY BALL

We would like to thank all of our sponsors and donors for their generosity.

You can place your bids by phone, call Jim Rae on 01403 242601 or 07810608678. If you can help with any of the above call Jim Rae or Dave Spensley on 01483 426276.



John Edward Foxwell Memorial Golf Day

In Aid of St Helier and Surrey Kidney Patients Association

(Registered Charity Number 266391)

Kingfisher Course Mannings Heath Golf Course (Horsham)

Friday 17th June 2011

Cost — £40.00 Per Person

The day will comprise of:

- A Two Tee Start
- A Singles Stableford Competition (Full Handicap)
- Prizes for "Longest Drive" and "Nearest the Pin"
- Post golf meal
- Auction & Raffle

For Further Details or to book a place please contact:

J C Rae
Event Organiser
24 Beaver Close
Horsham
West Sussex
RH12 5GB

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

Cheques should be made payable to St Helier and Surrey Kidney Patients Association whose members thank you for your support






Making choices and balancing priorities

By Dr JAMES MARSH
Clinical Director



OVER the weekend, two events happened in my household. Firstly (in the here and now), West Ham were cruelly eliminated from the FA Cup by Stoke City, abetted by some unusual refereeing decisions.

Secondly, my house was invaded by a host of young girls celebrating my daughter's tenth birthday party with a 'choc-o-doodle' party. This led me to reflect on the past ten years of my life and the need to balance priorities.

In 2001, when Anna was born, I had just completed an extended period of research in the labs at Guy's Hospital, and moved to work on the wards as a registrar on the Renal Wards at St Helier Hospital.

This period of time confirmed my decision that clinical renal medicine was the right career choice for me. I also remember the vitality that emanated from the Renal Unit, and the spirit that anything can be achieved.

Despite the challenging financial situation that we face, and the recognition that we don't always get things right, I am constantly impressed with the over-whelming positive energy that emerges from the Renal Unit – patients, staff and carers.

Over the past year, there have been some genuine steps forward including:

- Massive developments in infection control. Those of you on haemodialysis may have seen changes to nursing practices, and we have opened a dedicated cohort ward to manage patients colonised with MRSA. We have seen a 50% reduction in MRSA, and similar reduction in episodes of infective diarrhoea on the wards.
- Progress with home haemodialysis with more patients going home.
- Development of a self-care dialysis unit with the promotion of more active participation in your own dialysis.
- Funding for our own nursing staff to deliver the assisted peritoneal dialysis service. This should allow

better continuity of care.

- A record number of patients received a live-donor kidney transplant, with more people each year receiving a transplant before they ever need dialysis.
- Further developments in giving kidney transplants to patients with mis-matched blood groups (ABO-incompatible transplants)
- Opening of **Purley Dialysis Unit**
- Completion of the **Epsom Dialysis Unit** which is going to open shortly
- A new review of transport services. We are starting a pilot study at **Kingston Dialysis Unit** to get a better understanding of how we can offer a more efficient patient transport service for dialysis patients.

A change in focus to promote patient education, counselling and genuine choice for all patients starting renal replacement therapy so that an individual plan can be made based upon real knowledge.

The strength of the service is the relationship between patients and staff, and I count myself lucky every day to work alongside so many dedicated members of staff.

Special mention should go to **Elaine May** who works in the service manager's office. She has worked as an unsung hero for the past decade always going above the call of duty ensuring smooth continuity of administration and management. Although they will be annoyed with me, we should also recognise the unceasing work of the lead nurses, **Sue Woodcock** and **Susie Mallinder**. Sue was recently awarded the Trust Employee of the month following her sterling efforts to keep the dialysis units functioning during the winter.

Therefore, with grey weather, a club in financial peril, a string of poor results behind us, the prospect of relegation and the threat of the manager facing the sack there can still be room for optimism. If not, I will just have to concentrate on planning birthday parties.....

Donor and recipient Anne and Philip Slack

I CALL MY NEW KIDNEY...

BRITNEY

Philip's Story: How my multitasking new organ helped to raise £2,778 for kidney research

Since moving inside me last October, Britney has been getting to grips with a variety of tasks set to her and does not seem to miss too much, her old pal, Whitney (still inside my wife Anne).

She seems to be effectively carrying out a variety of tasks like looking after my bones to make sure they remain calcified; telling them to make enough haemoglobin as well as removing those awful toxins like Urea that made me sometimes feel like I had M.E!

I now have so much more energy and stamina! I no longer need a reviving nap in the afternoon so I can be active in the evening. Britney no doubt does feel some exasperation with her two male colleagues who jointly only seem capable of a fraction of the work that she manages (men!!!!).

Friends tell me that I am doing everything at 3

times the speed now. The yellow tint has gone from my eyes and my chiropodist says that my skin has improved dramatically post-transplant. Best of all, and very close to my heart, I can now eat nuts, dried fruit, cheese, chocolate etc (within reason, Doctor!) and potatoes and vegetables that have not been boiled to death. I was never that keen on grapefruit anyway!

