

RENALITY

The NEWSLETTER of...

February 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



Meet our 2014 Marathon team

I'M Kirsty Eaton, a 29-year-old tennis coach at Legends Tennis Centre. Running the London Marathon has always been a personal goal for me.

I feel very privileged to run for the South West Thames Kidney Fund because in January 2010 I lost a very special lady, my Nan to kidney failure.

Not only am I running to complete my goal and for my Nan I am also competing for someone else very close to me who also recently lost a family member due to kidney failure. **Meet ALL our runners for the London Marathon: Pages 12 & 13**

FAREWELL TO DR PHANISH

MANY of you may already have heard that I have made plans to leave St Helier for a one-year sabbatical from the 1st of February 2014.

I am going to a large nephrology and transplant centre in India and it is true to say that I may decide not to come back.

I have very mixed feelings about this change and time will tell if I am going to return or not.

I joined SW Thames Institute for Renal Research as a research registrar



in 2002 and since then I have very fondly associated myself with the renal unit and the research institute at

St Helier hospital. I was appointed to my consultant post in 2007 and the time seems to have flown by very quickly.

Looking back at this time, I have been privileged to do my Ph D research at the institute, to look after many dialysis and transplant patients and also help many kidney donors achieve their goal of rescuing their loved ones from dialysis.

Quietly, gradually and relentlessly this work and these patients, in particular, all the transplant patients have become a pivotal part of my life and I know I am going to miss it all very much.

I would like to thank all my colleagues, nursing staff, secretaries, admin and support staff, transplant team, the SW Thames Institute for Renal Research and all my patients at St Helier and Croydon University Hospitals and Mayday dialysis unit.

My email is phanishmk@gmail.com. Do keep in touch.

Best wishes,

Dr. Mysore Keshavmurthy Phanish

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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**

Leave us a **legacy** Call Anne on 0208 296 3698 for our online Free Will Scheme

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

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

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

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

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

Time for a Meeting!

Peter Andrews, Clinical Director

I am writing this during a meeting. I can count 18 people sitting around the table. I hope no-one knows what I am up to, though many may suspect. After all, they are probably doing something similar.

This meeting will last nearly two hours, and I will contribute to only a small proportion of it. So far, in between smiling at the Chair at intervals and feigning vague interest, I have checked my email inbox (work and home), tried to fix a dodgy internet connection, and charged the battery on my laptop.

Not sure that this is an ideal use of my time. On the other hand, some meetings are productive.

These are usually the ones where a small number attend (ideally no more than five), all have prepared properly, and all have a clear agenda and a preferred outcome from the meeting. I am on a bit of a high as - unusually - I have had two such meetings this week.

In the first, we have agreed a much overdue and improved pathway for access care. This will manifest in a number of ways.

First, we are setting up 'one stop' vascular access clinics at St Helier which will greatly streamline the process of obtaining vascular access and its subsequent monitoring.

Second, we plan to extend our philosophy of bringing care to the patient by starting vascular access clinics in our dialysis units in West Surrey.

Third, we agreed a new referral pathway for access problems which should provide a more efficient inpatient service and reduce the waiting time (and frequency) of access surgery.

These changes will be phased in over the next three months and I would be grateful for your feedback in due course.

The second productive meeting was this very morning. We have been in discussion for some time regarding capacity issues in our **dialysis unit at Farnham**.

There is no space to expand the unit, so we have been looking to develop a new dialysis unit nearby. I am pleased to announce that we will be partnering with Fresenius plc to develop a new 28-station



dialysis unit at Farnborough. This will be a brand new £1.2 million development and will have the capacity to dialyse more than 200 patients, more than twice the current number.

Recognising the increasing frailty of many of our patients, we are also increasing the number of nurses caring for these patients. So this is a real win-win for people with kidney disease in West Surrey.

Not only are we increasing dialysis capacity and nursing staff, we have managed to negotiate this at no increased cost. Indeed, looking forward, recent changes to the dialysis contracts are projected to save substantial sums over the next eight years which can be reinvested into the service. It's sometimes good to have a poker face!

There is lots else to report. In brief, we have just agreed:

The appointment of a new part-time Consultant Nephrologist. This will allow us to improve support to Croydon Hospital and the living donor transplant programme.

The development of a dedicated hypertension service based in the Renal Unit at St Helier.

Major progress regarding major service developments in West Surrey, St George's Hospital and at St Helier. I hope to report on some of these in more detail soon.

In the meantime, I hope you have noticed a significant improvement in the access to and timeliness of reports on **Renal Patient View**.

This has followed the introduction of our long-awaited IT system, CV5. It is hoped

that this will greatly improve the way we deal with data recording, audit and everyday issues related to patient care.

Getting used to CV5 will take some time, but already I am impressed by the quality of the reports that it can generate, seemingly at the touch of a button.

My thanks to all those who have helped the relatively smooth transition, especially **Vip de Silva**, who has worked 'above and beyond the call of duty' over the last 12 months. In recognition of all the additional work he has put in, he recently became the first member of the medical team ever to be awarded the prestigious ABCD award, a three-monthly award given by the Renal Management Team to recognise outstanding contributions to the Renal Unit.

My congratulations to him.

Lastly, you may be aware that one of my Consultant colleagues, Mysore Phanish, is leaving us in January.

Phanish has been a part of the unit for more than a decade, starting as an SpR, then studying for a PhD in the Renal Institute, and more recently as a Consultant at St Helier and Croydon.

In recent years he has been very involved in the living donor transplant programme, has coordinated our research and development, and has been our main link with basic science and the SWTIRR.

Like many colleagues, he has steadily taken on more and more work as the pressures on the unit have increased and he has done so with calmness and enthusiasm. He has even managed to suffer sharing an office with me!

Phanish is taking a one year sabbatical in the first instance, to be near his mother in Delhi. It is testimony to his talent and experience that he was immediately snapped up by the foremost hospital in India when he expressed an interest in returning, as well as being offered prestigious posts in Singapore and elsewhere.

We are holding his post open for a year in case he wishes to return and will shortly be appointing a one year locum to cover this period. In the interim, we intend keeping in touch and wish him well for the future.

Sorry, no space for the dog this month. But all is well!

MY 15-MONTH JOURNEY TO LIVE KIDNEY DONATION

By CAROLINE TSE

My husband and I took a road trip down south to visit friends and family members in April 2012. These trips used to be the norm when the children were young but not since they had grown up and moved abroad.

We were still working full-time – me and my sister in law Annie – me in Leeds, Annie in Mental Health in Surrey.

This trip served to be a wake up call for me. I hadn't realised just how desperate my sister in law was for a kidney transplant. Yes, I knew she was on dialysis but I hadn't realised it was every other day for 4 – 5 hours each evening, and she was still managing to hold down her full-time job in mental health nursing.

