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**Newsletter February 2018** 

INSTITUTE FOR RENAL RESEARCH ST HELIER & SURREY KIDNEY PATIENTS' ASSOCIATION

#### Featuring...

LONDON MARATHON RUNNERS

#### GALA DINNER

#### KPA GOLF DAY

### **Newsletter February 2018**

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

Make a **one-off donation** online, by text to SWKF22£\_ to 70070, or by cheque to

SWTKF, Renal Unit, St Helier Hospital, Wrythe Lane, Carshalton SM5 1AA

Create a standing order

Donate via payroll giving

Join our weekly lottery and play to win!

Shop 'til you drop and Give as You Live!

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

Sell an item on **ebay** 

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

Buy our Christmas Cards

Donate **shares** 

Donate your tax refund

# Useful Contacts:

RENAL UNIT reception: 020 8296 2283, 020 8296 3100

SWTIRR & SWTKF: 020 8296 3698

SOUTH WEST THAMES KIDNEY FUND, info@kidneyfund.org.uk

ST HELIER & SURREY KPA Dave Spensley, Chairman 01483 426276

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## **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

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.

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 Joanna Pope/Beverley Searles at the Renal Unit on 020 8296 3199/2587.

# News from the Mad House

A short message this edition as I don't have too much to report.

- We continue to progress the new dialysis unit at St Helier, with building now well underway and the latest date for moving in estimated to be July 2018.
- Plans for the new dialysis unit at Croydon are also progressing well, although we don't yet have a date for moving in.
- By the time you read this, we will have started inpatient dialysis at Frimley Park. Our new provision there has already been a huge success, with the rate of stage 3 (serious) acute kidney injury halved by the presence of four visiting Consultants from St Helier.
- The Trust has recently been re-inspected by the CQC. The results from this should be coming out at about the same time that you receive this article, so fingers crossed...

A particular bugbear over the years has been the lack of academic recognition of the research and teaching that comes out of the Renal Unit. For example, despite no protected academic time, the research output is far in excess of colleagues at St George's Hospital, where there are two Professors and one Reader in Nephrology.

It is therefore a particular pleasure to report that, in association with being co-applicant on a research grant worth £3.8M, Hugh Gallagher has recently been awarded the title of Honorary Associate Professor at the University of Southampton, where the research is being co-ordinated. It is a shame that other deserving colleagues do not get the access to academic recognition that they deserve. But we know who you are, and thank you.



Dr Peter Andrews, Clinical Director

The name plate outside Hugh's office has recently been changed to 'Ass Prof Gallagher', though this appears to be causing more confusion than had been intended...

Otherwise, it is that time of the year again that I should like to extend my heartfelt thanks to the nursing, medical, paramedical and administrative teams that help keep the show on the road. Behind every clinical interaction is a small army of people who only get their full recognition when they are no longer there. So thank you all, and I am sorry if I don't tell you more often how much you are appreciated.

# News from the Dog House

# A list of things I didn't like about Christmas:

- Having a large tree usurp my place in the kitchen and having to sleep by the back door
- 2. Getting in trouble for christening the said tree (*I had had a Christmas drinkie...*)
- 3. Getting in trouble for opening someone else's present on Christmas Eve (*it was delicious!*)
- 4. Getting in trouble for tripping up the alpha female's mother (*I think she had been drinking*)
- Getting in trouble for not wearing my reindeer antlers, novelty mane, or reindeer nose

Honestly, I don't see what the fuss is all about!



I much preferred New Year's Eve, when everyone felt so guilty that my morning walk was likely to be late that I was sneaked lots of leftovers.

# RENALITY

I hope the alpha female doesn't read this!

I understand that the tradition is to make a series of New Year Resolutions, but that it doesn't matter what you say as everybody cheats within a few days anyway. With this in mind, I thought about the following:

- 1. No barking at foxes at 2.00am in the morning
- 2. No chasing deer for more than 30

minutes when walking through the woods

- 3. No excessive slobbering at meal times (that Pavlov really knew his stuff!)
- 4. Coming when asked (fat chance!)
- Trying not to feel smug when I see Jennie, Steve Simper's former Guide Dog, and teasing her how she feels about being replaced by a younger, fitter model. Although, on reflection, I probably ought to

keep quiet about this. I'm now in my mid-30's in dog years and you never know what the alpha male may have in mind... (the alpha female can also read this bit!)

