

RENALITY

The NEWSLETTER of...

August 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



DAREDEVIL SUE RAISES SKY-HIGH £1,000 ON A WING AND A PRAYER

SUE SUTTON has just completed a WING WALKING experience for South West Kidney Fund.

Sue said: "I have suffered with kidney problems for many years and wanted to give something back for all the care and attention I have received from Dr Marsh.

"I had done a sky dive for South West Thames Kidney Fund in the past and thought I needed another adrenaline rush which is where the wing walking idea came in to play and my husband bought me the experience for my 50th Birthday.

"So on Sunday 29th June with family and friends in tow I went to Headcorn Aerodrome in Kent and did the Wing Walk. The experience was great and I was sad when I had to come out of the sky and back to the ground.

"I don't know the exact amount that I have raised for the South West Kidney Fund but think it will be in the region of £1,000.00. Thank you to everyone that sponsored me. Roll on the next adrenaline rush event for charity!"

Sue Sutton, New Haw, Surrey

DON'T FORGET YOUR SKIN CHECK

ANGIE MORROW raises a timely reminder as we enjoy the summer sunshine that kidney patients need to keep an eye on the condition of their skin.

She writes: We have noticed that not all Kidney Transplant patients on cocktails of medication have been put on the skin clinic lists.

Medication can sometimes cause skin problems for kidney patients.

Our son who had a Transplant 18 years ago had his 1st check up last month, and that only happened because Dr Subash Somalanka from St Helier noticed that no checks had

been listed. Thank goodness that this particular doctor took the time to check, and be interested in our sons wellbeing. After waiting 3 months for the skin clinic appointment he had a good report, and will now be put on a list for yearly check ups, a great result.

We of course do not live in a perfect world and things get overlooked, but this skin appointment should have been happening for the past 18yrs, so make sure you remember to mention it to your specialist and get it sorted. Good Luck.

In this issue:

Renal Unit News:

Elsa the Kidney Dog	6
Clinical Director	7
Patient Feedback	15

SHSKPA News:

Golf Day	3
Memorial Donations	3
Donations	4
BKPA	4
Chairman's Report	5

SWTIRR News:

Institute Director's message	16
------------------------------	----

SWTKF News:

Chairman	8
Transport Co-ordinator	8
Car Show	9
Ethan's efforts	9
Football Fundraiser	10/11
Marathon reports	12/13
Donations	14
Fund raisers	14

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 to SWKF22£_ to 70070, or by cheque to SWTKF, Renal Unit,

St Helier Hospital, Wrythe Lane, Carshalton SM5 1AA

Create a **standing order**

Donate via **payroll giving**

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

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

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

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.

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

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

A MAGNIFICENT SEVENTH

St Helier and Surrey Kidney Patients' Association seventh annual Golf Day, at MILFORD GOLF CLUB, raised more than £2,700



KPA Chairman Dave Spensley writes: What a fabulous day, warm, dry, well attended and profitable.

On Friday 20th June 62 golfers took to the fairways of Milford Golf Course to play what has become a fabulous annual event to raise funds for our KPA. This year's event was another roaring success with a great turnout and a financial surplus of over £2700.00p. The overall winner of the day was **Martin Oatley** with a magnificent 41 points (playing to 5 under his handicap).

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

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

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

Di and Anna Spensley for helping on the day and,

Jim Rae for keeping track of our finances.

In addition my thanks must also go to the following:

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

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

Ivor Connolly who handled our auction

Milford Golf Course, its members, Head Professional Simon and the Catering & Waitressing Staff for their welcome, hospitality and fabulous meal.

Everyone went out of their way to help and we've already booked next year's event, Friday 19th June 2015.

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

KPA Memorial Donations

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

Connie McCafferty

Eve McWilliams

William Frank Gibbens

Peter Ian Mackintosh

British Kidney Patient Association – making the difference

The BKPA is the leading grant-giving charity for kidney patients in the UK. We work to improve the daily quality of life for kidney patients and their families.

- we're the largest provider of patient grants to those on low income, helping with welfare and domestic costs
 - we support numerous projects in renal units to help improve patient care and patient facilities
 - we support national research projects that will help to improve quality of patient care, working for example with the British Renal Society and other kidney charities
 - we offer patient information and support
 - we fund short breaks and holidays for children, adults and their families
 - we have a Facebook Group and active social media
 - we have a counselling support line
 - we stand up for your rights at a national level

Each year, we supply up to £2.5 million in grants. We fund five of the eight NKF/BKPA Advocacy Officers and often support local Kidney Patient Association activities and your members.