We stayed a week and each time I went with her for dialysis I felt a longing to do something more for her than just being there. I wanted to try to see if I could help by donating one of my kidneys. Annie and I had been friends for 44 years, trained as nurses together, married two brothers, and each of us had two children now grown up with children of their own.

That's when my fifteen month count-down started.

I discussed it with my husband, Annie's husband's elder brother, who gave his approval with trepidation.

I then informed Annie who was so excited and anxious at the same time. Preparations were made for me to attend St Helier Hospital in Surrey for blood tests – the first of very many – plus a full body health screen of my heart, lungs, my kidneys and my own physical fitness, not difficult as we have two dogs who require lots of exercise.

At first we had positive feedback from all the tissue typing and bloods but due to Annie's peculiar antibodies there was going to be a high risk of rejection within the first four months following transplant.

Rejection was not the word we wanted to hear but a lifeline was thrown to us by the Kidney Transplant Authority whereby we would have all our details placed into the computer – one for donors and one for recipients – to try and find a more acceptable match with less risk of rejection.

Apparently this procedure is carried out a couple of times each year.

Sometimes no matches are found but sometimes a double couple or even a triple couple are found. We waited patiently until April 2013 and on April 3rd we had a call from the transplant team that we were one of a triple.

We were delighted as Annie needed my live kidney donation to be in with a chance of transplant. Up to this point the situation had been highly charged with emotion but now here we were given this choice – a triple or nothing.

Emotions ran high with me because at the outset I wanted to give my kidney to my sister in law, not to a stranger, but this was not to be the case. Lengthy discussions were held between us and the Ethics Committee and we decided to proceed with the plan to go ahead in Summer 2013.

August 15th was the date set for surgery at St George's Hospital

in London. We were admitted the day before for last minute health checks and discussions of the surgery with our surgeon.

The surgeon marked the points of surgery on my abdomen and the place where the kidney would be placed in Annie's abdomen. Apprehensions were at an all time high and the renal consultants were very clear that if we were in any way having second doubts we could withdraw with no prejudice to ourselves.

Backing out was not an option and by now it was exciting that Annie was going to have a new kidney and a second chance of a quality life with her grandchildren and family. Surgery took place for me early the next morning.

It should have been straightforward surgery with the risks that any surgery carries, but unfortunately I had adhesions for previous abdominal surgery which caused its own problems.

The day following surgery Annie's new kidney was sleeping and resting which we were assured was perfectly normal.

Annie had one more dialysis and then - magic – her new kidney which we called Pontus, the First Greek God of Water, woke up and is working so well.

Annie had produced barely any urine for the last 5 years and now she was producing litres. At first it was such a shock to her system that urinary incontinence was an issue but only for a matter of days. Once hourly toileting commenced she soon had that under control.

We are now both back at our respective homes. As I write, it is a month since surgery. I am improving each day, slower than expected at the beginning but now working on building energy levels ready for my return to work.

I haven't noticed any difference to my one remaining kidney output. Emotionally, following surgery, you feel grief for the one you gave away but I had been warned that would occur so I was prepared. I am fortunate to see the rewards in my sister in law's health and know it was oh so worthwhile. I would do it again without a second thought.

To give a kidney, either directly or indirectly as in our case, is the best feeling in the world. Through proceeding with the triple donation which must be a logistical nightmare to arrange nationwide, three people have received a working kidney – a new lease of life.

So to all who are contemplating kidney donation, be it directly or indirectly, go for it. People need you and you receive so much support and encouragement without prejudice from everybody on the Transplant team.

If anyone who is considering, or going through the process of kidney donation at the present time, and needs to talk to someone who has been there and done it, please do not hesitate to contact the Transplant Team at St Helier and they will put you in contact with me.

Thank you for reading my story – dedicated to the Transplant teams at St Helier Hospital, Carshalton; St George's Hospital, London; and St James Hospital, Leeds who have now taken over my follow up care.

Caroline Tse

My best birthday present

ANNIE TSE is enjoying a new lease of life thanks to her sister-in-law Caroline Tse, who tells her story on the page opposite, and the National Living Donor Sharing Scheme.

ANNIE writes: A kidney transplant has noticeably improved the quality of my life. I want to thank the anonymous donor and especially my sister-in-law Caroline whose kindness and selflessness I will never forget.

The words 'Thank You' are not enough for what she has done for me.

I believe that I am the luckiest person alive because there are people who care about me and are very kind to me.

I give thanks for the excellent care from the NHS staff at the Renal Unit in St. Helier Hospital; the Transport Unit; the Kidney Transplant Unit in St. Georges, London; the Dialysis Unit and my GP in Farnham.

At work (I am an Infection Prevention & Control Nurse for Surrey and Borders Partnership NHS Foundation Trust) I have good support from my team manager Debbie N, our secretary Sue and numerous colleagues.

At home, I have good support and care from my friends, my family and above all my sister-in-law Caroline whom I will never forget.

I am grateful to and thank Dr. Frankie (who was an SHO working on the ward with us 5 years ago in 2008) for escorting me to the A & E Department because she and my colleagues thought I looked very unwell. Dr. Frankie saved my life.

When I learned that I had a chronic kidney illness, within 24 hours, the General Hospital transferred me to the Renal Unit at St. Helier Hospital.

My stay at St. Helier was a very emotional time. At times, my mental battle would be the most difficult part.

Four years ago, I started to face the daunting prospect of dialysis. My children, grandchildren and my brothers' family were concerned about me.

However, my husband took very good care of me, and my special diet etc. and with the support of my work colleagues, the staff at St. Helier renal unit and above all, my dialysis nursing staff, I was able to return back to work, and try to live a normal daily life.

Once I returned to work, the feeling of unfairness stopped and I resigned myself to getting on with my life. During these 4 years of dialysis, 5 people (my husband, my children and 2 work colleagues) offered to donate their kidney to me. I had my reasons to refuse all of them, but feel touched and grateful



for their generous offers. My life turned a corner when my sister-in-law Caroline came to stay with me for a week's holiday about 18 months ago.

Caroline escorted me to and collected me from dialysis sessions.

Caroline was most upset at my prospect of continued dialysis 3 times a week, made up her mind to offer me one of her kidneys and contacted the Renal Transplant unit in St. Helier Hospital. The process took us a whole year. Caroline was very disappointed when we learnt the match was only 75%.

However, after some discussion with the Renal Transplant unit, we agreed to take the route of the National Living Donor Kidney Sharing Scheme. I was lucky to learn that a match was found.

After all the hard work from the Renal Transplant staff, I had my kidney transplant in the summer of 2013 just one day before my birthday!

Now I attend the Transplant Clinic weekly in St. Helier Hospital under the care of the Renal Consultant and staff and have a lovely quality of life again and I look forward to return to work soon.

I propose to undertake a Fund Raising venture in the Summer of 2014, and would be delighted if others could support/join me in this. Please watch this space!!!

Thank you all!