Obviously, Britney's move involved major surgery for both my wife Anne and me and it did take a little while to recover and stabilize afterwards.

The approachability and professionalism of the Unit's medical staff was a key factor. However, it has also been a very warming experience to get to know other donors and recipients and to chat with them in clinic about their experiences.

People are mostly very open about exchanging information and tips etc



and a lot of mutual reassurance arose from this contact, often with a good degree of humour.

There is a psychological as well as a medical battle to be won in transplantation both before and after the transplant.

As someone who has a scientific background, it is especially apparent to me that the way I feel now would not have been possible without the decades of research which has led to so many improvements being incorporated into

reveal both sides of their transplant tale...

**Anne's story:
We wanted
to use our
experiences
to help raise
money for the
Kidney fund**



Anne (left) and Philip Slack with Jeanne Weston on the tombola stand

Philip and I are now both 4 months post-transplant in this 'roller-coaster' experience of kidney donation.

We had always planned to do some sort of fund-raising event to raise money for the South West Thames Kidney Fund and kidney research.

We settled on a date mid January, 3 months after transplant but before I was fully back in the throes of work. We wanted to combine celebration and fundraising.

I gathered together everything from around the house that was new and unused and donations started to pour in from all directions. I also baked some gingerbread men and commandeered our most artistic friend to help with the decoration and packaging.

I planted some hyacinth bulbs in an assorted array of pots I had gathered from around the garden. We settled on providing everyone with drinks and nibbles and arranged for both a tombola and live auction.

I was able to gather lots of 'tips' from experienced fundraisers during outpatient visits, such as how to make up attractive baskets for auction, (a pineapple works well in a basket), and how to make sure that donations were not under-sold.

It felt a bit embarrassing 'cashing in' on being a recent kidney donor to raise funds, but people who knew us well, and especially family, were happy to donate to such a good cause.

By the time we came to our event we had already collected about a quarter of our total. When the day came, although I was exhausted, I was amazed both at how much I enjoyed it.

I was delighted too that people who had parted with their money were even coming up afterwards to me to thank me for inviting them!

It was great to see how unwanted Christmas presents could be repackaged as 'prizes' and leave a trail of good feelings as they passed hands from one person to another.

For us both this was a rewarding experience and a good way of ending this particular chapter in the Health Journey on a really high note.

As one of my friends pointed out, the pile of remaining prizes constitutes a 'nucleus' for the next tombola, so who knows where we will go from here.....

Anne Slack

the transplant protocol. I was recently shown around the South West Thames Institute for Renal Research to see how such research is carried out. We held a fund-raising event in January in favour of the South West Thames Kidney

Fund, which took place in the Christian Centre in Dorking on January 16th. The event was an outstanding success thanks to the support of family, friends and acquaintances from every aspect of our lives who rallied around us magnif-

icently. We raised over £1000 on the day and associated donations from family, friends and neighbours often in far-flung places including.

Also a £700 donation from Santander brought the running total to £2,778.08, including gift

aid. Well done Britney; thanks to the medical staff that eased her move, and to all our family and friends in Dorking and elsewhere who rallied in support of the fundraiser so generously.

Philip Slack

S.H.S.K.P.A Holiday home
St Helier and Surrey Kidney Patients Association



Come and enjoy a relaxing and fun-filled family holiday in our new holiday home for up to six people, to suit all ages. The Holiday Home has a ramp with decking to enable all patients to enjoy its facilities.

It is situated on 42 acres of grassland with tree-lined roads and the caravan centre sits on the edge of the popular seaside town Bognor Regis.

Children are well catered for, with The Riverside Rascals Club (4-13s) with its program of fun activities and games. A clubhouse also offers entertainment for the whole family, including cabarets, disco, live music, bingo and dancing. Please check with the reception office for entertainment and leisure facilities available during the period of your stay as it varies throughout the season. The Riverside Caravan Centre also has an indoor heated swimming pool and spa pool, outdoor heated swimming pool, outdoor heated children's fun pool, shop, amusement centre*, bar/off-licence*, pool table* and launderette*. Some of the clubs entertainment requires a membership for the duration of your stay and can be purchased from the reception on a daily or weekly charge. However S.H.S.K.P.A as a club member provides 6 free club memberships. (*chargeable)

2011 Patient Rates

March	£160
April	£160
May	£160
June	£230
July	£230
August	£230
September	£200
October	£190

To contact us:

Nita and Ravi Patel
 3 Darcy Road, London, SW16 4TX
 Tel: 020 8407 2525 Email: nita@nitapatel.com
Web: www.shskpa.org

Message from Holiday Home Managers:

We would like to welcome new and different members to book our holiday home. It has been newly furnished with crockery, cooking utensils, duvets, a new TV and DVD player. It will provide a very good break for new and regular patients alike.