The BKPA is here to help you. To find out more about the BKPA visit our website.

www.britishkidney-pa.co.uk

Or call us on Tel 01420 541424 or contact info@britishkidney-pa.co.uk



www.facebook.com/groups/TheBKPA

www.twitter.com/The_BKPA

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

Mrs S R Honeyman

A message from your Chairman

By the time you read this it will be August already, only 4 months to Christmas!!!!!!

It's been a relatively quiet few months so there's only a few things to report on.

Golf Day

Friday 20th June 2013 saw the annual KPA golf day at Milford Golf course in Surrey and this is covered in a separate article.

62 golfers took part and the event should raise in excess of £2,700.00 for the KPA, a fabulous total.

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

We've already booked next year's date Friday 19th June 2015.



NKF Conference

This will be held at the Hilton Hotel in Blackpool on Saturday 11th and Sunday 12th October and the KPA will pay the special package rate for KPA members.

Other News

KPA AGM:

This year's AGM will be held on Wednesday 19th November at 7.30 p.m. in the Blue Room at the renal unit of St Helier.

Christmas Patient Luncheon:

The KPA Committee have decided that this should no longer be held due to very low attendance numbers over the last two years. More patients now dialyse at a Satellite than in previous years and don't want to travel to St Helier on a Saturday.

That's about it from me,

Best Wishes

Dave Spensley, Hon Chairman

Elsa the Kidney Dog!

Dear Renality Readers

Looking back, it is just over seven years since my pet allowed me centre stage to write to you (or a year in your time, I am reminded). So I thought it was time to update you on progress, as he seems to be falling behind.

I am now nearly 18 months old in your money, and am pretty much fully grown. I look back on pictures of me as a puppy (below) and think how immature I was then – but also how handsome!

And while I am now a dog of the world, I can assure you that the latter has not changed at all!

By the time you read this, I will have competed in my very first beauty contest so -unless the judges are very blind - I am sure my kennel will be full of silver trophies to gnaw on. And I have also been practising my skills at 'catching the sausage'.



After some initial problems with eye-mouth-paw coordination, and also not understanding quite what I was supposed to do, I am now pretty good at this. And it's one area where I'm very happy to keep practicing until perfect!

There is other very exciting news. My pet keeps remarking on how often you all want to catch up with my progress rather than talk about your kidneys.

Finally, he has come to his senses (and the 21st century). As from this month, I pleased to announce that you can all follow my progress on Twitter (should really be called Woofer)!

Although my pet is a bit old fashioned, he realises that it is good to keep in touch, and my Twitter (Woofer) account will allow real-time news to be shared about the kidney world, as well as updating you all on my progress and opportunities for me to meet my fan club.

Please follow me on Twitter on **Elsathekidneydog**.

If you are anything like my pet, please ask any local teenagers to set this up for you. And please ask your friends and relatives to sign up.



My target is to have more followers than the Chief Executive and, if this is reached, the Trust has agreed to donate up to £1000 to kidney research! Though I would personally rather they gave me £10 of kidneys...

If you look now, you will be able to see pictures of how I have grown, and also some pictures of me with my pack. The Alpha male is looking a bit seedy, I'm afraid, and I still have work to do on his fitness levels. But the rest of the pack are pretty fit, I am told...

I look forward to rubbing noses.

Elsa (the kidney dog).

[Not Champion the Wonder Horse – ed.]



A Word in Edgeways

Peter Andrews, Clinical Director



So now it is official. Not only am I no longer in charge of the TV remote control, the ultimate arbiter of power in the family environment, but even the dog is more popular than me. And the dog is also better at IT – though this may not surprise everyone!

On a semi-serious note, I very much hope that many of you will take the opportunity to sign up to **Elsathekidneydog**.

Not only will it raise funds for kidney research, but it will provide another means of keeping in touch with the Renal Unit at St Helier and the 1.4 million patients it serves.

Although the Twitter and Facebook accounts will not be official channels of communication, I hope to upload important news on a regular basis so that everyone can keep up to date with developments in the unit. Let's see how it goes!

In the interim, I will briefly mention a few active issues:

