

RENALITY

The NEWSLETTER of...

May 2014

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



200 MILES BY DOG SLED ACROSS THE ARCTIC IN MINUS 30 DEGREES...

Entrepreneur SURBS BADHAN has raised more than £3,000 for kidney research on his latest challenge - despite having one kidney and CKD! He has 'taken life by the horns' in his own words, and is keen to push himself to the limit while running his businesses and continuing his fund raising. Story: Page 3

OUR MAGNIFICENT MARATHON TEAM RAISE MORE THAN £20,700.. SO FAR!

MO FARAH finished eighth on his London Marathon debut as 36,000 runners enjoyed another amazing race.

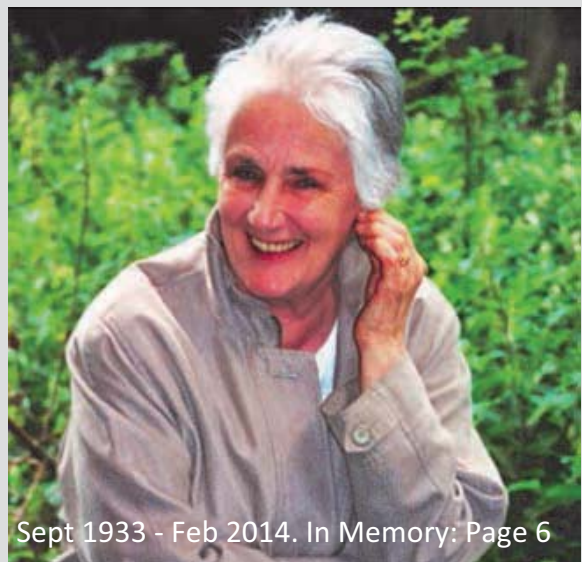
Many of them were running for charity – like our very own team raising money for the South West Thames Kidney Fund.

And didn't they do well. Not just in terms of their own personal triumphs by completing the gruelling 26-mile course, but in the fantastic amounts they have raised for kidney research.

In early April the combined efforts of each team member and generous donations from our Renality readers had resulted in a total of £20,726.00 for kidney research!

And it's not too late to sponsor – either at www.justgiving.com/kidneyfundteam2014 or by cheque made out to SWTKF to Anne Collard, SWTKF, Renal Unit, St Helier Hospital, Wrythe Lane, Carshalton SM5 1AA. **SWTKF runners: Page 14**

MARGARET RUTH SIMPSON



Sept 1933 - Feb 2014. In Memory: Page 6

In this issue:

Renal Unit News:

Clinical Director	7
Dialysis advice	18/19

SHSKPA News:

Donations	8
Treasurer needed	8
Chairman's Report	9
Holiday home	10
Golf Day	20

SWTIRR News:

Institute Director's message	15
------------------------------	----

SWTKF News:

ABOi Transplant	4/5
World Kidney Day	3
Margaret Simpson	6
Dragon Boats	11
Meerkat manner	11
2015 Calendar	12
Lottery winners	12
Chairman	13
Donations	13
Fund raisers	14/15
AGM	16

Useful Contacts:

RENAL UNIT reception:

020 8296 2283,

020 8296 3100

SWTIRR & SWTKF,

**Anne Collard, Administrator:
020 8296 3698**

SOUTH WEST THAMES

KIDNEY FUND,

HayleyAnne Fitzgerald,

Secretary: 07974 422424

ST HELIER & SURREY KPA

Dave Spensley, Chairman

01483 426276

There are many many ways in which you can help the **South West Thames Kidney Fund** and help ensure the future of Kidney Research. Further information on all of them can be accessed via the 'support us' page on our new website – or, if you do not have computer access and would like to know more, please do call Anne on 020 8296 3698.

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

Create a **standing order**

Donate via **payroll giving**

Enter our **car draw**

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

Shop 'til you drop and **Give as You Live!**

Recycle your old car at no cost via **GiveaCar**

Sell an item on **ebay**

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

Buy our **Christmas Cards**

Donate **shares**

Donate your **tax refund**

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

'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.

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

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

SWTKF: WORLD KIDNEY DAY 2014

The South West Thames Kidney Fund, Institute for Renal Research and St Helier Hospital Renal Unit celebrated World Kidney Day 2014 in style at the Bentall Centre, Kingston on Thames.

It was a long but satisfying day, starting at 8:00am and ending at 8:00pm.

Twenty two wonderful Kidney Fund supporters volunteered their time throughout the day to raise awareness of kidney disease, give out information on organ donation and answer any questions people had.

Renal Unit nurses, led by the irrepressible Nimmy Logeswaran, offered free blood pressure checks to the passing public and took the blood pressures of 110 people aged from 12 to 85 years – 77 women and 33 men.

Kathryn Harrison arranged a visit from the Mayor of Kingston who arrived at noon and spent quite a bit of time talking to everyone.

Both she and her aide had their blood pressure checked.

Sofhia Scala-Smith donated the most amazing and eye catching 'Mr Smiley' balloon centrepiece for our event.

Thanks so much Sofhia – it added a lot of brightness to the day!

Our thanks go to Renal Unit nurses: Nimmy Logeswaran, Mary Thomson, Susan Kareem, Jean Carr, Eleanor Carter



& Caroline Evans; Dr Mark Dockrell & Sarah Yates from the Institute and - in no particular order - our wonderful Kidney Fund supporters:

Richard Lee, Sue Beesley, Margaret Watford, Nathan & Juliet Fryer and Juliet's Mum, Danny Boyle, Kathryn Harrison, Vicky Harrison, Victoria Lee, Dr Robin Mulcahy, Pauline Hopkins, Dr

Subash Somalanka, Annie Tse, Hilary Smellie, John Sadler, Cilla Hashmi, Deepak Mahtani, Margaret Fiuza and Mr & Mrs Paul Steele.

In addition to raising awareness of Kidney Disease, the 2014 World Kidney Day can collection at the Bentall Centre raised £670 for our research, so an excellent day all round!

Surbs conquers the Arctic - by Husky sledge

Entrepreneur Surbs Badhan, 37, from West London, was born with one kidney and suffers with CKD which, thankfully, is stable. He writes:

I have been involved in a whole range of physical and mental challenges the past 2 years but the main one was Husky Sledding across the Arctic 200 miles in -30 degrees across sweeping ice mountains over seven days.

I've raised £3000 for The National Kidney Federation.

This was an Arctic expedition and camping in the ice mountains was a challenge, as was waking up to a snowstorm like in the movies.

Caring for the Huskies was a joy and I have been invited back to do the 1000 mile version which I may do next year.

I have taken life by the horns and literally living my life to the limit and taking ultra care of my health and this has stabilised my condition.

I am tri-athlete and train heavily most days and also use this strength to partake in an event called Spartan - a 5km army



assault course with 20 obstacles ranging from swimming in bog heaps to scaling electric fences.

I am still raising money for this charity with more challenges this year including scaling a Volcano and learning Italian in 6 months to navigate the whole country without using a word of English!!!

I'm an entrepreneur running a number of businesses but ideally want to be able to live doing just challenges around the world.