IF you would like more information on the National Living Donor Kidney Sharing Scheme, contact:
Tracy Norton-Smith on (020) 8296 4715/3155
Transplant Coordinator (Donors), Renal Services
Epsom and St. Helier University Hospitals NHS Trust
Email: Tracy.NortonSmith@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**



A message from your Chairman

I trust that you had an enjoyable Christmas without too many power cuts or flooding (we had both) and that you are looking forward to 2014.

Following re-election at the AGM in November, I have now started my eighth year as Chairman and the Committee and I will continue to work hard to benefit our members. A full list of your Committee members appears in this edition.

The KPA AGM was held on 20th November and was attended by 11 Committee Members and KPA members; it was disappointing to see only 2 KPA members attend! All of the Officers and Committee Members were re-elected.

The St Helier and Surrey KPA Christmas Patient Lunch took place on December 14 and was attended by around 30 patients, carers and staff who all enjoyed a superb spread prepared by Pat Harris, the Committees' Secretary, ably assisted by Di Spensley and the other Committee Members.

I would like to thank everyone for their help on the day.

It was a real shame to see so few patients attend but that's due to the fact that the renal unit is really successful and now has 8 Satellites and each has its own Christmas get-together sponsored by the KPA. We also sponsor the St Helier patient get-together. It was very different when the majority of patients dialysed at St Helier but I'd much rather patients get their treatment closer to home. The Committee will have to decide if we continue with the lunch for 2014.

The Grand Christmas Draw took place during the lunch and details of prize winners are published separately. The draw showed a surplus of circa £1425.00p compared to £2500.00p last year and my sincere thanks go to everyone who purchased tickets despite the uncertain economic climate and to Jim and Shirley Rae for organising the Draw, sorting the counterfoils and banking the money, a job I know they both love doing !!!!!. I'll be looking for a volunteer to take on the task this year.



Golf Day

Following the success of our previous golf days we are holding another event playing the lovely 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, it would be great to get 72 players or more so if you're a golfer please book your place and bring a friend. A poster on the event is included within this edition.

Other Matters

The KPA Committee is still looking for new members and patient representatives for Kingston, Epsom and Sutton.

The present Committee has served for a number of years doing an excellent job but it would be lovely to have Committee members for every Satellite with fresh ideas, to enable us to continue to represent you, the patients.

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 generally on the first Wednesday of the month. It isn't essential that a Committee member attends every meeting as a report can be sent by email, letter or even a phone call.

We are also looking for volunteers to help on the servery counter at St Helier, if you are able to spare a morning or afternoon you would be helping the patients enormously, obviously without volunteers we can't open.

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

KPA Treasurer

Jim Rae will stand down at the AGM in November so the KPA is desperate for a replacement. An article appears in this edition detailing a job description of the position. If you are that person or know of any family member or friend who can help us please contact me.

Finally, may I, on behalf of the Committee, wish you a happy and healthy 2014. Best wishes....

Dave Spensley, Hon Chairman

ST HELIER AND SURREY KPA COMMITTEE MEMBERS 2013/2014

Hon. Chairman

David Spensley
L'Alise
Guildford Road
Godalming
Surrey GU7 3BX
Tel: **01483 426276**
Mobile: **07836 750 433**
email: daspensley@btopenworld.com

Hon. Deputy Chairman

Satellite Liaison – West Byfleet
Paul Connolly
5 Acorn Grove
Old School Place
Woking
Surrey GU22 9PB
Mobile: **07837 344 732**
email: connollypaul@hotmail.co.uk

Hon. Secretary/Social Events

Pat Harris
10 The Gables
Banstead
Surrey SM7 2HD
Tel: **01737 352 154**
Mobile: **07732 110767**
email: patricia.mike@virgin.net

Minutes Secretary

Jackie Moss
7 Little Roke Avenue
Kenley
Surrey CR8 5NN
Tel: **020 8668 7435**
email: j.moss149@btinternet.com

Membership Secretary

Diane Spensley
L'Alise
Guildford Road
Godalming
Surrey GU7 3BX
Tel: **01483 426276**
email: dispensley@btopenworld.com

Satellite Liaison – Farnham

Barbara Parker
Email: b.e.parker1@hotmail.com

Holiday Home Managers

Ravi & Nita Patel,
3 Darcy Road
Norbury
London SW16 4TX
Tel: **020 8407 2525**
email: ravi_g_p@hotmail.com nita@nitapatel.com

St. Helier Patient Liaison/Stock Controller

David Theobald
10 Doveton Court
Doveton Road,
S, Croydon
CR2 7DH
Tel: **0208 680 1821**
Mobile: **07813 940 340**
email: d.theobald@btinternet.com

Satellite Liaison – Purley

James Edgar
8 Cranmer Road
Croydon
Surrey CR0 1SR
Tel: **020 8667 9952**
Mobile: **07851 589228**
email: jamesjohnedgar@gmail.com

Press & Public Relations

Fay Eves
Willow Cottage , Church Street
Rudgwick
West Sussex RH12 3EH
Tel: **01403 822537**
email: fayeves@aol.co

Satellite Liaison - Mayday

Emmanuel Eyeta
Flat 8, 4 Dunheved Road North
Thornton Heath
Surrey CR7 6AH
Tel: **020 8689 1746**
Mobile: **07957 343170**
email: eyeta56@yahoo.co.uk

Renal Social Worker/Amenity Sub.Committee

Celia Eggeling
Renal Unit, St. Helier Hospital
Tel: **0208 296 2940**
email: Celia.Eggeling@esth.nhs.uk

ST HELIER & SURREY KPA CHRISTMAS DRAW

Following the Grand Christmas Draw at the Patient Lunch on 14th December 2013, we are pleased to announce the winners were as follows: **FIRST PLACE: C Connolly**, Ashted—£500

SECOND PLACE: F Fogelman, Woldingham—£200

FOURTH PLACE: P Fifield, Croydon—£50

THIRD PLACE: P Connolly, Woking—£100

FIFTH PLACE: M Thomas, Molesey—£25

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 and Mrs P Steele

Roffe Swayne Chartered Accountants

Halstead Preparatory School, Woking

A & C Rooms

J G Rae

C A Sweet

R Mann

The Worth Lodge

S Shafiq

C Milne

MEMORIAL DONATIONS...

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

Eunice Rooms

Neil McCafferty

James Robert Priestley

M Leach

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

SWTKF Chairman Dr Michael Bending writes...

Hello Kidney Research Supporters,

Another hope-filled year and blasts of fresh initiative and talent in the Kidney Fund.

Many new ideas have been generated over the Christmas holiday and I would like to share some of these with you.

Hopefully this will give you ideas as to how you, yourself could help raise funds for the research which is the only way of making progress in the future.

Firstly the kidney fund lottery is doing extremely well. With each month there are more and more subscribers and so the prize money is escalating.

You will remember that half of the income from the lottery goes directly to renal research and we are so grateful to Steve Clark who administers this lottery so that all income goes to prizes or renal research without a single penny in administration or overheads.