- Building work is progressing well at our new dialysis centre in Crawley which we hope to open later this year.
- Planning permission has been granted for our new dialysis centre at Farnborough which we hope to open in early 2015.
- We are exploring the possibility of refurbishing the dialysis unit at Croydon Hospital, which is now looking rather tired. In parallel, we are examining the possibility of a new dialysis centre in the North Croydon/Streatham area.
- We are collaborating with colleagues at St George's Hospital to help them redevelop their renal infrastructure which, like ours, is long overdue for refurbishment. The team at St George's are very keen to hear from patients and relatives about things that they are doing well and badly, so this may feed into the redevelopment process. Please let them know through your KPA Chair, David Spensley, at daspensley@btinternet.com, who is part of the redesign team.
- We are also working hard on a strategic plan for the St Helier site, which we hope will involve an £8 million redevelopment of the renal facilities over the next 5 years. This is linked to the Trust's ongoing bid for financial stability and Foundation Trust status, which are progressing very well. Very exciting times, and more of this anon!
- We have appointed a new Quality Manager, a senior post that will help ensure that we are responding more effectively to problems, and hopefully preventing them!
- We are in the process of appointing a replacement for Dr Kate Shiell, who has moved to take up a post in Scotland to be nearer her family. Kate was a great colleague and friend, and we wish her well.
- Dr Anne-Marie Habib has also been appointed to a permanent Consultant position and will be leading our audit team, as well as extending her involvement in the Farnham dialysis unit.
- We heard recently from Dr Mysore Phanish, who is on a year's sabbatical in India. He is doing extraordinary work and sends you all his best wishes. He is not certain whether he will be returning to the UK. In the interim, we are very fortunate to have Dr Nihil Chitalia working with us and I know many of you will already have met him.

Lastly, and I have assured my wife that I can take no credit for this, many of you will have noticed that we are continuing our proud record of fecundity in the senior medical corps. By the time you read this, Dr Becky Suckling may well have delivered her first baby. We welcome Dr Marie Condon to cover her maternity leave, and look forward to wetting the baby's head.

I wish you all a happy and healthy summer.

Peter Andrews, Clinical Director

SWTKF Chairman Dr Michael Bending writes...

Dear Kidney Funders

Big changes for the South West Thames Kidney Fund in this quarter.

Firstly we must pay tribute to **Richard Sammons** who is standing down as vice-chairman after 30 years of service.

Fortunately, Richard plans to stay on the executive committee and of course he maintains his role as chairman of the Institute and director of Helier Scientific. This is not, therefore, a loss but just a reshuffle.

Alan Ratcliffe has come to the end of five years of service as treasurer to the fund. Alan has been instrumental in putting our investments on a sound footing.

He has even achieved a return on investments of over 5% despite the difficult times during his tenure. We really cannot thank Alan enough. I just hope he appreciates our gratitude.

At the annual general meeting of The Kidney Fund on 16 July we will be nominating **Helen Greene** as our new honorary treasurer. Helen introduced herself to the fund having read issues of Renality that she had seen scattered around the unit.

Helen brings so many varied experiences from the world of commerce and finance. I sense that her contribution over the next five years is going to build on the legacy that Alan has left behind.

Welcome to **Mat Dibb**, who has been



doing great things on the National Stage promoting the benefits of physical exercise for patients approaching renal failure treatment.

You must ask Mat to show you his video of extreme mountain biking. It will scare the lights out of you.

Mat has the physique of a Bradley Wiggins or a Chris Froome and when his health has been restored by kidney transplantation, I suspect we shall see him competing again at a high level.

Mat has enrolled a friend to work on rebranding the Kidney Fund's image and we are all having fun at present, considering our new logo.

Kathryn Harrison is developing many new strategies to generate income for renal research at St Helier.

At present she is working on a survey of other small charities. We are in the process of deciding whether we can

increase our income by employing a professional fundraiser. I am particularly hoping that the kidney fund can survive as an entirely voluntary organisation.

One of our strengths over the years has been that self-help from the whole renal community is the best way to improve things for the next-generation.

This is where YOU come in. If you feel that you have a few hours a week to spare, we are bursting with ideas for fund raising and a quick phone call to **Anne Collard** (0208 296 3698) will put you in touch with the fund.

Follow Helen Greene's example and make a difference to the future of all kidney patients and their friends and relatives.

Finally, as too often, the first shall be last!

The most important role in any voluntary organisation is the honorary secretary.

He (or more usually) she (I wonder why that is) is the one who does all the hard work writing and collating the minutes and preparing agendas and listening rather than talking.

We are so indebted to **Hayleyanne Fitzgerald** and **Margaret Porter** for filling this vital role in the last few months. They are both shining stars.

Must get back to watching the football!

Michael Bending, Chairman.

RENAL TRANSPORT COORDINATOR

I am writing to introduce myself as the new Renal Transport Coordinator.

At this point I can hear you asking " what does that mean to me?"

Well it is a new role in the renal unit and part of the remit is to offer the opportunity for your voices to be heard regarding transport.

Renal patients have a unique insight into the patient transport service and we at your renal unit want to improve the quality. The transport service is a very busy service and with your help we want it to run as smoothly and efficiently as possible.

That means we want you to be picked up at the right time, travel in the most suitable vehicle and ensure a prompt return after your appointment or dialysis has finished. Any other ideas that you may have to improve the patient experience would be very welcome.