Hopefully revenue from the businesses will allow me to do this in a couple of years.

I have a Facebook Fan page and Twitter account which has video footage of my group escaping a Snowstorm... plus all the other challenges from last year... If anyone would like to see them. And there will be a raft of new challenges from May

onwards.

You can find them at: www.facebook.com/relentlesschallenge
Twitter: @relentlesschall

My consultant is Dr Marsh and I am extremely grateful for his care and support over the last few years.

Alex Hilson tells his remarkable

Waiting for a return to normal life following kidney failure can seem endless, doubtful and lonely as life races away without you.

So, one year past what I call my 'middle life', do I consider it a happy ending? To help and inspire both those who are just starting on their kidney journey and also to share some views with those who are still on it, I wanted to tell a short version of my story - one that on many occasions, I never thought I would be able to tell.

On the evening of Sept 13th 2011, I left work for what I thought was a routine appointment at the doctor. I'd been feeling tired for months - a tiredness I couldn't shake off - and I'd had sporadic and frequent heart palpitations throughout the summer. On one occasion chest pain combined with sweats and a shooting pain down my left arm just as we were about to board a plane for the family holiday to Spain. It lasted 10 minutes.

My work as an IT consultant at a global energy company had been stressful, plus I'd just had my usual double espresso to counteract my tiredness in the airport lounge. We went on our way with me thinking a good holiday would sort it. I, like many men, could always find a naive excuse as to why I was perfectly fine. That evening on the 13th in my GP's surgery room, two blood pressure machines couldn't find a reading but the last machine we tried told us 220/130.

I was in Frimley Park's A&E within the hour. The next day I had my own bed with my name on it in Harry Secombe Ward at St Helier. I didn't understand what was going on but knew it was probably serious, for the time being.

It took a few more days again before the biopsy would be performed and a diagnosis committed to.

IgA Nephropathy, End Stage 5 Kidney Failure, not acute but *Chronic* Kidney Disease, 14% kidney function and deteriorating. The effect of the final diagnosis and the aggressive blood pressure pills taken that morning collided at that moment and I collapsed after phoning my family with the news. I was only 37 and reaching what I thought was my



A brave face for my CT scan

prime. My health ignorance was at its most obvious in those moments and it took some time to learn about and accept my new 'middle life'.

My parents, Sandy and Peter, who were in good health and in their 60s stepped forward with offers of a kidney. Despite their own fears they desperately wanted to do whatever it took. On the surface a kidney from a healthy parent presented as an obvious solution but several emotional and medical complications developed as time went on. Dad was in good health but getting on a bit but more importantly the wrong blood group, i.e. ABO Incompatible (ABOi). Mum was the right blood group but the kidneys were too small (I'm 16 stone and 6'4"!).

Assuming dialysis was only a bridge to transplantation, three options emerged: Cadaveric list with the associated wait; live ABOi donation from Dad and all its reluctant caveats; finally trying the Paired Living Kidney Exchange, where your donor's emotional barriers are more intense for them.

Live kidney donation is a bold, infinitely generous gift that most people cannot comprehend unless put in that position. Yet the acceptance of a kidney physically and emotionally is largely overlooked and also requires significant soul searching... to survive I would need to put someone else's health and life at risk. Why should they do it? Why can't this be something I sort out on my own? Could I cope with waiting on dialysis for a younger, blood group compatible

kidney? I battled with the turmoil of being selfish on one hand and finding the best outcome for everyone involved for many, many months.

The bad news kept coming. At my first clinic I was told that they'd found an adenoma during biopsy. A CT scan would be required but this couldn't be performed until dialysis had started. I didn't start dialysis until late January '12 and had the scan ASAP few weeks after that. Five months waiting to see if my situation had gone from bad to worse finally came to an end... 'Unequivocally clear' of cancer. There were more tears but to celebrate we drove the children and my APD machine to Disneyland Paris to treat those brave little souls.

My work-ups for the transplant list and for APD took all my focus and remaining reserves of energy. On advice, Dad bravely agreed to submit our names to the Paired Living Kidney Exchange programme. In the meantime, I was accepted onto the cadaveric list and undertook APD every night... for what became 13 hard months.

In the meantime, the attempted pairing failed four times, my numbers didn't come up for a cadaveric kidney, the APD was becoming less effective with continued infections, my condition was worsening and I felt really very poorly every day including chronic headaches, dizziness and 15 hours sleep each night and afternoon. Dad was also another year older since the saga had begun.

My hard-earned career was a distant memory and my insurance policy at work was running out.

Towards the end of 2012 we were given a firm date of Feb 27th 2013 for a live donor ABOi transplant, pending a final paired run attempt. It moved us on to the next equally emotional stage. I put my game face on, Dad kept his poker face - the same one he'd had from day one.

ABOi transplant comes with additional complications over and above a regular (I use this word reluctantly) transplant and I'll save that for people who specifically want to know. February arrived and I started my ABOi antibody treatment. In the transplant week we both had minor complications, relatively speaking.

story of ABOi Transplantation

But over the next few days positives started to emerge. As I came around from the operation at St George's, the sun was shining through the recovery room and I felt my headache gone, over and above the seven hour anaesthetic, for the first time in 18 months (a good start indeed).

Mum told me later "you look 10 years younger" and my sister exclaimed "I've just witnessed a miracle!". The next morning Ms Heap visibly delighted told me "There was urine everywhere as soon as we put the new kidney in!".

Dad was sore too but remained publicly unfazed. The gradual tweaking of our post-op care saw small improvements each day. Dad was home the following Monday, I was home on the Tuesday. The new immunosuppression routine kicked in quickly and aftercare, although demanding particularly with travel to and from the hospital, kept rewarding me with blood results that were turning from red to green.

After eight weeks both Dad and I were driving again mixed with regular gentle exercise, after 12 weeks I tried my new mountain bike for the first time. In July I took the family camping – previously impossible with no energy and an APD machine. In August I drove my family across France to Lake Annecy and onto Lake Garda. More camping followed, then in September I was the support van driver from my brother-in-law's charity cycle ride to Paris. Life was starting to exceed my expectations by a long way.

I then joined Camberley & Farnborough hockey club, playing for veteran's side, the Owls. After my first match I shared my recent history with the team and their chins dropped to the ground. The Man of the Match award meant more to me than they could.

At Christmas we took the children with us to the Austrian Alps to do something I'd honestly thought would never happen again – I dusted off my snowboard and boarded whilst my girls skied next to me.

This outcome that has only been made possible by medical advances, courage from pioneering doctors and dedicated professionals, not forgetting my father who committed himself from day one and my mother who helped me make



My own personal miracle, from St Helier to St Anton

sense of it all. Being an ABOi recipient of a 65-year-old kidney isn't the solution of choice but 40 years ago, I wouldn't be here without it. There are many wonderful people in both St Helier and St George's that have cared for me and other kidney patients and I hope they take five minutes to read this with a sense of personal achievement.

A deserved and heartfelt thank you from me and my grateful family.