An application form to join the lottery can be found on the back of this edition



of Renality. We are so grateful to HaleyAnne for stepping in as secretary to the kidney fund. HaleyAnne is making enormous progress in following the sterling work that Pat Godden has done for the fund over so many years.

We're still searching for a new treasurer to the fund. This post requires someone with knowledge of accountancy and a sharp eye to manage our investment fund. All of the hard work in terms of

bookkeeping is ably provided by Anne Collard.

Our marathon team comprises nine runners this year and you will read more about this elsewhere in this edition.

It will be great if supporters of the fund could arrange fundraising coffee mornings and local bring and buy sales to raise funds to support our athletes who are putting so much to effort into their training on cold January evenings!

Finally, we are searching for a Legal Advisor with experience of drawing up Wills. Many kidney fund supporters have approached me to enquire how they can make provision for funding Kidney Research in their will.

In line with other major charities we would like to be able to provide free, impartial, and sound, legal advice as to the best way to achieve this.

With every best wish in the New Year,

**Your chairman,
Michael Bending**

JOIN YOUR LOCAL BRANCH OF THE KIDNEY FUND!

You may not know that there are presently three existing branches of the Kidney Fund covering the Sutton; Croydon; and Frimley/Camberley/Guildford areas.

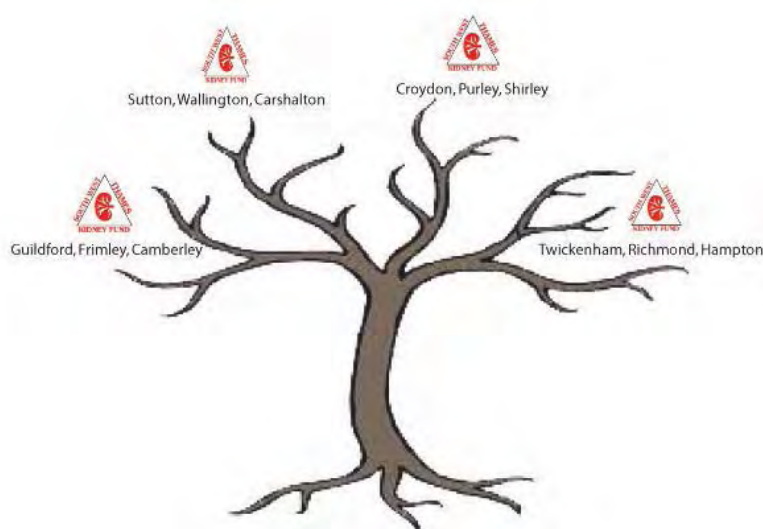
Why don't you contact your local branch and find out when their next meeting is? They would make you very welcome and you might find it helpful to meet once in a while with a group of people whose experience is similar to yours.

The ethos of each of the branches is to put the fun in fundraising so if you would like to be part of that and meet other people with a common interest please contact your local branch. Each branch finds enjoyable and social ways to support kidney research – and active, enthusiastic new people with new ideas would be welcomed to any of the branches with open arms!

For information on the Sutton area email margaret.porter@kidneyfund.org.uk; for Frimley/Camberley/Guildford email graham.morrow@kidneyfund.org.uk and for the Croydon area email info@kidneyfund.org.uk. Or, if you don't have email, please call Anne Collard on 0208 296 3698 and she will put you in touch with the right branch.

If there are any of you in the Twickenham/Richmond/Hampton areas who would be interested in forming a new group, Kathryn Harrison, one of our trustees, has offered to set one up. Kathryn has already raised lots of money for us running pub quizzes, a bike-a-thon, Christmas Fayres and has twice entered her own team (The Red Hot Kidney Beans) in the Dragon Boat Race. Please contact Kathryn at kathryn.harrison@kidneyfund.org.uk

Please contact the branch nearest to you if your town isn't listed above!!





OUR THANKS TO THE SURREY FREEMASONS

The Surrey Freemasons conceived their 'Surrey for Surrey Scheme' in 2009. Since that time over £450,000 has passed through the Fund for the benefit of Surrey Charities. The South West Thames Kidney Fund was chosen as a beneficiary of the Scheme. On 16th December, Dr Mark Dockrell attended the Presentation Event and was gratified to receive a cheque for £1,434.00 on behalf of the Kidney Fund.

Many thanks to the Sir Francis Drake Lodge and the Riddlesdown Lodge who contributed towards this donation and to the Surrey for Surrey Fund for their support of our work.

Photo: Colin Antill - fotoseeker.com

The South West Thames Kidney Fund is very grateful to have received donations in memory of:

Carol Margaret Sammons

Timothy John Saben

Jim Leahy

William Groves

Peter Ronald Margetts

Lionel Prosser

Nieves Gamboa

Robert William Edwards

SOUTH WEST THAMES KIDNEY FUND

TREASURER WANTED

**Become a key member of our team
of doctors, researchers and fundraisers**

We are looking for an experienced accountant to take over the role from our current treasurer Alan Ratcliffe.

Duties include preparing management reports and attending quarterly Executive Committee meetings at the renal unit at St Helier and exclude bookkeeping.

In the first instance please call Alan on 01932 851055 anytime for an informal discussion about this vital role.

OUR LONDON MARATHON

NINE intrepid runners will be taking part in the London Marathon to raise money for the SWTKF. We introduced KIRSTY EATON on the Front Page. Here the remaining eight explain why they have taken up the challenge:



Alicia Martin

I am an Aussie who has been living in the UK since January 2013. My main motivation for living abroad

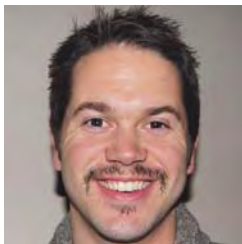
was to have the opportunity to work and travel throughout Europe. I am a Personal Assistant at the Biomedical Research Centre, Guy's Hospital in London.

I lost my pop in July 2013 to kidney failure. He was one of the most important people in my life and to witness the decline in his health of the past 5 years has been heartbreaking.

In his memory I am running the 2014 London Marathon to raise funds for the amazing South West Thames Kidney Fund. Research into renal disease is

something that is obviously very close to my heart and I am so determined to raise awareness of the amazing work the institute undertakes.

My pop grew up in London and to be given the opportunity to compete in such an incredible event in his home town will be something I will cherish forever.



Stuart McSweeney

One of my sisters and my wife - Kirsty and Keri McSweeney - ran the Marathon in 2012 for the South West Thames

Kidney Fund. We travelled to London on the day to cheer them on and it was such an incredible atmosphere that I felt inspired to apply for a place.

Seeing the support for the runners, the general feel-good feeling and taking in the atmosphere was brilliant with the Olympics only a few months away.

I have really enjoyed taking part in events for the South West Thames Kidney Fund such as organ recitals and doing the Bristol 10k twice and I look forward to taking part in some more events such as a mini series of organ recitals all on one day in local churches! The work the

South West Thames Kidney Fund provided for my dad, Derek McSweeney, has been incredible and I feel it is only right to be able to help support the Kidney Fund to be able to provide such care and support.