That's where I need your help. I am looking for volunteers to meet quarterly, regarding your patient transport service. A patient focus group would really help us to tackle all the issues surrounding transport and make a real difference.

If you could help me with this task, please call Debbie Burgess on 0208 296 4520.



Enterprise for Charity

DAVID BAILEY writes: My wife Joan Bailey recently died in the Renal Unit and during her last few days our youngest grandchild, Ethan aged 8 years, gave her as a gift a loom band bracelet to wear.

He also gave me a band "like Nanny's" so we could feel together. I said to him after my wife died that I was going to wear my bracelet until after Nanny's funeral to which he replied 'why wouldn't you wear it forever?'

At my wife's funeral on July 4 there were 17 of us (myself, our children, their partners and the 10 grandchildren), and over 100 other family and friends.

We all wore our loom band bracelets as did a few friends who had shared the story of where Nanny's bracelet had come from in the days before she died. She too wore her bracelet as promised to Ethan.

For the afternoon the grandchildren had wanted and we organised a "Celebration of Nanny's life — a lady who loved us all and cared about everyone."

Ethan had suggested to his Mum and I that the grandchildren should make dozens of loom band bracelets and ask people to take a band and make a donation for it to his Nanny's charity



the "SWT Kidney Fund", which is what happened.

Ethan (left in the picture) and his cousin Alex, aged 9 years, toured the room of 120 people promoting donations for a loom band bracelet whilst some of the older grandchildren were recruited (very willingly) to join them in making the bracelets to ensure that demand could be met.

The reward for Ethan's initiative and his team's efforts is a donation to SWT Kidney Fund of £171.60.

Camberley Car Show 2014

The Camberley Car Show will again take place in and around the main streets of Camberley Town Centre, on Saturday 30th August 10.00am - 4.00pm (Sat. after the Bank Holiday).

The streets involved will be closed to all other traffic for the day. For details and images from last year's show please see: <http://www.camberleycarshow.co.uk/>

We are expecting to have a fantastic selection of up to 150 vehicles of all types and eras on static display plus live music, street entertainment, free children's face-painting - in fact, something for everyone!

As it is a town centre location, there are lots of coffee shops, restaurants and pubs on hand and of course all the shops and stores will be open as usual, for those who may wish to pursue some retail therapy!

As previously, all proceeds from the event will be donated to the South West Thames Kidney Fund and we hope that many Renality readers will come along and join in the fun - in fact, if anyone would be prepared to assist on the day by helping in the street collections, etc., their help would be most welcome.

Anyone prepared to offer help, please contact

kenbonner@btinternet.com

Ken & Glenise Bonner, Camberley, Surrey



FOOTBALL FUNDRAISER SCORES A HUGE HIT

South West Thames Kidney Fund 5 Aside and Family Fun day 6th July 2014 @ Croydon Power League

ANKUR PATEL put his passion for football to good use by raising more than £1,100 for the South West Thames Kidney Fund.

He writes: Sometime at the turn of the year I was thinking about doing something to show my appreciation for the kindness, care and support that has been provided by the staff team at the renal unit at St Helier hospital.

I wasn't quite sure what to do and how to go about getting the ball rolling, I did some research and was directed to Anne Collard at the hospital who was really helpful in getting some ideas together and also keeping my ambitions a little grounded.

It was hard at first to drum up interest and I can't lie, it did dishearten me a little, but then after talking to a few close friends things started to come together. With all the brainstorming and groundwork complete the idea was decided to have a world cup themed football tournament and a fun day for families.

As the date approached we had a long list of teams, some trophies and team prizes, and lots of support flooding in.

I was overwhelmed by the amount of support that we'd managed to pull together.

The day finally arrived and to begin with started off giving us all a bit of a scare as the weather was looking quite bleak, although the forecast did say that things would improve throughout the day, the rain coming down on us whilst loading up the cars had a different agenda. The good thing was that around 11am the weather did improve and clouds spread apart for the sun to shine down on us.

Overall we had a fantastic turnout and great football tournament, which was won by patient Dave Stagg's son's team. Second place went to another patient's team entered by Michael Bradford and his Sutton Knights squad, who had 2 teams entered. His second team also took fourth place behind the team entered by Suraj Patel from Bromley Car Audio.

The total raised on the day was £1100 and we are still receiving donations via the just giving page (www.justgiving.com/loveprinting)

We've also had a huge demand for another tournament to be held next year and are in talks about potential dates and venue for a return for this event it was a great day and all in all a huge success.