When attempting to understand my fate I found comfort in reading the stories of others and communicating with people in similar situations. I'd seek every last

piece of information I could, attending the transplant evening, to help me comprehend whether I'd ever experience life in its most fundamental form again or whether I had to let life move on without me. Finding your way through an overwhelming set of circumstances to a seemingly healthy result is very difficult and is not achieved easily but I hope my difficulty, discomfort and eventual euphoria will give hope to those in similar situations and allow them to think positively about what can happen once all the challenges are seen off. A happy ending? Unequivocally yes, for now.



Playing hockey again after 20 years (back row, second from right)

Leaving a Legacy - Looking to the Future

A gift to the South West Thames Kidney Fund in your will would provide a lasting legacy for future generations. We believe that research is vital if we are to continue our work towards finding a cure for kidney disease and any gift left in your will help fund research projects in the Institute for Renal Research and improve our world for the next generation of those who suffer from kidney disease.

The Institute for Renal Research opened in 1998 after years of fundraising, funded by people like you who already have a personal interest in advancing medical science in this area. We have already accomplished so much, and yet there is still so much more to do.

A will is a uniquely personal document, and will give you peace of mind knowing that your final wishes will be carried out.

It will ensure that those you love are provided for and is an opportunity for you to help those causes you have supported during your lifetime. By reading this you have shown that you care about those with kidney disease which is why we are asking you to consider leaving us a legacy.

Making a will or amending an existing one can be easier and cheaper than you think although we do recommend you visit a solicitor and get professional advice. See our website at www.kidneyfund.org.uk/leave-a-legacy for more information.

If you have already remembered the South West Thames Kidney Fund in your will or intend to do so please let us know. All information will be treated in the strictest confidence.

If you would like more information or would just like to talk it through with someone please call Anne on 0208 296 3698 or e-mail us at legacy@kidneyfund.org.uk.

MARGARET RUTH SIMPSON

September 15, 1934 - February 27, 2014

On 27th February 2014 we lost a dear friend and a friendship lasting over 23 years sadly came to an end.

Margaret had always been a very strong and determined lady and with Peter, her devoted husband, always ready to support kidney patients and the staff at St Helier.

At the SHAK AGM in 1996 there was a call for new committee members – there were no volunteers, but Margaret said she would be willing to help out!

By the following year, Margaret was Assistant Secretary and Peter was Assistant Treasurer. By 2000 Margaret was a fully-fledged secretary and she and Peter (now Deputy Chairman) were joint newsletter editors!

In 2001 she took over responsibility for Membership. To reach a wider audience, Renality was founded in 2002, incorporating news from SHAK, SWTKF and SWTIRR. In November 2006 they both resigned from SHAK to concentrate on the Kidney Fund and raising funds to search for a cure for kidney disease.

For many years Margaret has had many hurdles to jump and has not been the luckiest person health wise but we have never heard her complain – she has always faced challenges with determination and a positive attitude and also a sense of humour; and has had strong support from Peter and their wider family.

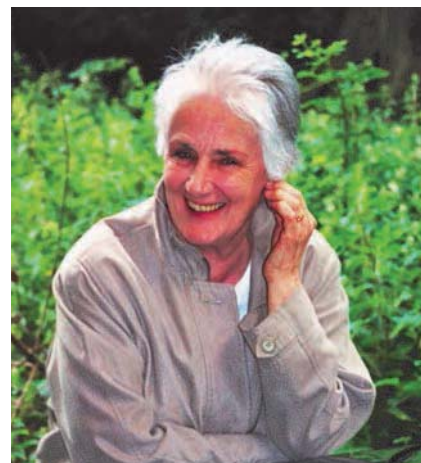
We were always greeted with a smile and a hug and, near the end, reminded she had her “end of life medication – but I’m not ready yet” - even though she would be in terrible pain. Amazingly, her transplanted kidney remained healthy. On our last visit to see her in St Helier, as we entered the ward she looked up, smiled and said “just look at me, I’m like a garden sprinkler” as she was struggling with a huge fluid build-up leaking through her skin.

As a family we will remember her as a positive, inspirational lady whose motto must surely have been “Don’t let it get to you, just get on with it”. Thank you Margaret, we will all miss you.

Instead of flowers Margaret had requested donations to SW Thames Kidney Fund – if you would like to send a donation in her memory please send it to me:-

G Morrow, The Cedars, Horseshoe Lane, Ash Vale Surrey GU12 5LL

Graham and Angie Morrow and family.



PERSPECTIVES!

Peter Andrews, Clinical Director



As I write this, the wonderful panorama of the Jungfrau lies before me. For those who remember 'O' level geography, it is the most perfect example of a U-shaped valley hedged by mountains, arrêtes, corries, waterfalls and truncated spurs. Spring skiing paradise! (See picture, below)

Also as I write this, my wife – who cannot ski at present because of a hip problem – is enjoying the spring sun, lazy days reading and walking, and a well deserved break from the domestic chores.

The children, who should be revising, are playing with bits of electronic technology which purport to tell them who skied fastest and furthest, and who has the best ski style (all of which is considered infallible until it indicates the least favoured result).

The dog has its own perspective (see below).

Meanwhile, the work of the renal unit continues. I keep in touch with some of it by email and text, but the truth is there is only so much that can be done remotely, and thank goodness for that. The most important parts of my role remain the personal ones.

Why do I mention the above? Because with distance comes perspective. Taking a few days out from the whirlwind of the renal unit allows spent batteries to be recharged, and also allows time to consider the bigger picture: Work – Home – Life – Balance.

As I attain the exalted height of senior (read oldest) clinician, it is becoming increasingly clear that some of the ways in which we work need to change.

Some things need to be done more, especially with a post-Francis focus on quality, acute kidney injury and weekend/out-of-hours working. So we are putting major new nursing and medical resources into all these areas.

But another perspective is that some things need to be done less. I would love to attend fewer meetings (fat chance!). Failing that, I need to decide on the areas where I and colleagues add value. What can we stop doing? In many ways, by freeing up time for more important things, this deserves an equal focus.



The renal unit is fortunate to boast an extraordinary collection of some of the hardest working and most dedicated people you will ever meet. And if they are to be effective, we need to stop them burning out. And this is where emails and texts will never do the most important job of all, that of telling people how much they are valued.

So my Easter message, drawn from long distance perspective, is that we should all spend some time doing less, taking the longer view, and appreciating the things we love. Excuse me now. I'm just off to kiss the wife, and embarrass the teenagers.

News from the Doghouse...

I am writing this from gaol. I have been here for a week for no apparent reason, confined with another retriever and a strange type of dog they keep calling 'Heinz 57'. We have all been abandoned by our pets while they go 'on holiday'.

What did I do wrong? I have sat, brought, carried, dropped, shaken paws, gone to my room, and returned when called. I have submitted to inexperienced grooming and tick removal. Goodness, I have even pretended to like the mother-in-law!

When I get out – and the word is that it may be tomorrow, following good behaviour – I'll show them! Perhaps an 'accident' or two, blamed on the strange food...