© Niyam Patel

St Helier and Surrey Kidney Patients' Association



A message from your Chairman...

Another grey and wet day so rather than cut the grass as planned I've decided to do the paperwork.

Summer Draw

With this edition you'll find our Summer Draw Tickets and the proceeds from this will go to our "No Place Like Home" appeal. I realise that it must seem like we're always after your money but can I ask you to purchase these as it will help us to get patients onto Home Haemodialysis. If you do not wish to purchase any tickets could I please ask you to return them to the address shown on the tickets as this will allow us to sell them to those who may request more.

The draw will be held in the Blue Room at St Helier on Saturday 6th August.

Our appeal total stands at £12,000 including the generous donation of £10,000 from the Sussex Freemasons.

Golf Day

Our annual Golf Day will be held at Mannings Heath Golf Course in Horsham on Friday 17th June. If you're a golfer and know of anyone who plays please come along and help support this fundraising event.

In this addition you'll see a list of auction items which we hope will boost our receipts. If you wish to bid for any of the items please contact either Jim Rae or me.

Surrey Renal Service

As I said in the last edition I've written to the Chief Executive of NHS Surrey seeking the reason for withdrawing the tender but to date I've had no reply so I'll be writing a reminder!

Additional Satellite

Epsom is complete and patients will start to transfer in the near future.

Treasurers Position

Jim Rae was due to stand down at our AGM but I'm pleased to advise that he has agreed to stay on.

Other Matters

We are still looking for Patient Representatives for Kingston, Farnham, Sutton and Purley and it would be lovely to have some younger committee members to allow us to represent the entire age group of our members. If you are interested then please contact me on 01483 426 276

I have to sadly report on the death of one of our Committee Members, Michael Carpenter (see below). Lots of you would have met Mike at the Patient Education Program or Expert Patient meetings. Mike served on Committee for about 8 years and also served various voluntary groups in Sutton and across South West London and Surrey. He will be sadly missed.

I think that is all I have to report and the sun has started to shine...

Best Wishes, Dave Spensley, Hon Chairman

In Memory of Michael Charles Carpenter

04 January 1959 – 02 March 2011

Mike served on the KPA Committee for 8 years; he also worked for many other voluntary groups both locally and across London and the Home Counties.

Nothing was ever too much trouble for Mike and he worked tirelessly to help others whilst battling his own ill health. He was a source of help and comfort to so many at St Helier, particularly through his work on our patient education programmes. He will be sadly missed by his family and friends.

Rest in peace Mike, you were one of life's nice guys — Dave



PHYLLIS GWENDOLINE HUTCHINGS

15th April 1926 to 29 October 2010

MY late wife was known throughout her life as 'Gwen'. That is until early 2007 when she was diagnosed with kidney failure. It was at that time that all of those involved in her treatment and care as she began kidney dialysis called her Phyllis, her first name not used since her schooldays.



She attended St Helier hospital for her fistula operation in the autumn of 2007 and for initial dialysis treatment in 2008, prior to eventually moving to West Byfleet's Dialysis Centre for her regular sessions 3 times per week. Both she and I made very good friends over the two and a half years with the other patients, several of whom had been receiving treatment for many years.



Sadly Phyllis (left) encountered additional health problems in her 84th year with deterioration of her spine and other complications. She bravely, with our support, and the assistance of her doctors and Woking hospice, decided to stop dialysis treatment and passed away peacefully at home, as was her wish, on the 29th of October 2010.

Throughout the two and a half additional years that we were blessed with Phyllis received only the best of treatment. My daughter Dawn and I wish to thank all of the St Helier Hospital specialists, doctors and nursing staff, together with the entire staff of the West Byfleet Dialysis Centre who provided dedicated and understanding treatment and reassurance to her and us.

As part of her Will, Phyllis left a legacy to the Kidney Patients Charity which we were pleased to hand over to Mr David Spensley (pictured above receiving a cheque from Mr Bob Hutchings and his daughter Dawn) at the West Byfleet unit on Wednesday 9th February, 2011.

WORLD KIDNEY DAY 2011, STREET COLLECTION, HORSHAM TOWN CENTRE.

On March 10th 2011, seven intrepid volunteers took to the streets of Horsham for a Street Collection that made £303.49 towards the work of the KPA and the "No Place Like Home" appeal.

I would like to thank those volunteers who were:

Mary Quek, Dave Spensley, Di Spensley, Karen White, Karen Smith, Debbie Noble and Paul Connolly.

Given that there were only seven volunteer collectors out there, the sum collected was really quite impressive.

If you know of another Local Authority or business that would be willing to host another "can rattling session", please contact Dave Spensley or Jim Rae.