THIRD PLACE



On behalf of the South West Thames Kidney Fund, the patients at the renal unit and myself, I would like to thank the following businesses and people that supported the event and helped to make it what it was:

Anne Collard (SWT Institute of Renal Research)

Jo, Caroline (Nurses from St Helier renal unit)

Lola's Kitchen (Sponsored the bake sale with 144 cup cakes)

Tresea's Cake Boutique (Sponsored the bake sale with 120 cup cakes and a modeled cake)

Shameer Hossembux – First Standard (Sponsored £100 of the event cost)

Lisa Hunt of Asda Wallington Store (donated a gift voucher for the tombola and is also trying to setup an in store collection for 2 months for the fund that may be rolled out to Sutton as well)

Neil and Maria at Croydon Bouncy Castles (donated the bouncy castle and rodeo bull)

Bintesh and Raj of LovePrinting.co.uk (They sponsored the cost of shirt printing and set up the Just Giving campaign online)

Christine Stacey and Paul Southall of Veolia and the team of volunteers that attended the event(Provided volunteers for the day)

Younus Mogul (Designing the marketing material)

Paula Rowe and Family (for providing the BBQ and tombola stalls)

Kathryn Harrison (helped with setting up and volunteers on the nurses tombola)

Doctor Pschygo and DJ Goliath (for hosting and providing the music for the event)

Lee and the team at Croydon Power League

Hailey Spring and the H.Spring Photography team (covering the event)

Rachel Owusu Dappah (videography)

The team at Jessops Oxford Circus (raising money in store for the fund)

Anandiben Patel and Anjuben (both ran the vegetarian food stall)

And a special thanks to the following people for helping with every aspect of organizing the event at some point in the last 7 months: Jordan Roach, Paul Eveleigh, Matt O'Reilly, Mitesh Patel, Mitesh Patel, Medhavi Phieffer, Anjali, Patel, Hassan Laljee, Harshil Patel, Ludejero Batista, Keith, Earl, Sneha Patel, Mitesh Patel.



ANKUR AND TROPHY



GETTING STUCK IN



TOMBOLA STALL

OUR LONDON MARATHON RUNNERS REPORT BACK ON 2014'S BIG EVENT

Jo Bending (4h 25mins)

My overriding memory is the sense of collective endeavour - I must admit I was blubbing before I started the race - probably a mixture of exhaustion and fear - but seeing all these people running for something so close to their hearts, many with pictures of loved ones on their t-shirts, was quite humbling and very moving. London has never looked better in my eyes.

I won't share with you any photos of my feet but in a few days I will only have 3 of my toenails left. A small price to pay for over £30,000 raised for such a good, real and important cause. It was great to have my family and friends supporting me on the day, including Dr Bending wearing his wide-brimmed sun hat!



Alicia Martin (5h 34mins)

I can't put into words just how proud I am of finishing the London Marathon and raising funds for such an incredible charity in memory of my beloved pop. I won't lie - it was physically exhausting. I became unwell at the 18 mile mark but somehow managed to find strength inside me to finish. The moment I crossed the finish line is something I will never ever forget. Being able to ring my family back home in Australia was incredible. The love and support I've received over the past 6 months as I've embarked on this journey has been nothing short of amazing. I will be returning to Australia this year with a memory embedded deep in my heart that no one can ever take away from me. The 13th April 2014 is a day that I will never forget.

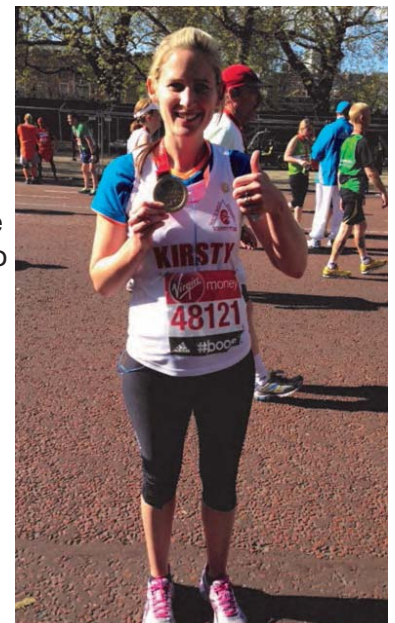
Kirsty Eaton (5h 34mins)

After 6 months of hard work, long runs, the injuries, the wind, the rain and the frustrations the day of the marathon was finally here. Up early to prepare my kit bag and to get my special marathon outfit on I was so excited to get to the start line. Arriving at the red start there were thousands of people all running for different reasons and it was such an amazing sight.

I finally made it passed the start line and off I went on the 26.2 mile run. I can't really put into words how I felt while I was running except it was an amazing atmosphere with everyone calling your name - I felt like a star! The miles were going by so quick as I was checking out all the sights. Seeing my family at miles 13 and 22 was just what I needed to keep me going. Buckingham Palace was soon in sight and I have never smiled so much in my life, all I could think about was crossing that finish line, receiving my medal and having a well deserved beer!