Yours disgruntled, Elsa



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

Spencer Varley

J R Rodway

Milford MOB

MEMORIAL DONATIONS...

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

Maurice Fell

John Charles Burch

Pamela Forsey

Reginald Percy Wells

Leslie Cooper

George Hughes

Gladys Pidgley

Robert Anthony Scott

Clive Bradshaw

Philip Hanrahan

We are also grateful to have received a **Legacy** donation in regard to **Eric Day**

FOLLOWING THE DECISION OF OUR EXISTING TREASURER TO STEP DOWN WITH EFFECT FROM THE AGM IN NOVEMBER 2014, ST HELIER & SURREY KPA WILL DESPERATELY REQUIRE A NEW TREASURER.

KPA TREASURER

ANYBODY INTERESTED IN THE POSTION SHOULD IDEALLY HAVE KNOWLEDGE OF BOOKEEPING /ACCOUNTING TO AAT STANDARD.

AN UNDERSTANDING OF CHARITY ACCOUNTING AND STATEMENT OF RECOMMENDED PRACTICE (SORP) AND MICROSOFT EXCEL WOULD BE AN ADVANTAGE.

THE ROLE WOULD CONSIST OF:

- 1) ACCURATELY RECORDING INCOMES AND EXPENDITURES IN AN EXISTING EXCEL WORKBOOK FORMAT INTO THE VARIOUS CATEGORY HEADINGS AS REQUIRED COMPLYING WITH SORP ACCOUNTING STANDARDS.
- 2) COMPILING A SHORT CASHBOOK REPORT ON INCOMES AND EXPENDITURES TO THE TRUSTEES AND COMMITTEE OF THE KPA ON A MONTHLY BASIS.
- 3) ASSISTING THE TRUSTEES WITH THE SELECTION OF INVESTMENT OPTIONS FOR THEIR DECISION IN ORDER TO SAFELY MAXIMISE THE RETURN ON RESERVES.
- 4) RAISING A SMALL NUMBER OF INVOICES IN RELATION TO THE DISTRIBUTION OF COSTS AND INCOMES OF THE RENALITY MAGAZINE.
- 5) THE ISSUING OF CHEQUES TO CLAIM RECEIPTIENS.
- 6) COMPILING A NUMBER OF SIMPLE ANALYSIS WORKSHEETS TO ASSIST WITH YEAR-END REPORTING WITHIN THE EXISTING EXCEL WORKBOOK PACKAGE.
- 7) COMPILING FULL YEAR-END TRUSTEE REPORT AND ACCOUNTS FOR INDEPENDENT REVIEW BY EXTERNAL CHARTERED ACCOUNTANTS.
- 8) THE FILING OF THE SIGNED-OFF ACCOUNTS AND ANNUAL REPORT WITH THE CHARITIES COMMISSION.

FOR FURTHER INFORMATION ON THIS POSITION PLEASE CONTACT DAVE SPENSLEY, HON CHAIRMAN ON 01483 426276 OR daspensley@btinternet.com

A message from your Chairman

Hopefully by the time you get to read this it will have warmed up and the sun will be shining. This is a generally quiet time of year for the KPA but there is one important date for your diary...



Friday 20th June, Golf Day

Following the success of our previous golf days we are holding another event playing the superb Milford Golf Course in Surrey. The event will be held on Friday 20th June 2014. This is a lovely venue which will provide a great day of golf for players of all abilities, 2013's event broke records both with the number of players and money raised so it would be great to get 70 players or more for this year.

If you're a golfer please book your place and bring a friend. A poster on the event is included within this edition.

Purchase of Equipment

Since the last Renality we've purchased the following items

- 23 Bedside chairs for the wards at St Helier.

- Overlay Mattresses for St Helier and its Satellites.

- 2 Profiling beds for the Farnham Satellite

- 3 Televisions together with power and aerial installation for Beacon ward

- 3 Televisions together with power and aerial installation for Snowdrop ward.

- Sponsorship of training manuals

We have agreed to provide a bariatric dialysis chair and Body Composition Machine (BCM) a machine which will allow an accurate dry weight to be set.

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

Margaret Ruth Simpson

The Committee were sad to hear of the death of Margaret Simpson on the 27th February 2014. Margaret joined SHAK in 1996 and her and Peter served on Committee in various positions until 2006 when Margaret stood down from the Secretary's position and Peter from the Chairman's position. Margaret developed Renality in 2002.

Graham Morrow has written a separate article in memory of Margaret.

Our thoughts and prayers are with Peter.

Other Matters

The KPA Committee has 3 new members but we still don't have patient representatives for Kingston, Sutton and Crawley. 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.

We also need a replacement Treasurer or Accountant as Jim Rae will stand down at the AGM in November

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

That's about it for my report; I'm off to cut the grass.

Best Wishes

Dave Spensley, Hon Chairman

S.H.S.K.P.A Holiday home

St Helier and Surrey Kidney Patients Association



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

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

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

2011 Patient Rates

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

To contact us:

Nita and Ravi Patel

3 Darcy Road, London, SW16 4TX

Tel: 020 8407 2525 Email: nita@nitapatel.com

Web: www.shskpa.org

Message from Holiday Home Managers:

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



© Niyam Patel



2014 DRAGON BOAT CHALLENGE

Once again the South West Thames Kidney Fund will enter a team in the annual Kingston-on-Thames Dragon Boat Challenge.

This year's event will take place on Sunday July 20th and, as always, it's a whole day event located at Canbury Gardens.

Around 50 teams take part in three heats and the final (if they place high enough). Teams have a maximum of 16 paddlers and 1 drummer.

Would you like to be a member of our team – the Sweaty Kidney Scientists? You don't have to be a swimmer; it doesn't matter if you've never paddled a boat before; you don't have to do all three heats – all we ask is that you are 12 years old or older and that you try to raise £200 in sponsorship. It's great fun and we would love to see you there!

We will as usual have our charity stall at the event. This is always really successful and well attended. Is there anyone who would like to organise the stall this year? We also need volunteers to help out during the day.

And last, but not least, we need prizes for the stall. If you have any unwanted gifts that you would like to donate we would be happy to take them off your hands. Also, items like packets of biscuits, bottles of squash, wine, alcohol, bars of soap, lotions etc. all work really well.

For more information on a place on the team, helping out on the stall or donating prizes please contact dragonboat-day@kidneyfund.org.uk or phone Anne on 0208 296 3698.

RAISE MONEY... SIMPLES!

BECKY HAMLING writes: Me and my colleagues Karen and Cat make up the Aggregator Team here at LV= and we have been busy raffling off a set of meerkat toys that we were kindly given by ComparetheMarket. People in the LV= office were really generous, and we are proud to have raised **£261** for South West Thames Kidney Fund which we donated online.

The even better news is that the LV= Charity Committee have promised to match this, so they'll be in touch with a cheque for **another** £261, so that's a total of **£522** in all!

Pictured here are Katherine Hart (top) with Yakov and Sandra Young and Bogdan, while Aidy Drummey displays the whole set. Keep up your wonderful work.