MANNINGS HEATH VILLAGE FAIR, JUNE 25TH 2011 (organised by HORSHAM ROTARY)

This is advanced notice of a really good day out, also requests for items for a Tombola table and for volunteers to help with the day.

For the last two years Shirley & Jim Rae ably assisted by Mary Quek have put on a Transplant and Organ Donor Information table at this event, along with side shows such as a Putting game and Hoop-la – this has raised awareness of the renal condition; but generated little in the way of fundraising. This year along with the very important Donor Register Information we would like to run a Tombola – that is where you the patients, carers and friends can help.

Can you contact your local businesses and ask them to donate small items for a tombola, anything from a can of beans to a bottle of sauce to a bottle of wine would be most appreciated.

If you have donated items, either drop those items off at the Tea Bar in Renal Outpatients at St. Helier or call Jim Rae or Dave Spensley – and if you are able to lend a few hours of your time on the day that would be much appreciated.

NO PLACE LIKE HOME

The KPA has so far donated £11,000 to the Renal Unit towards the 'No Place Like Home' Campaign.

Major events coming up include the John Edwards Foxwell Memorial Golf Day and, on June 25th, fund raising at Mannings Heath Village Fair.

You can help too. Lots of small fund raising events around the South West Thames area can help enormously to build our total towards this fantastic cause of ensuring home dialysis treatment for those who can benefit from it.

Go on, see what YOU can do!



KPA Memorial Donations

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

Phyllis Hutchings	Nigel Lionel Mearns
Eva Harman	George Armstrong
Mrs I Sampson	Mr Harding
Alan Leslie George	Michael Charles Carpenter

The KPA would also like to apologise for an error in the last edition which listed Clive and Justine Dechant within the memorial donations. Clive and Justine were, in fact, donating to the KPA following the death of Ruth Dechant, Clive's mother. We would like to apologise for any distress caused by this error.

KPA Donations

St Helier and Surrey KPA would like to thank the following people for their much appreciated donations either to the KPA's general funds or the 'No Place Like Home' appeal:

R & J Austin	Dr Mona Wahba	Mrs H Webster	Mr and Mrs Bradshaw
JR Rodway	PJ Steele	Lindsay Harris	Joan Loughran
Miss KA Johns	Mrs Joyce Johnson	J & S Webb	

THANKS FOR ALL YOUR FUND-RAISING EFFORTS

South West Thames Institute For Renal Research



Dear Kidney Research Funders,

As you are probably aware, our Kidney Failure Unit in South West Thames, based at St Helier Hospital Carshalton, for the past fifty years, also provides one of only three independent Kidney Research Centres in the UK.

This kidney centre serves patients from Wandsworth, Croydon, Redhill, Reigate, Crawley, Sutton, Epsom, Ewell, Guildford, Farnham, Camberley, Chertsey, Ashford, Surbiton, and Kingston. This equates to the bottom left hand corner of London (South West) as bounded by the M25 and beyond.

Our research effort has been possible only because patients, relatives and

friends of kidney patients, people like you, have determined to do something to help our family and friends unfortunate enough to have contracted kidney failure.

In the 1980's and 1990's over a Million Pounds Sterling was raised to see our research effort come to fruition. Since then our scientists and clinical researchers have made increasing impressions around the world and particularly in North America.

This year our efforts have been boosted by a bequest of £ 50,000 from a couple in their nineties who were so modern as to realise that the only way forward for the future, is to invest in research.

So many of you have set up fund raising initiatives in the last year, and it is your £50 pounds here and £75 there that makes all that our Scientists do possible.

Everyone who has reason to be thankful for the South West Thames Kidney Service at St Helier Hospital, Carshalton, must be aware of the INTERNATIONAL contribution to renal research that is being made by Dr Mark Dockrell and his team. Please contact us to offer you help in our exciting work.

Yours sincerely,
Michael Bending, Chairman

IN THE MONEY..

SWTKF Lottery Winners

07/01/2011	101103	Ash, Hants.	£72.50
14/01/2011	101140	East Horsley, Surrey	£73.50
21/01/2011	101032	Shepperton, Middx	£73.50
28/01/2011	101074	Sutton, Surrey	£74.50
04/02/2011	101128	Wallington, Surrey	£76.50
11/02/2011	101143	Matfield, Kent	£76.50
18/02/2011	101133	Belmont, Surrey	£77.00
25/02/2011	101045	Cheam, Surrey	£77.00
04/03/2011	101026	Worcester Park, Sy	£77.50
11/03/2011	101078	Ash Vale, Surrey	£77.50
18/03/2011	101071	Weybridge, Surrey	£77.50
25/03/2011	101157	Headley Down, Surrey	£77.50

ARE YOU WILLING?

News Flash: Here's another reason to 'Use Your Will Power'

In the January issue of Renality, we encouraged our readers to Use Your Will Power' to leave the South West Thames Kidney Fund a legacy in your will, and help ensure the future of kidney research.