Charlie Gilmartin

I am an Account Director for a marketing agency in East London. My role involves developing shopper-focused campaigns for

clients including; Coca-Cola, Samsung, and Bacardi & Grant's Whisky.

I have always loved running, and in 2007 I decided to take on the challenge of running the London Marathon for the British Heart Foundation.

At the time a family friend had just passed away as a result of heart failure, and so it felt especially poignant to run for the BHF.

I have to admit, back then, I really did think the marathon would be something I would (hopefully) complete, and then never contemplate doing again.

However, finishing the marathon, and raising over £1,500 for the BHF in the process, was one of the most fulfilling and enjoyable experiences of my life.

The support in London is like nothing I have ever seen, and I genuinely enjoyed every minute of the run.

I knew that it would not be my last. Although, knowing quite how arduous the training regime is, I wanted to wait several years before making the commitment again.

Since then, I have taken part in numerous different fund-raising events up and down the country.

They include; the National 3 Peaks, the Yorkshire 3 Peaks, a 50 mile cycle ride, a duathlon around Loch Ness and several others.

Now that I'm a bit older, I feel determined to take on the London Marathon challenge once again, and I feel very lucky to have a place with the South West Kidney Fund - such a worthwhile cause.

Although I do not have any personal connection with kidney-failure, I recognise the important and life-saving work that they do for those who are unfortunate sufferers,

I am very proud to be running in their name.

2014 London Marathon Team



**We aim to raise £20,000!
for kidney research
and - with your help - we can do it!**

Please take a sponsor form and ask your family, friends and colleagues to help you and the team make this event a huge success.

**Or you can sponsor online by visiting
www.justgiving.com/kidneyfundteam2014**

RUNNERS TO RACE IN 2014



Joanna Bending

Hello I am Joanna Bending. I am Dr Michael Bending's daughter. He is the chairman of the Kidney Fund. I spent my formative years

watching him and his team of amazing colleagues and patients and friends raise millions of pounds to build the research laboratory.

I remember looking at the first plans and then going to the grand opening and being awed by both my parents and their dedication to the cause.

My links with the kidney unit at St Helier go back to my childhood though - many a Christmas day popping in to the ward with chocolates, sitting in Dad's office with his long-suffering secretary Jean raising her eyes to heaven in despair and humour at the mess (!) - rather like what Anne has to put up with now - although luckily for her on a less frequent basis now he's semi-retired.

I remember being fascinated by dialysis and seeing how transformative a kidney transplant can be.

Dad used to take us as kids to go and cheer on marathon day, failing that we'd always watch it on the telly. 26.2 miles.... it was barely imaginable to me. It still isn't!

How can anyone run that far? Those that have a desire to must be insane and/or fantasists.

Well, people run because they have something to prove or because the cause they are running for means so much to them.

It's always a very emotional day and I think shows London and its people at their very best. I'll be thinking about the oodles of money I'm going to cajole out of people for the benefit of the kidney fund, the research laboratory, the effect on so many people's lives and I'll be desperately hoping those uplifting thoughts will get me round on the day.

Who can read Mark Dockrell's column in each edition and fail to get excited by the discoveries and little victories.

When I first gently enquired about the possibility of running the marathon and a golden bond place being available Dad produced a for and against list:

For: I'll cut down on my drinking, get fit, have a focus etc.

Against: ruin my joints forever, get fat and go to seed after. Weighing it up: it's definitely worth it.

Dad aged 60 did it, Jonathan Kwan did it, my sister Laura did it, OAP's in tutus do it,

amputees do it, transplant patients do it, people in gorilla outfits and suits of armour do it.....

I can definitely give it my best shot (even though I have broken both my legs in the past and I really hope they don't give up on me!)



Sophie Blaker

Although I enjoy running, I only started in my forties and am not a natural athlete.

To me, the idea of running a marathon compares to that of

climbing Everest. The London Marathon is the best-known marathon in the world, and if I am going to try

I want to run for the South West Thames Kidney fund as it is a charity that is very close to my heart.

From a young age I watched my stepfather suffer from polycystic kidney disease. He eventually ended up on dialysis before dying far too young in his early sixties.

My two younger brothers have also been diagnosed with polycystic kidneys, which may in time lead to kidney failure. I want them to have a more hopeful future than my step-dad, and consequently want to raise money for a charity that is aimed at improving and extending the lives of people suffering from kidney disease.



Pauline Hopkins

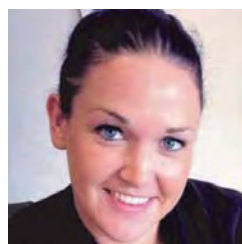
My husband Matthew (CEO of Epsom & St Helier University Hospitals NHS Trust) had been badgering me for a long time to get

back into running, as I used to be very keen athlete prior to my career in the NHS and then my second career as a Mother of my two wonderful children.

So I started running again early in 2013, building up my distances, and I really enjoy it. I ran my first competitive event in the Kingston 10k in December and managed quite well, so decided to see if I could manage 26.2 miles.

And why raise money for the Kidney Fund in South West Thames? Well, Matthew has adult polycystic kidney disease, which means our children have a 1 in 2 chance of having it as well.

I know that the research that the SWTIR is conducting won't help prevent the progression of my husband's kidney disease, but perhaps it will help to improve the prospects for my children.



Lucy Vanson

I own and run a Beauty Salon in Epsom, Surrey and this will be my second time at running the marathon. My Grandad was

diagnosed with cancer of the kidney 8 years ago and we sadly lost him from it.

I also have an auntie who was born with kidney problems which resulted in her having to undergo major surgery before she was 5 years old. I really want to raise as much money as possible for the South West Thames Kidney Fund - an amazing charity that supports research into the causes of, and preventions, for kidney disease.



Michael Tyler

Hi, my name is Michael and I have always wanted to run the marathon. My friend has been supported for a number of years by kidney research

for treatment that he has needed. When the opportunity arose to provide some funding for this organisation which is essential to his well-being my decision was an easy one. I am a keen runner and can't wait to get started on the day. The training is the only downside! Good luck everyone!

CHALLENGE YOURSELF

If you fancy challenging yourself in 2014, you could do it both for yourself and your favourite charity (South West Thames Kidney Fund!)

The variety of challenges are endless from walking or running along the Thames Path to biking or trekking the Great Wall of China.

You can either self-fund an adventure of a lifetime and raise as much sponsorship as you can for your charity...

OR you can partially self-fund, committing to raise a minimum amount of sponsorship (with a portion of your sponsorship covering the rest of your costs).

We are registered with Charity Challenge an excellent site. If you would like to find out more, do visit <http://www.charitychallenge.com/index.html> or call Anne on 0208 296 3698.