Becky Hamling
Aggregator Co-ordinator





JANINE'S DRAMA SCHOOL RAISES £400

Janine Eaton shares her thoughts on fundraising and best of all - seeing Dr Bending again after many, many years:

"In my role as Principal of The Italia Conti Associate School Reigate, a Performing Arts School, I along with my daughter Madeline and niece Claire were so very pleased to be invited to go and present a cheque for £400 that my pupils, staff and parents had raised organising, performing and buying tickets for one of our cabaret evenings.

"The evening was in memory of my mother Olive Eaton who received such amazing care and treatment from the renal unit at St. Helier and in special thanks to Dr Hugh Gallagher, Dr Phanish, Mr Mohamed Morsy and Mr Nicos Kassaris who gave my niece Claire and nephew Matthew [Claire's sibling LIVE donor] such brilliant care and treatment for a LIVE kidney transplant on 29 Feb 2012.

"Our family along with my sister Ann [who also has APKD] are so grateful for this and all the efforts in Polycystic Kidney Disease research. Meeting Dr. Bending again was very special for us and amazing to see the research unit all built by fund raising.

For details on more fundraising events to benefit the South West Thames Kidney Fund, Janine Eaton can be contacted on janineeaton@msn.com or 07841 144071

LOTS OF WINNERS IN OUR LOTTERY

Why don't YOU join our weekly Lottery? It's easy to join and costs just £1 a week and 50p of that goes straight to kidney research.

We've now paid out £17,717.00 in winnings in 198 weeks that we've been going.

If you have any questions or would like more information, please phone Anne on 020 8296 3698 or email lottery@kidneyfund.org.uk

11/10/2013	101188	Byfleet	£107.00
18/10/2013	101086	South Croydon	£106.00
25/10/2013	101138	Addiscombe	£108.00
01/11/2013	101158	Sandhurst	£109.00
08/11/2013	101174	Stoneleigh	£112.00
15/11/2013	101213	Farnham	£112.00
22/11/2013	101212	Sutton	£113.00
29/11/2013	101187	Carshalton	£114.00
06/12/2013	101172	Aldershot	£117.50
13/12/2013	101055	Carshalton Beeches	£117.50
20/12/2013	101191	Guildford	£117.50
27/12/2013	101177	Carshalton	£118.50
03/01/2014	101098	Croydon	£121.50
10/01/2014	101099	Carshalton	£121.50
17/01/2013	101060	Horley	£121.50
24/01/2014	101146	Sandhurst	£121.50
31/01/2014	101196	Dorking	£121.50
07/02/2014	101175	Broughton	£123.50
14/02/2014	101226	Cinderford, Glous.	£124.50
21/02/2014	101220	Selsdon	£124.50
28/02/2014	101176	Cheam	£125.00
07/03/2014	101231	Farnborough	£123.50
14/03/2014	101222	Wallington	£123.50
21/03/2014	101236	Carshalton	£124.00
28/03/2014	101005	Guildford	£124.00
04/04/2014	101233	Elstead	£125.50
11/04/2014	101223	Sutton	£126.50



GET SNAPPING FOR OUR 2015 CALENDAR

Last year our Calendar Competition resulted in a very attractive 2014 Kidney Fund calendar with all photos taken by kidney patients of St Helier Hospital renal unit and satellites and their immediate families.

We are now running a competition for a 2015 Kidney Fund Calendar.

There will be no particular categories for the photos which opens up the range for entries.

We do ask that all photos submitted are in digital format, and are landscape orientation, with a resolution of 300 dpi.

We also ask for a maximum of two submissions per person.

Send your entries to calendar@kidneyfund.org.uk.

The deadline for entries will be 31st May 2014 and the winners will be announced in our July/August edition of Renality.

SWTKF Chairman Dr Michael Bending writes...

Dear Kidney Research Funders,

This year I have the dubious honour of being elected the Hon. President of the Sutton and District Medical Society.

This Society was founded by local General Practitioners in 1919 that is some 27 years before the advent of the National Health Service.

In those days local GPs would perform appendicectomies on the kitchen table and all the hospitals of note were in the centre of large cities.

For any more serious illness Sir Lancelot Spratt would be summoned down to Carshalton, often on his horse from Guys or St Bartholomew's. In those days there was no such thing as continuing medical education or further learning for had pressed local doctors. They were left to do what they could with the knowledge acquired in the few years at Medical School. Our local Medical Society, the fourth oldest in the country, was set up to rectify this absence of postgraduate education.

The Society functioned for some 40 years before hospital doctors were admitted. Since then it has gone from strength to strength in forging partnership between hospital and community practitioners

I say that this appointment is a dubious honour because a lot of extra work is involved in arranging and chairing meetings. It does, however, give me the privilege of inviting many of my friends from around the country to come and talk at our monthly meetings. It is also a



dubious honour because holding the post is reserved for doctors who have become a little long in the tooth.

One of the most important meetings of the year involves a visit to a local hospital provider and this year I invited members of the society to attend a renal symposium in our Research Institute and on the renal unit at St Hilier.

Contributions to the symposium were provided by Dr Hugh Gallagher and by Dr Pauline Swift. Hugh presented the current state of understanding of the importance of proteinuria in chronic kidney disease. This helps clarify a lot of the confusion that surrounds chronic kidney disease for non-specialist doctors.

Pauline talked about her interesting work on the use of radio frequency ablation of the nerve supply to human kidneys in an attempt to control high blood pressure. Many of you will have read much about this experimental approach to blood pressure treatment in

the national press. It is extremely pleasing that some of the pioneering work has been conducted at St Helier.

The major part of the symposium, on the scientific side, was provided by Dr Seema Jain who presented her work on cyclosporine toxicity in cultured human kidney cells. Ever since the introduction of cyclosporine we have been concerned about the fibrosis that can occur because of the toxicity of this highly effective anti-rejection treatment.

Investigating the mechanisms of this toxicity in the test-tube will help to produce safer anti-rejection treatment in the future.

Dr Mark Dockrell, Scientific Director of the Institute concluded the evening with a masterly lecture on the many ways our research Institute is investigating scarring in human kidney disease

Leading senior doctors from south-west London and other members of the Medical Society were most impressed to hear of our Research Institute at St Helier and they were even more impressed when they heard of the Institute being built by patient power from the renal community. Your effort in supporting our work over the past 30 years is now being appreciated at the highest level

Well done, and many many thanks to one and all,

Yours sincerely,

Michael Bending, Chairman

We have received donations in memory of:

Keith Gordon Hodson

John Frank Nicholson

Margaret Ruth Simpson

Vipin Patel

Phyllis May Hoggett

Our thanks go to:

- The Martin Way Methodist Men's Club for their donation of £625
- The late John Charles Burch for his thoughtful legacy of £2,500
- The G M Morrison Charitable Trust for their donation of £800
- The Country Market in Bordon, Hants for raising £2,175 (including gift aid) from their Buy a Brick x-citing Welcome campaign to launch their new venture following the fire that destroyed the original market (reported in our May 2012 issue of Renality). Watch out for the Grand Opening of the new market in May!
- Janine Eaton & Family for the funds they raised from Janine's stage school fundraiser.
- Vicky Clark and the Surrey Downs CCG Team who held a bake sale to benefit the Kidney Fund and raised £90.00
- The Goulburn Trust for their donation on the instructions of Lord & Lady Hamilton of Dalzell
- Antionetta deChristafaro and the staff of the Chartered Institute of Personnel & Development for donating the £147.15 raised from their Dress Down Friday.
- Aileen Coote for donating £60 to support her daughter Jenny's 'Dry January'.
- The staff of Cyclops Electronics who had a dress down day and donated the £80 they raised to the Kidney Fund.
- Lindsay Sone for donating the Bungee Jump that she won in the Great Big Small Charity Draw

LONDON MARATHON UPDATE

The magnificent efforts of the SWTKF team in the 2014 London Marathon and the generosity of Renality readers has so far raised £20,726 - with more to come!