There is further encouragement in this direction via the Chancellor's recent budget which states that if more than 10% of the value of an estate is donated to charity, the inheritance tax on that estate will be reduced from 40% to 36%.

Frimley Park and Guildford Branch:

Although a quiet period for the Branch yet our funds have increased by £557.96.

This is comprised of £160 of donations, £27.90 from Mali's Store in Ash, £25.65 from Tilford Holiday Homes and £14.96 from Frensham Post Office and a final total of £94.45 from Budgens.

We would like to thank Kate Shipton and friends who ran the raffle which, together with a donation from the Cake Stall at the monthly Frensham Village Lunch, raised £235.

We have two can-rattling collections booked for the summer – we will be at the Meadows, Camberley on Saturday 27 August and on Saturday 7th May for a collection at Sainsburys, Watchmoor Park.

£3,225.55

Budgens

This is the sum raised over the last three years by staff and customers at Budgen's of Ash Vale. It has been the most wonderful support

Three years ago, Angie Morrow, our collection co-ordinator, approached the Store and asked if they would agree to having our tins alongside their tills. They not only agreed but took the Fund to their heart.

They raised money in many ways - customers could buy a carrier bag at the checkouts to support the Kidney Fund. They could put donations in the cans. Raffles were held in the Store each Easter, usually a very large Easter egg.

Stalls were run by the staff at local events each summer and at each Parish Christmas Fayre. The goods were provided by Budgens, usually cakes and drinks and the proceeds donated to SWTKF. We thought we would be adopted for only one year but the Staff have worked for us for 3 full years. They have been magnificent. The final letter of thanks has been sent. We feel very privileged to have had so much support.



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Mad Hatters go green

IT hardly seems like a year has passed since our last St Patrick's night supper.

This time the dress code was 'green hats' – preferably mad ones, with a hint of theatre.

Once again my girlfriends rose to the occasion, bringing wine, gifts to raffle and 'donations' for SWTKF while I prepared supper.

A lot has happened for us in the last 12 months. To begin with, my husband has been a patient of Dr Marsh for the past 7 years and the time is drawing near for him to need dialysis.

This time last year I didn't know there was such a thing as a 'living donor'! Since then, Mike and I have been to an evening to

meet the complete transplant team to learn more about being a living donor and we've met and spoken to quite a few donor/recipients.

I'm terrified of needles – even the smell of disinfectant is enough to make me faint. However, it was no contest and I put myself forward for testing as a suitable donor last autumn. It's been a journey, never far from my



mind but continuing hopefully.

We've received wonderful guidance and support from everyone who we've come into contact with at St Helier. Not to mention Christina Ho – the transplant coordinator who is always cheerful, helpful and ready to listen.

St Patrick's night was great fun, made all the better by our friends not only

donating to help fund kidney research but in giving us emotional support in our journey.

We've raised £230 which will be gift aided and the Mad Hatters are already talking about what they will wear to the next one.

MARIE MOORE

ANNUAL GENERAL MEETING OF THE SOUTH WEST THAMES KIDNEY FUND AND INSTITUTE FOR RENAL RESEARCH

**WILL BE HELD ON WEDNESDAY 13TH JULY 2011 AT 7.00 PM
IN THE BLUE ROOM OF THE RENAL UNIT**

Please come and attend the AGM to hear from Dr. Bending the results of our Fund Raising and plans for the future and hear from Dr. Mark Dockrell the interesting projects which are being undertaken in the Institute. Refreshments will be served.

In appreciation of Margaret and Peter Simpson

Dear Renality Addict,

Today, Wednesday the 30th March, five days after the deadline for Renality submissions, I was phoned by Dr Hugh Gallagher to say "did I know that Peter and Margaret Simpson were retiring", and had I written to Renality about this momentous milestone.

Did I know....too right I knew (I have been worried silly for months) had I done anything about it? (Shamefaced....NO).

Margaret and Peter Simpson were introduced to the South West Thames Renal Service in NineteenHundredand EightyFrozentothedead. At first meeting it was obvious that Margaret had been a nurse some fifty years earlier, and she was never allowed to forget it.

Since then they have been through dialysis and transplantation and lymphoma together, but right from the start they threw themselves into supporting other patients, and Renal Research. Their contribution to the NHS in SWThames and Surrey goes far beyond Renal Medicine in their role on Patient focused groups. Peter was also involved in the Leonard Cheshire Foundation. What a contribution those two have made in what might otherwise been a blissful slipper and pipe retirement !!!!!

Finally, some fifteen years after statutory retirement age (I am sure the European Union has laws against this sort of exploitation of the elderly) they are hanging up their pens and agendae and committee meetings, to sail into a well earned retirement.....FINNALLY.