OUR THANKS TO THE MILLS FAMILY

On December 11th Mr Andrew Mills came to the Institute to meet with Dr Bending and Dr Dockrell and present a cheque for £2,000 representing a bequest from his mother Mrs D M Joy Mills who died in August.

This was prompted by the excellent treatment her husband Geoffrey Mills had whilst a kidney patient at St Helier.

He was diagnosed with kidney failure in 1987, and had both haemodialysis and CAPD before having a kidney transplant in 1989.

This continued to function until 1997, when he had to revert to dialysis and sadly he died in March 1999.

During this time he wrote a small book about his treatment and experiences as a kidney patient, copies of which have been given to the hospital.

The South West Thames Kidney Fund is extremely grateful for this legacy.



...and to the family of Keith Hodson

We are thankful for the legacy of £1,000 from Keith Gordon Hodson .

People find many and varied ways to donate to us. To all those individuals who have made donations to our research and to those that make regular donations ... thank you so much.

We really appreciate, and very much need, your support.

WELL DONE TO THE CALENDAR TEAM

...and now you can buy one for a reduced price of £5

To the many of you that have supported our Christmas Card sales and who have bought our lovely 2014 Calendar you have helped us raise a further **£800** for kidney research.

Thanks so much to all of you and to the following who enthusiastically promoted the sales of the cards and the calendars:

Sarah Mitton & the ladies at St Helier Renal Reception

Helen Wood at the SHSKPA tea stall in the outpatient waiting area

Karen Robertson at Farnham Dialysis

You've all been a fantastic help – thank you for your support of kidney research!

We have a few calendars left and have reduced them from £8 to £5 (postage included). Please contact Anne.collard@kidneyfund.org.uk if you haven't bought your 2014 calendar yet!

Don't forget to email calendar@kidneyfund.org.uk with your entries for the 2015 calendar. Photos must be in digital format, landscape orientation and any subject.



A breakthrough... and a goodbye!

MARK DOCKRELL,
Institute Director

Seasonal greetings (despite unseasonable weather)

Eleven years ago I first came to work in the hallowed halls of the South West Thames Institute for Renal Research, although neither it nor I were as well known at the time.

One of my first students and colleagues was a very energetic, bright, affable clinician called Dr Mysore Phanish, generally known as Phanish.

Phanish was interested in a relatively new growth factor/hormone called Connective Tissue Growth Factor – or CTGF for short. This was a bit of a challenge for me as I had only heard about it myself a couple of years earlier after a handful of papers suggesting it might have a role in kidney disease.

There was growing evidence of its role in fibrosis in other organs but we didn't know that much about it in the kidney.

Phanish spent the full 3 years of his PhD studying this growth factor and the first paper we published after I came to the Institute was on the production of CTGF by human kidney cells. The work Phanish did brought us attention and admiration in the field.

We started to build our reputation in the understanding of CTGF, but 3 years is only the very start; we had only scratched the surface and as dedicated as we are at SWTIRR we are only few, progress can take time.

Some years later Phanish and I recruited another young registrar interested in continuing the investigation of CTGF in kidney fibrosis. **Simon Wynn** was very bright. Before doing his medical degree he had done a science degree at Imperial



Phanish & Mark in 2003

FUNDING
=
RESEARCH
↓
RESEARCH
=
CURE



College, he was ideally qualified.

Phanish (in lab, above) had demonstrated that the resident cells of the kidney could make CTGF, Simon set out to determine how it acted to cause the fibrosis and could we stop it.

Simon worked very hard, when we hit difficulties we went back to our collaborators at Imperial College who had expertise in the field to seek their advice. It was proving a more complex problem than we had envisaged.

For example you couldn't even buy CTGF and treat the cells with it the way you might with adrenaline or angiotensin. No, CTGF was so difficult we had to make it ourselves.

Simon set up a new system in our labs for using human kidney cells as little factories to make growth factors and proteins, a technique we are still using.

It was difficult, at times Simon became disillusioned but then the positive feedback he would get from other researchers spurred him on.

Just towards the end of his 3 years he started to get interesting positive



results – isn't that always the way? Just as you're finishing things begin to look up.

Some of Simon's work has been carried on by another scientist, and just recently **Tarun** has made a major breakthrough.

On Boxing Day when many of us were still digesting Christmas dinner Tarun was in the lab getting ready to make more CTGF to push the work forward.

One of our colleagues in the US who is one of the big men in the CTGF field is impressed with Tarun's results and would like to collaborate with us to advance the work to try and solve more of the puzzle.

In fact I just had an email from Bruce yesterday and we're discussing where we might apply for money to fund the next phase of the work.

If we can put one more piece of this puzzle in place we will be a lot closer to developing a novel medicine for kidney disease.

It's hard work, it takes a long time, it takes dedication and it takes team work, but I think I've told you before we don't give up easily at SWTIRR, especially when the prize is so important.

Phanish has decided he has to go back to India for a while, he has things he needs to do but his contribution to this work will not be forgotten.

Phanish was the South West Thames Kidney Research Fellow 2002-2005, your support made this possible and with your further support we will continue the work he set in motion 11 years ago.

Funding = Research

Research = Cure

Cycling towards transplant

Earlier this year you might have read in Renality about a patient under our care, MAT DIBB who is facing transplant soon as a result of renal failure due to a condition known as Focal Segmental Glomerulosclerosis.

Mat created the cycling event called “Dibbfest” which in March this year raised over £6,800 for the South West Thames Kidney Fund. We caught up with Mat recently to see how things are going and here's his latest update:

Although my kidney function has deteriorated I've carried on cycling all year. The weather this summer has been fantastic for riding and I did quite a lot, no specific events but I did go to the Isle of Man to do some cycling, which was awesome.

There is some great mountain biking to be had over there with stunning views of the coast wherever you are up on the mountain.

But I'm now starting to notice a fairly steady decline in energy levels when I ride now. The deterioration of my kidney function dictates that I'm now 6 to 12 months from needing a transplant. I've been referred to the transplant coordination team at St Helier and we're looking at tissue matches for possible live donors. That's the stage I've gone into in the last month.

My brother-in-law has stepped forward to be a potential donor, which is exciting because he's a keen cyclist: he's fit and he doesn't drink or smoke. He has to go through a blood test initially — if it's not a match on blood type then it doesn't go any further. It looks like it might be OK so far but it's early days.

Being so close to transplant means I'm having to consider energy levels and general health in all my cycling plans now. Before a ride I have to take a look at how I'm feeling that day or that week. I have to consider things like the temperature outside, and try to be sensible.

The cold saps anyone's energy, but it seems to be even worse with me at the moment. I'm also more prone to colds and chest infections because my immune system is suppressed from all the steroids and medication that I've been on. So I have to be careful with that, which in turn determines the length and routes of my rides on any particular day.

Then post-ride I am increasingly suffering from muscle cramps which is possibly due to my kidneys not filtering away electrolytes and just not doing their job properly.