Amongst the SWTKF runners to report in before this edition of Renality had to go to press were:

Sophie Blaker, (top picture) who writes: Just to let you know that I ran the race in 4 hours and 51 minutes. I am really pleased with the time, and thank you to the South West Thames Kidney Fund for not only giving me the opportunity to run, but also for all the work they do.

Alicia Martin (pictured with her dad) and **Kirsty Eaton** write: We are proud to announce we successfully completed the marathon in 5 hours 34 minutes.

We will update you on our runner's experiences and publish the final total in our August issue of Renality. Thanks to everyone who has had a part in this very successful event.

It's not too late to sponsor – either online at www.justgiving.com/kidneyfundteam2014 or by cheque made out to SWTKF to Anne Collard, SWTKF, Renal Unit, St Helier Hospital, Wrythe Lane, Carshalton SM5 1AA. Please let us know that it is for the Marathon and include your name and address for acknowledgement.



LONDON 10K RUN PLACES UP FOR GRABS!

Do you fancy a lovely 10k run around London on Sunday 13th July?

Starting at 9:35 am on Piccadilly outside The Guards & Calvary Club, runners will pass the new WW2 Bomber Command Memorial which was unveiled by HM Queen Elizabeth 11 in June 2012, two weeks prior to The British 10k London Run in Diamond Jubilee Olympic year with Wellington Arch at Hyde Park Corner as backdrop.

Runners will pass The Ritz, St. James's Palace, Trafalgar Square, the magnificent St. Paul's Cathedral, the unique London Eye, the worlds most famous clock Big Ben, the British Houses of Parliament, the historic Westminster Abbey before finishing on Whitehall (the portal of British Government) at the junction of Royal Horse Guards and Banqueting House after passing Downing Street (the official London residence of British Prime Ministers) and The Cenotaph, the national memorial to those who made the ultimate sacrifice for their country.

The Kidney Fund has 12 places in the British 10k Run. We are asking runners to pay a non-refundable registration fee of £15 for a place, and commit to raise £150 in sponsorship for the South West Thames Kidney Fund. If you are interested in one of our places, please email british10k@kidneyfund.org.uk.

HALF MARATHON HEROES

In March Jo Fulturer, Richard Norris & Jo McSweeney all ran half marathons and raised money for the Kidney Fund.

Richard finished the Reading half marathon, Jo Fulturer completed the Surrey half and Jo McSweeney finished both the Reading and Fleet half marathons. Well done to them all and many thanks for raising vital funds for Kidney Research!

While the half marathons were going on Sue Beesley endured a chocolate-less Lent and (to date) raised £496.00 and that the efforts of the half marathon runners raised over £1,000.

WHO IS UP FOR THE HIGH JUMP

The Kidney Fund has been given a voucher for a 160 foot **Bungee Jump** and are offering it to the person who emails in the highest bid.

The jumps can be done at a few places including the London 02 Arena and vary in price from £60 to £75. The voucher expires on the 2nd September 2014.

Bookings can be made online or over the phone and the lucky winner will need to take the voucher with them on the day of the jump.

Have a look at this website www.ukbungee.com to see available dates and venues

And email your bid to bungeejump@kidneyfund.org.uk by May 19th.

Remember, if there are duplicate high bids the voucher will go to the person whose email arrives first.

The winner will be informed on the 22nd May and the winner's name and bid amount will be published in the next edition of Renality. **Bid HIGH!!!!**

FIVE-A-SIDE FUN DAY

Please mark Sunday 6th July in your diary and head down to the Lucozade Power League Croydon, located at Hannibal Way, Wallington, CR0 4RW to enjoy a Five-a-Side & Family Fun Day, complete with bouncy castle, bake sales, BBQ and lots more.

The event is being organised by Ankur Patel, a patient at St Helier Renal Unit and will benefit the South West Thames Kidney Fund and research – thank you Ankur!

If you play Five-a-Side football think about entering your team in the tournament.

The information for the tournament is £35 registration fee, teams of 7 (to include 2 substitutes) registration form can be found at <https://www.facebook.com/5asidefunday> and interested people can use the information on the poster to contact Ankur.

MARK DOCKRELL Institute Director

Spring greetings from SWTIRR.

As I write to you all it is clear that spring is definitely here; the gardens around the Institute have sprung to life with bright and beautiful daffodils.

It's such a positive time of new energy and new growth. It's a season that helps spur me into action, looking for new ideas to incorporate into our strategy to beat kidney disease.

Of course with the arrival of new life and growth comes the work, I'm sure some of you have been out mowing the lawn, potting on seedlings, tidying up the sweet peas, the list goes on and on doesn't it? And so it is with the Institute, new ideas are all fine and well, but what's the best way to get them started?

We have to plan the project; dig out those project management skills. Most importantly, how are we going to fund it?

Your support of the Kidney Fund is much appreciated but times are tough, we don't have as much money as we used to and I have to look for new ways of funding our work. I recently submitted an application for funding for a project to Kidney Research UK to try and continue on our successful theme of work into the scar forming growth factor CTGF; keep your fingers crossed for us.

Another productive strategy for getting

the most from our resources is to collaborate with other groups who have shared interests. Those of you who are regular readers of my musings from the Institute will be well aware of my creed that collaboration is one way that the Institute can get more work done and have greater influence.

Currently we work with researchers at King's College and St George's and the latter collaboration is proving very successful. Dr Seema Jain is leading on that joint project and although all the lab work is carried out here in the Institute we wouldn't have been able to recruit so many patients if it hadn't been for our contacts up the road in Tooting.

Seema gave a talk on some her work at the British Transplant Society earlier in the year and has been selected to talk at the joint Renal Association/British Renal Society meeting at the end of May on some different data.

This has definitely been a successful collaboration and I shall hope to build on it in the future, but even setting up collaborations can be hard work.

Henry Ford, he of the motor car company fame once, said "Coming together is a beginning; keeping together is progress; working together is success". In this light I have many beginnings, a decent amount of progress and at least some success.

Next time I write I will tell you how it went at Renal Association/British Renal Society meeting in Glasgow, how Seema



and all the other Institute staff got on with their various presentations, I think we have nine this year!

I will also let you know how my funding application got on – so keep those fingers crossed.