Why have I been worried to death? **HOW DO WE REPLACE THIS SORT OF COMMITMENT?**

Fortunately we have recruited Steve to take on as Editor of Renality. This really is such an important task because it is the focus of all who have a deep interest in the welfare of renal patients in SW Thames and Surrey.

We desperately need volunteers to take on the other Roles lead by Peter and Margaret.

With all our best wishes to you both.

Michael Bending



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Kidney Fund Marathon men & women...

John Turner will have run the **Brighton Marathon** on 10th April, and as Philip and Kevin Lofthouse (kidney donor and recipient) are relatives of John's wife, he felt kidney research would be an appropriate charity to raise funds for.

You may remember that Kevin Lofthouse was part of the Farnborough Arrows team who competed in the Goodwood Roller Marathon in August last year - again, raising funds for kidney research! John Turner can be sponsored via <http://www.justgiving.com/John-Turner3>.

Our Kidney Fund team has been training fast and furious for the **Virgin London Marathon** on 17th April. You can still sponsor the team - Vip, Sue, Patrick, Richard, Adrian, Stuart and Patrick at <http://www.justgiving.com/kidneyfund2011>. We will update you on how they all did in the next issue of Renality

Stuart McSweeney who in the last year has organised a Musicathon and a recital for the Kidney Fund is completely changing direction for his next fundraiser and is running in the **Bristol 10K** on the 15th May. Good luck Stuart! You can sponsor Stuart by going to <http://www.justgiving.com/Stuart-McSweeney>.

SO, JUST HOW DID START...

Renality

Margaret became Secretary of SHAK in the 1990's and one of the duties to take on from Pat Godden was to write the SHAK newsletter – a matter of 2-4 pages depending on how much news there was.

A black and white publication, it was circulated to the 500 (approx.) members of SHAK.

After a couple of years, Peter became Chairman of SHAK. During his reign, in the late 1990's the Strategic Health Authority decided to move transplantation operations from St Helier Hospital to St George's. Various reasons were given but the SHAK Committee and other patient carers, including Richard Sammons, decided to campaign against this as it would split a successful Renal Unit. A public consultation was carried out and of course, transplantation operations went to St George's Hospital.

Although we hadn't succeeded in changing this course of action, it was seen by the then Management of the Renal Unit that we were in touch with the patients – we had presented a petition of over 2000 signatures to the Strategic Health Authority.

Also, at this time (about the year 2000), patient representation became very popular and all organisations within the NHS had to be seen to be working in partnership with patient representatives. The patients' voice should be heard!

We were asked by the Management - Jonathan Kwan, Kay Sandhu and David Newman, the Scientific Director of the Institute – if we would expand the SHAK newsletter to include news from the Renal Unit, the South West Thames Kidney Fund and the South West Thames Institute for Renal Research. They all agreed they needed a newsletter but no one could be spared to put one together. After much discussion, we agreed to take it on.



In the first edition, we held a competition among patients to give the newsletter a name. John Carter won it and Renality was born.

We started by printing 1700 copies which would be sent out to the 'most active' patients – those on dialysis and transplant patients at that time. The staff arranged the labelling of envelopes and 'stuffing' took place in our dining room. We organised friends to help. Then we took the boxes back to the Renal Unit for posting.

BUT, Dr Kwan wanted all patients to have the newsletter. Our dining room couldn't cope with the number of boxes of envelopes and newsletters so 'stuffing' is done in the Blue Room at the Unit.

Over the years we have developed Renality from black and white to 20 full colour pages. Now, we print nearly 6,000 copies each time. Sometimes, we have so much to report we have to leave items out but we always make room for our regular contributors.

We have an Editorial Board and a great team of 14 -16 people who meet to do the 'stuffing' every quarter. It is hard work but very much a social occasion where friends exchange news.

Many of the tasks involved in the organisation have been taken on by others and we have appreciated the involvement of Graham Morrow and Dave & Di Spensley in particular.

Now, we are retiring as Editors and the job is being taken over by Steve Purcell. We wish him every success in the job and hope he gets as much pleasure from it as we have had.

We would like to thank all the regular contributors who have co-operated with us despite pressures of work and time. Also, thank you to all the staff, particularly Sara Jobson, Elaine May and Anne Collard who have helped us along the way to make the organisation go well.

Margaret & Peter Simpson

South West Thames Institute for Renal Research

Mark Dockrell, Institute Director

Well, it seems to have taken a while to arrive but I think spring has finally sprung and we are well and truly into the season of new growth. And with that somewhat tentative link I thought I would write to you all about another kind of growth.

Last month Graham, one of board members of the Kidney Fund and Institute, asked me if I'd seen a particular TV programme earlier that week. Well after I muttered something about "no time for television, grumble grumble, working too hard, grumble grumble..." Graham showed me a little of the programme that he had recorded for me. It was called "Mending a Broken Heart".