Those are all the negatives, but there are plenty of positives: I'm still exercising and I'm very lucky that I'm still able to. I continue to drag myself out whether I feel like it or not, because I very quickly get the benefits afterwards, and I feel so much better for it.

One thing that I've started to look at for the next difficult few months is electric bikes. I've always thought they were for old people or for those carrying excessive weight but now realize how wrong I was!

Having done some pretty extensive research I've been looking specifically at pedal-assist bikes. With this type you're still pedalling but you also get the help whenever you need it.

I've had a whole series of conversations with a fantastic company called **50cycles.com** who specialise in e-bikes — I met company director Scott Snaith on their stand at the NEC Cycle Show and I told him about my medical situation.

Astonishingly, since further discussions, they've let me use an electric bike free of charge, which is amazing, and I've agreed to help them look at how e-bikes can help pre and post-transplant patients in their recovery process and get back to full fitness. I think there's a massively untapped market of patient recovery through e-biking generally.

Doctors recommend gentle exercise post-transplant, with activities such as walking, but I can see how e-biking could also be a huge help to patients and especially given that the technology can now even monitor heart rates and assist accordingly.

Dr Alice Smith is based at the university of Leicester and leads a national kidney exercise network. She said to me: “As well as helping to prevent health problems, exercise is now being used as part of the treatment of many of

diseases. But what about kidney disease? Research shows that appropriate exercise is beneficial for kidney patients, but at the moment very few UK Renal Units offer any kind of exercise advice or support for their patients.

“Unfortunately, people with kidney disease can suffer from a variety of symptoms and health problems, and it's not surprising that all this can lead to anxiety, depression and a reduced ability to enjoy the pleasures of everyday life. Research has shown that being physically active can have a beneficial effect on many of the health issues associated with kidney problems.”

I'm sure it wouldn't be recommended for me to jump on my mountain bike and climb a steep hill straight after surgery, but it seems to me that gentle exercise via pedal-assisted cycling has to help recovery and be more enjoyable for existing cyclists.

So with my new e-bike, a **Kalkhoff Pro Connect Xion** I've started commuting to work, which is about 12.5 miles away, through the very hilly back lanes of deepest Surrey. When it's not tipping it down or sub zero, I'm doing a 25-mile return trip on the electric bike at the moment.

If I get to the stage where I don't fancy pushing myself on my mountain bike I've still got the e-bike to fall back on which means I can still continue cycling to some degree but never end up stranded away from home.

Follow Mat's progress over the coming months at www.cyclingweekly.co.uk, via DibbFest on Facebook and follow his daily biking encounters on twitter via @KalkhoffEbiker.

TASTY TREATS FOR YOU TO TRY

Some delicious recipe ideas suitable for kidney patients, from 'Food for Thought' with a foreword by our Renal Unit dietician Annabel Harman ...

LAMB CHOPS WITH REDCURRANT & MINT SAUCE

Note: The fat and calorie content value will vary depending on how well the chops are trimmed.

Serves 4

Ingredients

4	Lean lamb chops, any cut (approx. 140g each)
4 tbsp	Redcurrant jelly
1 tbsp	Mint sauce
1 tbsp	Lemon juice
4 tbsp	Water

Method

1. Mix the redcurrant jelly, mint sauce, lemon juice and water together in an ovenproof dish.
2. Trim the chops and place in the dish with the sauce, turning to coat each chop well.
3. Bake uncovered in a pre-heated oven at 180C (Gas mark 4) for 35-40 minutes until the lamb is tender. The sauce may need to be thickened with cornflour mixed with a little water before serving.

Serve with boiled potatoes and a boiled vegetable of your choice.



ASPARAGUS BRUSCHETTA WITH GARLIC & BASIL Serves 2

Ingredients

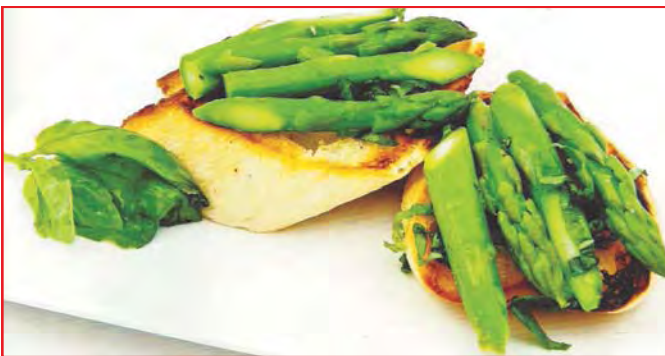
1	Ciabatta or any other uncut small white loaf
4	Fresh asparagus spears boiled until tender*
1 tbsp	Olive oil
1/2	Garlic clove, crushed and finely chopped
1 tbsp	Basil, finely chopped

*tinned asparagus may be used but should be well drained .

Method

1. Cut four slices of bread from the loaf, approximately 2cm thick, and place on a baking tray. Lightly toast one side under a medium grill.
2. Cut the asparagus spears in half lengthways and cut each strip into two or three short lengths.
3. Mix the olive oil, garlic and basil together and spread on the untoasted side of the bread.
4. Top with asparagus, brush lightly with olive oil and return to the grill until the edges are browned.

Serve immediately while still hot.



LEMON DELIGHT Serves 2

Ingredients

25g	Polyunsaturated margarine
50g	Caster sugar
1	Egg, separated
25g	Self-raising flour
120ml	Water
1 small	Lemon, zest and juice

Method

1. Put margarine, sugar, egg yolk, water and flour into a bowl and mix until smooth.
2. Whisk the egg whites until stiff and carefully fold into the batter mixture using a metal spoon.
3. Pour into a greased ovenproof dish and bake in the oven at 180C (Gas Mark 4) for 20-30 minutes or until the top is golden brown. Serve warm sprinkled with caster sugar.

Serve with whipped cream.



Let's make Dialysis Better Together

Fluid and Shared Care

By DEBORAH NOBLE

Dialysis is a hard necessity of life when your kidneys don't work.

If it's Haemodialysis, then the 3 x week process of going to the unit can be seen as a burden, but most people find that when they understand what is going on, it becomes easier. You start to feel better and more in control of what is happening to your body.

Over the next few editions of Renality I would like to discuss the various issues relevant to Dialysis. Some will be solely Haemodialysis but most will, hopefully, be useful for PD patients too. Today I shall be writing about Fluid and Shared Care.

When your kidneys aren't working properly most people produce less urine. Some people don't make any at all, not a drop. Whereas a few people still produce lots of urine, it's not getting rid of all the toxins but it does allow them to drink more liquid.

Periodically someone will give you a 'Dry Weight'; this is also sometimes called an aim weight or target weight. This is your weight with just the right amount of fluid onboard. You won't be overloaded with puffy ankles nor will you be dehydrated and dizzy when you stand up.



Dry Weight = YOU with just the right amount of fluid in your body.