I will tell you a little about my increasing interest in the heavy metal pollutant cadmium, how it damages the kidney and ideas about how we can prevent it.

Just before I sign off I will mention that the journal *Frontiers in Pharmacology* had a special edition identifying new targets and therapies in diabetic kidney disease, this is where you'll find the latest publication from the Institute on a particular molecule called Erk5; one little step closer to finding new cures? I hope so.

Funding = Research

Research = Cure

BUY A BRICK for Kidney Research at the new Country Market, Bordon, Hampshire.

In 2010 Country Market suffered a devastating loss when an electrical fire broke out destroying 95% of the farm.

On the day of the fire the original owner of Country Market, Peter Marshall, was scheduled to have a kidney transplant, which had to be delayed. However, just a few weeks later the transplant went ahead and now Peter is enjoying renewed good health thanks to the kidney donated by his daughter, Sharon Edwards.

At this moment, rising from the ashes is the bigger and better Country Market. In March 2014 the unveiling of the new Country Market will reveal a variety of concessions, a lake side family restaurant and café, an extensive garden centre and plant nursery and a huge selection of home grown fruit and vegetables.

To celebrate the new store opening, they have launched their 'X-citing Welcome' Campaign to raise money for the South West Thames Kidney Fund – a kidney research charity dear to the hearts of both Peter and Sharon.

Between now and December 31st you and your family have a chance to be part of the Grand Opening and the future of the new Country Market. You can have your family name/personal message engraved on a brick which will be laid in the Welcome Path leading up to the new store ready for the Grand Opening in March 2014. It will then stand the test of time, viewed by the hundreds of people each week visiting Country Market.

Each brick is £40 and all proceeds will be donated to the South West Thames Kidney Fund. It is a great opportunity to not only have your name or message set in stone but also to help raise money for our incredible charity.

We have included the link to the Country Market page if you would like to find out a little bit more information on the company. If you click on the link :

<http://countrymarket.co.uk/news/title/x-citing-welcome> it will take you directly to the page with the form to buy a brick.



Invitation to the **ANNUAL GENERAL MEETING**



of the South West Thames Kidney Fund & the Institute for Renal Research

to be held on the 16th July 2014 at 2:00pm

in the Carew Room, Post-Graduate Medical Centre, St Helier Hospital

This is your chance to meet some of the people who are raising funds for kidney research and the scientists and doctors who are conducting the research.

It is also an excellent chance for them to meet you!

Everyone is invited. We encourage anyone suffering from kidney disease or who knows and cares for someone suffering from kidney disease.

All will be made very welcome and light refreshments will be provided.

You will learn about what we have been doing with the funds that are raised, and hear from Dr Michael Bending and Dr Mark Dockrell about the exciting research progress we have made.



Mat Dibb, a keen cyclist, who was elected to the Kidney Fund Executive Committee last year will speak about 'Managing Regular Exercise with FSGS' –a presentation he also made to the Scottish Renal Association in March.

New faces and new ideas are very important to us and to the future of our research!

Can you spare time for about 4 afternoon meetings a year and would you like to be involved in the running and the future of the Kidney Fund and the Research Institute?

You might consider joining our committee.

Or you may know of someone you would like to nominate for a place on the committee.

Either way, please email the Kidney Fund's Hon. Sec. HayleyAnne Fitzgerald at hayleyannedesigns@hotmail.com or phone HayleyAnne on 07974 422424

with any nominations by the beginning of July.

WHAT'S GOING WRONG?

A recent visit to one of the renal wards left Amanda Witt feeling standards may have slipped.

She writes:

I have been a patient of the excellent St Helier renal unit for 11 years, first on peritoneal dialysis, then haemodialysis, followed by a living donor transplant from my husband in 2010.

Sadly, I learned my transplanted kidney was failing last year and found myself on Richard Bright ward on Boxing Day.

The care and kindness I experienced was wonderful and I have nothing but praise for the very hard-working nurses, doctors and maintenance staff. Some of the nurses really do go above and beyond the call of duty, with some old style patient care, and I would particularly like to mention Myra and Anna.

What is interesting, however, are the things you begin to notice as you feel better. We all know that funds are tight and the whole issue of potential redevelopment at St Helier is in the balance. However, bearing in mind the hospital is currently under the media microscope, there are some matters that

need consideration now.

The ward is very obviously under-staffed, especially at weekends, and as hard as everybody is working, patient care is not as good as previously experienced over 11 years.

It is particularly noticeable if you are in a side ward, where you can be forgotten because you are not in sight of the staff.

This is not a criticism of the staff themselves, rather the shortage of people and the extra administration duties imposed on the senior nurses.

I remember a time when your water jug was changed at least once a day, and before you went to sleep. Now you're lucky if you even get a water jug, let alone fresh water. Yes, I know that many patients are on restricted fluids, but you should still be able to get fresh iced water on a regular basis.

Also, why the acute shortage of clean linen – I had the same pillowcases for three days on one occasion.

Another issue is patient discharge. It took four hours after the doctor's agreement for me to finally leave the hospital.

The reason - waiting for medication to come up from pharmacy. Once you are told you can go, you contact whoever is picking you

up, they spend a fortune on ridiculously high parking charges, whilst everybody waits for the medication to arrive.

Surely this particular time issue could be resolved in some way?

The most pressing problem, in my opinion, is catering. **The food is simply awful**, no other way to put it. Tasteless, too much sugar (bearing in mind a large proportion of kidney patients have diabetes), unappetising, lacking any form of restorative nourishment, poorly cooked and the same choice every single day. Let me give you some examples.

A chicken pie with inedible uncooked pastry, five very small pieces of chicken and one pea – rather sorry I didn't get a photo of that one!

An omelette cooked so long beforehand it would have been more useful as shoe leather. Lukewarm stewed tea. Toast that was so old it was impossible to bite into. Uncooked pasta in a lasagne. Over-sweet steamed puddings, jellies, crème caramel. Sandwiches served in a packet with no salad whatsoever.

Part of the criteria for getting better is nutrition and if the food is unappetising and inedible, progress is going to be restricted.

You know there's a problem with the food when the nursing staff suggest the patients get someone from home to bring food in for them. This is all well and good, but visiting doesn't start until 2 p.m. which means a patient wouldn't be getting anything to eat from about 8.30 a.m. until visitors arrive. This means no food for over 5 hours after what is a very sparse breakfast.

What **should** happen is obvious – more money spent on the food itself, more fresh food prepared within the renal unit and food served sooner after initial preparation.

Other hospitals have improved their food and general catering facilities, so why not St Helier?

Surely someone in charge of catering must notice how much food is left on patients' plates and by serving something better, there must be less waste?

The cost saving could then be added to the allowance per patient for catering. Money may be tight, but at the expense of patient well-being?

I've always maintained the St Helier renal unit is one of the best in the country medically, but I think we are falling behind on our back up facilities.

My sister has a renal condition and is treated at the brand new facility in Portsmouth. It's new, clean and up to the minute.

Please, something must be done to bring our own renal unit into the 21st century and back amongst the very best in the UK.