Just before you leap to any conclusions, I have not recently had my heart broken following some disastrous romantic tryst. The programme in question was actually from the fabulous Horizon series on the BBC and it was absolutely fascinating. I don't know if many of you managed to see it but it was about some research that is on-going about producing hearts for transplant by using stem cells. The work is still at a relatively early stage and they were using experimental animals for their work but they did manage to "grow" a new heart that could function.

It all sounds pretty amazing; what they did was strip all the cells from a heart so that they were left with a "scaffold of a heart" but with no cells in it! They then introduced stem cells, which after a while filled the "scaffold" and they managed to produce a heart that could pump. Now, this is still preliminary stuff because, as far as I understand, they had not yet arrived at the stage when they could then transplant this heart into a donor animal and successfully make it work. None the less I think you'd agree that it is a very impressive leap forward in how in the future they might be able to repair or even replace a damaged organ.

For me one of the particularly interesting aspects to this research project is that they grow the new heart on a "scaffold" of an old heart. Here at the Institute we have been thinking about how important the scaffold that kidney cells grow on is. As you probably know one of the ways we try and study kidney disease is by growing human kidney cells in the lab and trying to understand what goes wrong when someone gets kidney disease, but importantly we also consider what we might be able to do to turn that around and try and make the kidney healthy again. When we grow cells in the lab we want to try and create a situation similar to that in your own kidney, or at least as close as possible. That way we can try and get our model a little closer to real life.

In order to do this we have been thinking about how we can mimic that scaffolding I was talking about. We also know that in many cases a diseased kidney develops a damaged scaffold and this damaged scaffold can further damage the cells and so on in a vicious circle. Could there be some way to intervene, promote a healthy scaffold and therefore healthy cells, thus stopping the vicious circle?

These are some of the questions that our new Post-Doctoral research fellow, Dr Felicia Heidebrecht, has already started addressing. Felicia arrived in February and comes to us from Germany where she published some very interesting work in this area, except with liver cells rather than kidney cells. She has already made a really positive impact in the Institute. We were only able to bring Felicia over to work with us thanks to your kind support of the Kidney Fund and now that she's here I plan to find a way to keep her.



DRAGONS' DEN..

Last July the 'Sweaty Kidney Scientists' had a great time at the Dragon Boat Racing event organised by the Kingston Rotary Club.

We are looking again this year for enthusiastic paddlers and fundraisers for the event on Sunday July 17 at Canbury Gardens, Kingston. Each team has a maximum of 16 paddlers plus 1 drummer, and as it's quite a bit of physical effort it's good to have a few reserves. It's an all day event running from around 9:30 or 10:00 am until about 4:00 pm, and is a lot of fun involving a huge amount of 'team spirit' if not paddling expertise!



If you would like to be on the team, or be a reserve, please contact me as soon as possible as this event is quite popular. We would like all team members to commit to raise a MINIMUM sponsorship of £250.00.

We are also able to have a charity stall (or stalls if we get enough volunteers and good fundraising ideas) on the day so let me know if you have any good ideas and/or would like to help. **Anne Collard**

Letter from the Lead Nurses

I am writing this after having just completed my final long training run for the London Marathon - 21.5 miles, three times around Richmond Park. Beautiful warm weather and very hard work but my goodness was I euphoric once I had finished, a super endorphin rush, amazing! Just hope I feel that good on the day once I have finished!

Anyway onto all things Renal....

Last month Susie updated you on the huge amount of work we have done to improve infection control on the unit.

We are currently carrying out a similar level of work to try and improve transport provision. As you probably know this is one of the real bugbears for dialysis patients who often have to endure long journeys to and from dialysis units.

In particular, Sister Angie Wright is carrying out some initial work at Kingston Dialysis Unit, speaking to patients and trying to find out what their experience and opinions are and how these can feed into improving the service. She is also looking at how journeys are planned and the criteria that are used to plan journeys.

We are hopeful this work will lead to some good recommendations that we can apply across the whole of our renal service, but we would also appreciate feedback from the wider renal patient community for ideas. In fact, your feedback does not only need to be about transport but also about the way we deliver the service generally.

You can contact us via the renalfeedback@esth.nhs.uk email address or via dialysis staff, ward managers, doctors and renal outpatient staff. However, we also realise that for some this can be a daunting prospect, so we are currently working with the Kidney Patient's Association to see what other feedback methods we can implement for patients and carers to use that are more accessible and less daunting. This is really important for us to achieve as we are keen to do whatever we can to continue to improve the service, so if new ideas crop up I will keep you informed.

Anyway that's enough from me. The next time I write will be post marathon, hopefully I will survive it, but for now I am off to put my feet up.....

Sue Woodcock, Joint Lead Nurse Renal.



SWT Kidney Fund Donations...

MANY THANKS TO:

Aileen Cootes for the donation for her 70th birthday

The Surrey Freemasons of The Pilgrims Way Lodge who organised a charity event and raised £1,150.