I sprinted passed the finish line and when I was finally wearing my medal I was so excited and happy knowing I had just completed the London Marathon and it had finally sunk in what I had just achieved.

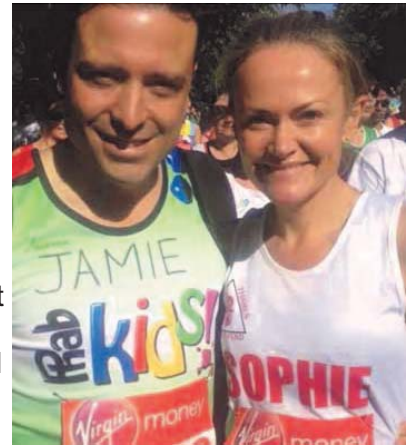
Thank you so much for letting me support such an amazing cause and sharing my biggest challenge with South West Thames Kidney Fund.



Sophie Blaker (4h 51mins)

I had a great marathon experience. I ran along side my brother who himself suffers from polycystic kidney disease, but is a veteran marathon runner. I had felt extremely tired when I started as I had only managed two hours sleep the night before as I was so nervous, but the adrenaline makes up for that pretty quickly.

The atmosphere on the day was amazing, and felt like one large carnival with the crowds ten deep in places, music playing, and children handing out sweets along the way. The weather was rather too warm, but there were lots of drinks being handed out. I felt very tired by mile 18 but then I saw all my family at Canary Wharf cheering us on. That gives me a real boost for another few miles.



After mile 23 I really was feeling exhausted, and every bone in my body was hurting. I had done all my training on soft ground in the countryside, and running on tarmac for nearly 5 hours hurts! But the crowd were fantastic, and every time I started to slow down, someone would yell out some supporting words. My brother was brilliant too as he was so positive and distracted me from the pain by pointing out the great London sites, and counting down the miles as we ran.

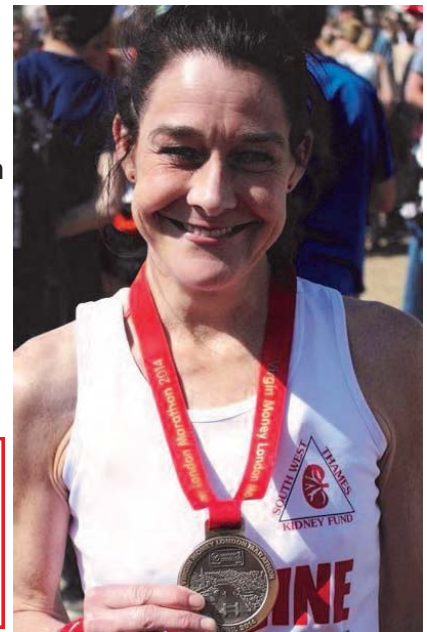
Finally we crossed the finish line hand in hand. It was very emotional and I have to admit that I started crying as we finished. I was so pleased to have raised my sponsorship money from my fantastic friends, and run the race with my brother in under 5 hours.

Pauline Hopkins (3h 19mins)

"I would like to say a big THANK YOU to everyone for their support during my training & in being so generous for the charity.

I had such a great day, it was truly amazing, particularly seeing Mo Farah running past at 21 miles, in the other direction at Tower Bridge, whilst I was on the other side of the road at 14 miles - bizarre!

The spectators and race marshals were so brilliant and thanks to my fellow runners for the encouragement through those long winter months. But the highlight of the day was seeing my family waving and cheering me on at several points along the course, this certainly kept me going.



ALSO taking part were Lucy Vanson who completed the course in 6h 33mins; Michael Tyler (4h 19mins); and Charlie Gilmartin (4h 17mins).

COMMONS TOUCH FOR MARK AND KATHRYN

Dr Mark Dockrell and Kathryn Harrison, one of the South West Thames Kidney Fund trustees, were lucky enough to be invited to the summer reception of the Association of Medical Research Charities at the House of Commons in June.

The reception, hosted by Lord Turnberg of Cheadle, was attended by a wide range of charities including dementia, cancer research, genomics and of course kidney research and had the theme *A Healthy Future for UK Medical Research*.

Mark took the opportunity to catch up with Paul Burstow MP for Sutton and Cheam and supporter of St. Helier Hospital.



OUR HEARTFELT THANKS GO TO...

A special thanks to transplant patient Mr Alan Andrews and his wife who have raised £200 so far for research into kidney disease through a plant sale.

Nora and the members of the Sheltered Housing Group in Addlestone held a fundraiser for the Kidney Fund and raised £414.80 – a fantastic result!