STOP PRESS: Amanda adds: I am given to understand that changes are due to be made to the catering arrangements and I look forward to hearing more in the next issue.

NGS OPEN GARDEN

Manor House, Old Lane, Dockenfield
GU10 4HL



SATURDAY & SUNDAY 21ST 22ND JUNE 2014

1 - 5pm

Tea & cakes, plants, displays of textile work.

In aid of NGS charities and South West Thames Kidney Fund

Tel: Pam Hibbert 01252 792573

Admission £4

Donations of plants, cakes and prizes most welcome

Let's make Dialysis Better Together

2. Shared Care and Blood Pressure

In article 1. I discussed Shared Care and how you need to understand Fluid Balance, lots of positive feedback, thank you for your comments and taking the time to read the article. I'm glad it was useful.

2014 is 100th anniversary of the 1st World War. We will see references to the old posters saying 'Your Country needs You'. I don't think Lord Kitchener would mind if we alter the tag line slightly for the purposes of renal disease:

'YOUR BODY NEEDS YOU'

And because your body needs you; the concept of Shared Care is going to be a continuing theme.

Today I will be discussing Blood Pressure (BP). Hopefully if you understand a bit more; you will feel confident to monitor your own BP.

High Blood Pressure is in itself, a major cause of kidney failure. So for those of you not yet on Dialysis, keeping a well-controlled BP may help postpone dialysis.

What is Blood Pressure?

When your heart beats, it pumps the blood round your body.

As the blood moves, it pushes against the sides of the blood vessels. The strength of this pushing is your blood pressure.

If your blood pressure is too high (Hypertension), it puts extra strain on your arteries and your heart, this may lead to heart attacks and strokes.

If it is too low (Hypotension) it may be that there isn't enough blood being pumped around your body.

This can restrict the flow to organs including your brain, which can lead to symptoms such as fainting and sickness. If your heart muscle isn't getting enough blood you may get chest pain or palpitations.

Every blood pressure reading consists of two numbers. They are shown as one number on top of the other - e.g. 120/80.

The first (or top) number is your **systolic** blood pressure. It is the maximum pressure in the artery at the moment the heart is beating and pumping blood around the body.

The second (or bottom) number is your **diastolic** blood pressure. It is the lowest pressure in the artery at the moment between beats when the heart is resting.

Before taking your BP

There are several things that you should know. They are not rocket science but sometimes when we are rushing they might fall by the wayside.

Don't smoke, drink caffeinated beverages or eat a big meal up to 30mins before taking your blood pressure. If you need to pass urine (I know chance would be a fine thing for many of you) or open your bowels, do it before taking your blood pressure.

Always take your blood pressure when you are sitting down and rested - and make sure your arm is well supported and relaxed. Wear loose-fitting clothes like a short sleeved t-shirt so that you can push your sleeve up comfortably. With 'access surgery' it isn't always possible to take your blood pressure in your arm but you should if you can; blood pressure is often significantly higher in your leg.

Finally use a blood pressure cuff that is the right size for you.

Taking your Blood Pressure

1. Locate your pulse (pictured below)

Locate your pulse by lightly pressing your index and middle fingers slightly to the inside centre of the bend of your elbow, this is where your brachial artery is. Get to know how your pulse usually feels. Is it strong or feint? Is it regular or does it seem to skip around? How many beats are there in a minute? If you are concerned you should talk to your nurse or doctor.





2. Secure the cuff (pictured above)

The lower edge of the cuff should be about 1 inch above the bend of your elbow. The arrow on the cuff should be pointing to the place where you felt your pulse. Use the fabric fastener to make the cuff snug, but not too tight.

3. Inflate the cuff

Most machines now are digital, you just need to press the start button. Air is then blown into the cuff and the increasing pressure and tightening is felt on the upper arm. The cuff will inflate to a point where it stops the blood flowing down the arm. It will then slowly release and as it does, it will listen.

The point where the blood is just able to push past the cuff is the systolic or top figure. The cuff will continue to deflate, the point where the sound disappears will be recorded as the diastolic or bottom figure. The cuff will then deflate fully.

Factors that may be within your control and influence your Blood Pressure

As we discussed in the last article keeping your fluid balance right is very important. If there is too much water in the body (fluid overload) blood pressure will go up. If there is too little water in the body (dehydration) the blood pressure will drop.

Think about your salt intake. The amount of salt you eat has a direct effect on your blood pressure. Salt makes your body hold on to water. If you eat too much salt, the extra water stored in your body raises your blood pressure. To cope with the extra strain, the tiny muscles in the artery walls become stronger and thicker. Yet this only makes the space inside the arteries smaller and raises your blood pressure even

higher. So, the more salt you eat, the higher your blood pressure.

Take your blood pressure medication as prescribed and don't wait until you've run out before you collect some more.

Lifestyle changes. Regular exercise, keeping to the correct flesh weight and stopping smoking, will all help your blood pressure.

At first, food without salt can taste bland, but persevere with less. It's just the same as giving up sugar in tea. After a few weeks your taste buds will adjust and you will start to enjoy food with less salt. In fact, you'll wonder how you ever ate food that was so salty!

Factors that influence High Blood Pressure - but not necessarily in your control.

Diabetes

Family history

Kidney disease

For those of you that are interested:

The kidneys play an important role in keeping blood pressure within a healthy range.

If your blood pressure is low, your kidneys make a substance called Renin. Renin is an enzyme (enzymes are substances in your body that help chemical changes to happen).

Renin begins a series of chemical reactions in your body that play a part in raising your blood pressure by constricting or narrowing your blood vessels. Diseased Kidneys often make too much Renin; so the high Blood Pressure medicines most often used by the Renal doctors, work by blocking the Renin chain of reaction; they are known as ACE inhibitors and ARBs.

Blood pressure management is hugely important so we have a new Nurse lead for BP; her name is Susan Kareem and her email is susan.kareem@esth.nhs.uk

We would both be very happy to answer any questions.

I hope you feel that you understand Blood Pressure a little better.

Please do get involved with the measurement and control of yours; not just at home but in hospital and in the dialysis units.

Very best wishes,

Deborah Noble

Sister for Home Haemodialysis and Shared Care

deborah.noble@esth.nhs.uk



John Edward Foxwell Memorial Golf Day

**In Aid of St Helier and Surrey
Kidney Patients Association**

(Registered Charity Number 266391)

**Milford Golf Course
(Surrey)**



Friday 20th June 2014

Cost — £43.00 Per Person

The day will comprise of:

- **A shotgun start**
- **A Singles Stableford Competition (Full Handicap)**
- **Prizes for "Longest Drive" and "Nearest the Pin"**
- **Three Course Sit Down Post golf meal (Please advise of any vegetarian dietary needs)**
- **Auction & Raffle**

**For Further Details or to book a place
please contact:**

**Paul Connolly
Hon.Vice Chairman
St Helier and Surrey KPA
5 Acorn Grove
Woking
Surrey
GU22 9PB**

Telephone: 07837 344 732

Email: connollypaul@hotmail.co.uk

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