The many Renality readers who have sponsored our London Marathon team.

Kathryn Harrison for organising a charity collection at the Croydon Waitrose, resulting in a cheque for £390 - and many thanks to Waitrose as well for this charity project.

Santander for their matched funding for Philip & Anne Slack's 'Post Transplant Celebration'

To Shelagh Cook who marked World Kidney Day at her Fitness League in Guildford with a Bring & Buy Sale, combined with a Coffee & Cake morning. The 28 strong membership managed to raise an amazing £150!

To John and Jackie Treharne who run the Wednesday mini Market in West Wickham and gave us a cheque for £900 as the yearly profit from the stall holders. They also collected £66.85 over the year in the collecting tin.

Donations in memory of:

Ken Lovell John Reader Nigel Meears Denis Lynch Margaret Alice Johnson
Robert Allen Chapman Mr Robert Edward Trotman

The much-needed Legacy from Mrs Dora Hettie Jelley of £50,000.

TRANSPLANT PETER RUNS FLEET HALF MARATHON..

I'M Peter Brookes, a 56 year old kidney transplant patient with a graft that I received in 2001 at St. Helier.

My underlying condition is polycystic kidney disease, diagnosed after the problem was discovered during a routine medical. When I was almost at end stage kidney failure I was referred to the Renal Unit and spent five months on APD at home, using the 'Lifesite' access site which was being trialled by the St Helier CAPD department.

I was very, very lucky, receiving a transplant after only three months on the waiting list. I had the phone call just on the day when I told my wife Julie 'I think that I'm used to this dialysis and can live with it now'!

I received my transplant, which worked just fine, but I had some other problems that left me barely able to walk let alone run.

However, I was determined to return to fitness and set myself the target of running a half marathon. I also wanted a way of expressing my gratitude to the Renal Unit for the excellent care that I had received there and in the CAPD department.

In particular, I wanted to do something to help people that have not been as fortunate as me and who are still on dialysis.

My first steps were to walk to the end of the road, with the assistance of my 7-year-old daughter! Once back at work I was soon out on an old running circuit of mine, around Lambeth and Vauxhall bridges.



Meanwhile, at the weekends I started to run in the army training area which is near my home in Aldershot. I had found an exhilarating new experience. This area is a little bit of wilderness nearly on my doorstep and, early in the morning, I virtually had it to myself.

It has everything that a trail runner could want; hills, valleys, forests, lakes, sandy plains and an Iron Age hill fort with splendid views, especially as the sun rises!

The longer runs were hard but after about two years I felt that I was ready to enter the Fleet Half Marathon, which is a local road race. Then injury took over. Over the following years I was off running, back on and then off again with a series of injuries common with runners.

I restarted in April 2010 and, putting what I had learnt from my previous mistakes into

practice, I avoided any major problems and entered the 2011 race, held on 20th March.

I finished my training sure that I could cover the distance and 'tapered down' towards the day. That didn't stop me from being quite nervous as I lined up near the back of the field on race day, knowing how much money for the Association was resting on my performance that day.

The weather was perfect; dry, no wind and cool. The course took in Fleet town centre, with two passes along the high street before disappearing into the countryside and then back to the town's Calthorpe Park.

I tried to concentrate on keeping to the pace that I had practised in training but, come the 9 mile point I had six minutes in hand. I was on course for a good time, for me.

Then it happened. At 10 miles I 'pulled' a thigh muscle and thought 'I'm out'.

However, I half limped and half ran for a while and the pain eased. I was able to resume running but saw my six minute 'bonus' dwindle. I managed a token spurt at the end and finished in 2 hours and 10 minutes.

I'm very glad to achieve what I set out to do almost 10 years ago.

And I'm proud to announce that, at the time of writing, friends, family, neighbours, work colleagues and contacts have donated just over £700, with gift aid counted in.

2011 Adidas Women's Challenge - a 5K (3 mile) fun run/walk/stroll/stagger/crawl in Hyde Park

This year's Hyde Park Adidas 5K run is scheduled for Sunday, 11th September 2011. It's a 'Female Only' event with no age limits for participants. As long as you feel you can get around the course - whether by running/walking or crawling - you can enter.

So ... give some thought about female relatives/friends/colleagues who might like to take part with you and enjoy a really fun day while raising funds for Kidney Research. More information will be available by visiting www.womenschallenge.co.uk/home/.

Once the online entry is opened, you can register online, or contact me for an entry form. For online entries please type in the South West Thames Kidney Fund as the charity you would like to support and then £5 from your entry fee (which last year was £15) will come directly to us. You will not be able to choose the Kidney Fund from a list as we do not pay for that service.

We will supply you with a Kidney Fund T-shirt, sponsorship forms and lots of support!

Anne.Collard@kidneyfund.org.uk or phone Anne on 0208 296 3698 or 0208 296 3698