Many thanks to Mat Dibb, one of our Kidney Fund Trustees, who went to collect the cheque and talk to the group. They thoroughly enjoyed his visit!

A big thank you to Mat Dibb's neighbour who donated her bingo win to the Kidney Fund!

Dennis Court took part in the Shepperton Rotary Club 10k walk once again, and raised £77.00 for the Kidney Fund. Thanks so much Dennis!

The McSweeney family hosted another fabulous evening at their Palace of Varieties event on Friday 13th June, and raised total of £492.00! Thanks so much again to the McSweeney clan for their continuing support of kidney research!!

Chiltern International raised £21.53 from their Dress Down day – thank you.

We are extremely grateful for the legacies we have received from the wills of Mrs Pamela E C Cook and Mr John Mackness and to John Medhurst who died on the 16th April and asked that £1,000 be donated to the Kidney Fund in his memory.

A huge thank you to all of you who supported this year's London Marathon team and helped with this year's excellent result, and to all the generous people who have made donations to the Fund.

We have received donations in memory of:

Edward Wratten

Barry Thomas

Persis Saunders

Julie Lamb

Beverley Roseanna Platt-Higgins

Patricia Smart

John David Medhurst

Doreen Joan Philps

Sarah Gibbs

The New World of Communication

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



Hospital data and your body – no difference!

TRANSPLANT patient IAN HARRISON writes:

Dear Renality.

I may be odd (that's both my wife and James Marsh nodding) but having seen a couple of 'constructive criticisms' in previous copies of Renality, it's not the usual moans and groans about hospital life that get me tutting.

It's when I see things in the NHS similar to those that used to happen in my former big public sector organisation.

Here's a few of the renal examples I've experienced (mainly because that's the area where I've taken up residence) but I could equally cite other examples in different parts of hospitals.

1) When I had my transplant at St George's following years of fabulous care at St Helier, I was processed out the hospital.

Them: 'Here's a copy of the letter that's been sent to your GP explaining everything'

Me (looking at letter heading): 'Who's Dr Andrew Aardvark, of the A1 Surgery, Addington? (name and address changed to protect the real Dr Aardvark). He's not my GP.'

Them: 'Oh, your GP wasn't on the system, we're not allowed to add doctors, and the computer won't let us put a blank in, so we just picked the first one on the system list'.

This is more popularly known as 'Computer says no' syndrome!

2) In the A&E at a hospital in the West of Middlesex. 'Sorry Mr. Harrison, I know you've only been here an hour but we've lost your notes so we'll have to start again. Now I seem to remember you've got polycystic ovaries...' (another odd look from my wife.)

3) In the ward at St.Helier (half an hour after doctors' rounds).

Angry mum: 'Who's Ian Harrison?'

Me: 'Er..I am.'

Angry Mum ' Well why is your medicine chart in my handicapped son's folder?

Me: ' Good question..'

4) Renal Patientview. A brilliant concept allowing patients to monitor their own

test results on line and so come prepared for the next outpatient appointment with their consultant.

Except my record on the system will only show inpatient tests I've had done at St.Helier and none of the outpatient blood tests from St.Peter's in Chertsey. As a result I can only see < 25% of my data. Fail.

Now all of the above don't scream incompetence or lack of care to me. They howl of data and (data) communications. I know this because I spent many years trying (and failing) to persuade managers to avoid the same situations in a similarly large public sector organisation.

You'll have seen the saga in the papers, probably over and over again.

Stage 1 - Managers announce: 'To improve the IT in the department we're engaging a large IT company who are contracted to deliver an end-to-end robust IT system fit for the future, that will do everything and even make the tea.'

Stage 2 – Delays announced by contractor citing various excuses.

Stage 3 – Newspaper headline. 'Major IT contractor sacked, leaving department with £35million bill to be paid for by the taxpayer'.

Stage 4 – Everyone in the department/hospital moans about the rubbish IT systems that can't now be replaced because there's a £35 million pound hole in the IT budget. System limps along with manual paperwork plus bits of systems.

I could probably write a book on the subject of data in large organisations (but suspect that no-one would read it, including me) but there are ways to overcome these issues and strangely, in a hospital there are a mass of IT specialists who don't realise it – they're called doctors and nurses.

Data and data communications are the lifeblood of a record. If blood isn't getting into part of a human body, for example a kidney (seems on-topic!) then I hope that the doctor wouldn't say 'Well Mr Harrison, your kidney's not doing so well, and the blood doesn't seem to be reaching it properly. So what we're doing is



designing a completely new body for you that'll do everything for you, and you'll even urinate tea.'

No, you make the system respond better by either gentle or radical tweaks and if that database/kidney appears to be doomed **then** you contemplate replacing it. But it's a big operation even at that level and there are risks of failure.