If it's possible we try to make this Dry Weight, the weight that you are when you finish your dialysis session, your post dialysis weight.

I am old enough to have been taught in imperial weights and measures and have often wondered why we bothered to go metric; one answer is that it really helps with Dialysis!

When you arrive we ask you to weigh yourself, you may wonder why?



The New World of Communication

We can tell you about our research news as it happens!

On a frequent basis we **'Tweet'** and **'Post'** our Research Institute or Kidney Fund news. We also send out **email updates** to our Kidney Research Supporter email group.

To be able to read these 'Tweets' and 'Posts' and 'email updates', you must be signed up for Twitter or Facebook or join the Kidney Research Supporter email group.

If you aren't yet signed up to **Twitter** or **Facebook** it's very easy to do. Just go to www.twitter.com or www.facebook.com, give as much or as little information about yourself as you like (your name and email address need to be correct) and then search for us.

You can find and 'like' the Kidney Fund on Facebook by searching South West Thames Kidney Fund or going to www.facebook.com/kidneyfund. You will find the Kidney Fund on Twitter at www.twitter.com/renalresearch.

If you aren't signed up for **email updates**, that's very easy too. Just email anne.collard@kidneyfund.org.uk – type 'email updates' in the subject line and 'sign me up' in the message. It's helpful if you give your first and last name as well. Your information will not be shared with anyone and you can ask to be removed from the group at any time.

We all know how important research is. Only through research can ways be found to improve conditions or even cure them and we want you to keep you up to date with what we are doing!

Let's get communicating! Together we can beat Kidney Disease!

'YOUR BODY NEEDS YOU'

The reason is quite simple; 1 Litre of water = 1 Kilogram in weight (Kg). If at the beginning of dialysis (Pre Dialysis) you weigh 1 Kg more than your 'Dry Weight' we will take off 1 Litre of water during the session. But because we also give you a cup of tea and the machine tubing has fluid in it, we will also add another 500mls (0.5litres) to the amount we take off. So this becomes $1 + 0.5 = 1.5$ litres to remove during the session.

So IF you finished your last dialysis session at the correct weight (Dry Weight), the next session the machine will be programmed to remove:

What you have gained in Kilograms + 0.5 litres that we give you whilst you're there.

Just to complicate things your Dry Weight is very likely to change. For example, if your appetite improves and you eat more, then your flesh weight will increase, so we would have to adjust your Dry Weight up accordingly. Otherwise, we would be dehydrating you too much if we stuck to the same Dry Weight.

On the other hand, if you are unwell or eat less then your flesh weight will reduce. We will then need to lower your Dry Weight because otherwise you will be carrying too much water.

Keeping your fluid balance right is important; too little fluid in your body will make you dizzy, tired, may give you a headache, your Blood Pressure will be low and you will feel unwell. Too much fluid may collect in your ankles but it may also collect in other parts of your body, if it collects in and around your lungs then you will get breathless.

Too much fluid will also cause your heart to overwork which will make it less able to push the blood around your body. Your Blood pressure will rise and this will further damage your blood vessels.

Living in a temperate mixed climate, like ours, means that as long as it's not a really hot day, you will lose about 500mls or 0.5 L per day of fluid by sweating and opening your bowels etc.

So unless you have diarrhoea or it's very hot; if you drink anything more than 500mls your body will rely on your kidneys making urine to exit the body. If they can't make the urine then to protect your body from the damage that too much fluid can do, we suggest that you restrict your drinking to 500mls per day plus the equivalent volume of your urine output.

This is really hard and to make things worse you need to think about how much fluid is hidden in your food. Some food like rice and pasta absorb water, as well as thinking of the sauces and soups.

Having a restriction to the amount you can drink is really, really hard, but we do know that it is important.

Over the coming months we will be asking you questions, about you and your dialysis. One of the questions will be about the amount of Urine that you make.

As I have just discussed, getting your fluid balance right is very important. We will be giving many of you a plastic jug so that you can accurately measure how much urine that you are actually making over a 24 hour period. Using



this information will enable us together to understand you and your dialysis better.

Working together, (not about you, or for you BUT WITH YOU), to make things better is a philosophy of care called Shared Care. This is a term that you will often hear spoken and hopefully feel that you can embrace.

We know that everybody is different and only you know, really know, You the best. So please get involved with your dialysis and treatment. When I visit the units some patient's are very independent, which is fab but it's not for all.

Not everyone can do everything but they can always do something.

A good start is making you and others as safe as possible in the unit. Preventing the spread of infection is so very important. The antiseptic wipe that we use is great but to kill all the germs you need a combination of soap and water and the antiseptic; so please always wash your hands when you arrive. Those who have a fistula or graft should also wash that before they sit down.

Then maybe start with thinking about fluid gains and the right Dry Weight for you. Talk to the nursing staff in the unit, or the Doctors in clinic; discuss fluid removal and how you feel during and at the end of your session.

Many aspects of your Dialysis session involve tasks that you might do at home, or would like to learn about doing - so please get involved.

The whole idea of Shared Care is that we work together to make your therapy as individual as you are - Shared Care Better Together.

If you have questions relating to what I have written, then please email or write to me, I will be very happy to answer them. If I don't know the answers then I will ask someone who does. If it's ok with you then we could publish some of these Q and A's in the next editions. If you would rather that they were private, then that's ok too.

Wishing you a happy and healthy New Year,

Debbie Noble,

Sister Home Haemodialysis and Shared Care

Deborah.noble@esth.nhs.uk.



**** EXTRA EXTRA **** **READ ALL ABOUT IT**

Have you heard about our Weekly Charity Lottery?
Have you heard that £16,220 has been given out in prizes?
AND that £16,220 has benefited kidney research?

HAVE YOU JOINED YET?
*** YOU'VE GOTTA BE IN IT TO WIN IT! ***

Each weekly entry costs just £1
Each week's entry money is split 50/50 between the owner of the winning number and the South West Thames Kidney Fund

Start 2014 off right! Let's beat kidney disease! We can do it!
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To join the Lottery please complete the form below and return it to the address on the form.
Once received, we will contact you to let you know your unique number or numbers.

IMPORTANT: please return to: The Lottery Office, c/o 10 Pelton Avenue, Belmont, Surrey SM2 5NN

Title: _____ Initials: _____ Surname: _____
Address: _____
Postcode: _____ Home Phone: _____ Mobile: _____
Email: _____ add me to the Kidney Research Supporter email group _____
Please note that to save on postage we prefer to communicate by email or telephone. Please tick here _____ if you require a letter

There are two ways to pay. Please choose ONE of the following:

1. Standing Order Mandate

My Bank's Name: _____ Branch: _____ Post Code: _____
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Pay to: Kidney Fund Lottery; Bank: CAFbank Ltd, West Malling; Account Number: 00019588; Sort Code: 40-52-40

Monthly Payment:	_____	number of entries @ £4.34 per month	=	£ _____	& thereafter each month
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