If you wouldn't transplant multiple organs, don't change multiple data structures - it comes with the same inherent risks. Data, like the blood system or the nervous system is complex and needs regular care and close examination. Sometimes data, like blood, is incompatible and you have to circumvent the issue or refuse a change.

To quote some clever IT person, 'The system is not the system – the system is the data.'

And again, if a manager proposes a stand-alone system to fix a specific problem, doctors should ask themselves whether a stand-alone organ would be of any particular use...

I realise there are a host of issues here – data protection, mis-matching data constructs, legacy systems etc. etc. and that I've only skimmed the topic to get my rant letter-sized but compare the complexity of IT with the complexities of the human body and it should put them into perspective.

Next time managers propose a system change, think in terms of a patient's body. Don't be put off by the IT jargon (not that you could ever accuse a doctor of using jargon!) - there'll be a medical parallel that you can use. Show the same care to our data and the pipelines it travels along as you do to us and we (the patients) will come to see the benefits.

MARK DOCKRELL

Institute Director

"Ah, summer, what power you have to make us suffer and like it." How true, but I hope you're not suffering too much because once again it is time for Tales from the Lab; my chance to update you on what's been happening in your very own Renal Research Institute.

At the end of my last instalment in true pulp fiction style, I left you with a cliffhanger, in fact I left you with so many cliffhangers you need a cliff wardrobe to put them in.

If you remember we were preparing for UK Kidney Week. The meetings with over a thousand delegates were being held in Glasgow. It brought together the Renal Association, the British Renal Society and most of the other associations and societies representing people with an interest in kidney disease.

The team had been feverishly busy preparing. Many of them had two presentations to give including Dr Seema Jain who was talking on advances in transplantation.

Glasgow is definitely a city of mixed blessings – I mustn't say anything too bad about it because I wouldn't want to upset Dr Pauline Swift - but I think it's safe to say it not a capital of cuisine and perhaps not where to go if 12 hours of sun is a priority for you but they do have a good conference centre on the banks of the Clyde.

In the shadow of the giant Finnieston Crane, over 50 metres tall with a 45 metre cantilever jib, a reminder of the industrial past of what was once the second city of the empire, are the bright glass and steel building of the SECC precinct which include the conference centre. It turned out to be a great meeting, the centre buzzed with activity and the 10 presentations from the Institute were well received taking home two prizes!

The team was a real tribute to all you in the Kidney Fund who have worked so hard to support our research. Thank you.

The other teaser I left you with was mention of cadmium. "Cadmium?" I

hear you cry "what's he talking about cadmium for, that's the stuff they put in batteries, what's it got to do with kidneys?"

You may well ask. You do indeed get cadmium in batteries but it also crops up in a variety of other things as well including car exhaust and cigarette smoke. The reason I'm interested in it is we believe it damages the kidneys. This might be part of the reason that kidney disease often clusters around areas of heavy traffic.

Also in countries like China and Bangladesh they have found very high levels of cadmium in rice posing a real health risk; some cases are thought to be associated with industrial pollution.

Yet we've known about cadmium toxicity caused by contaminated rice since the 1950s!

So what does the cadmium actually do to the kidney and can we prevent it? It won't surprise you to know we don't have the answers, yet.

To try and make a start on finding some of the answers I have designed a pilot study and in collaborations with a friend and colleague of mine from St George's, Dr Iain MacPhee, we have recruited a very bright young medical student to carry out the work as her research project.

With financial support from Kidney Research UK our student, Hendor, will be starting in the autumn. So, wish her luck because I think this is an important under-investigated area

Oh goodness, my time is almost up



and I had so much more to tell you. I still haven't had a chance to tell you about the other grants I submitted to Kidney Research UK and the MRC.

I'm afraid that will have to wait till next time because there is something else which is quite important that I wanted to tell you about.

Are you paying attention? Because it might involve you, particularly if you've had a kidney transplant or are on the waiting list.

The Institute and the Kidney Fund are in the process of signing up to the Kidney Transplant Priority Setting Partnership. This is an organisation that aims to bring together for the first time patients and clinicians with an interest in kidney transplantation to develop joint priorities for future research.

They will design surveys open to patients, carers and clinicians, to ensure equal voice, which will seek to get your opinion on the areas of kidney transplant that you think are important and that you think merit more research. So if you're interested please get in touch with Anne Collard and ask her to put your name on our Kidney Transplant Priority Setting Partnership panel.

If you get in touch with Anne there may be other ways you can help. That's Anne.collard@esth.nhs.uk on (020) 8296 3698. Thank you and till next time keep caring for those kidneys and remember...

Funding = Research

Research = Cure