Hope you are all well and looking forward to the joys of Spring. Woof woof!

Elsa xxx

# **Quiz without Fizz**

. . . . . . . . . . .

On 23rd December, the renal unit had its usual Christmas Quiz. Attended by over 70 staff we all had a great opportunity to show-off our intellectual prowess, with the winning team getting just over 50% of the questions right – despite it being multiple choice! We enjoyed good food but no 'fizz' as we were all still on duty!

## Thanks to all the Elves – Santa's little helpers

I am sure you will all join me in thanking all of our dedicated staff who worked over the Christmas period to ensure all of our necessary services were kept running and that those patients who were unable to be at home for Christmas were well looked after on our wards.

We can be thankful for our National Elf Service.

\_\_\_\_\_

#### Transport is driving us mad

Providing good quality transport to everyone using our services is a considerable challenge. With thousands of journeys each month spanning a wide geography there are bound to be some problems. However, we recognise that every delay or cancellation is one too many and so we have been tendering all of our transport contracts and have appointed a number of different providers each with a unique provision to support you.

The new services will start to be in place in the next few weeks and we are hopeful that you will see a definite improvement.

## Did you Did, or Did you Didn't

In the health service we have an abbreviation known as DNA. This is not deoxyribonucleic acid in this case, but 'Did Not Attend'. Have you ever DNA'd an appointment in outpatients or a dialysis session without letting anyone know? Given sufficient notice, we can always book another patient into an outpatient appointment and if you notify your



dialysis unit 24 hours in advance the session can be cancelled.

Despite this opportunity, between April and September 2017 patients did not attend 371 appointments where notice was not provided. This means that we were still charged for the unused dialysis session at a massive cost of £42,000.

This means we are wasting over £80,000 each year, which we could of course be putting to good use elsewhere.

Since we are still in the season for making New year resolutions, why

not make one of yours to inform your dialysis unit 24-hours in advance, if you are unable to attend.

# There is no such thing as a 'free delivery'

I am sure many of you will have shopped online this year buying presents for family and friends. Although many suppliers now offer free delivery, they do of course add this into the price somewhere, so it is not really free.

So what about your dialysis fluids when they are delivered to your home for home hd or PD? Well, there is quite a large delivery cost, However, this is of course part of your therapy so is funded by the NHS. But what happens when you are not in to receive your delivery, despite agreeing a fixed time with the supplier? Well, we have to rearrange this and there is a duplicate cost.

As we make every effort to ensure that you are fully aware of and in agreement with delivery times, failure to receive a delivery will in future incur a cost to you.

For those people affected by this, you will have received a letter from me by now and I hope you will understand why this is necessary.

## Goodbye Techs, Hello Fresenius

Many of you will know that our main units at St Helier and Croydon Hospital will this year be moving to a new service managed by Renal Services UK. We are excited by these changes as they bring fantastic new facilities on both sites whilst retaining all of our current nursing staff. However, one casualty of this change is the reduced work available to our technicians, Lee, Dave and Don. Consequently, each, for different reasons have now left the unit for pastures new. This has given us the opportunity to review how we provide technical support to the unit and to our home patients.

Within our own units at St Helier, Croydon and Kingston, our equipment will be serviced and maintained by Fresenius, until Renal Services take on St Helier and Croydon. Fresenius will also be providing technical support to all of our home patients using Fresenius equipment. If this is you, you will already have been provided with all the necessary information.

One great outcome of this change is our ability to fund new home installations. Therefore, we are even more actively encouraging home dialysis for those patients for whom it is suitable. If you are interested, please speak with your consultant.

#### Taking some control



As well as being able to pursue other modalities of dialysis, such as home dialysis, you can also get access to lots of information about your treatment from Patient View.

PatientView shows your latest test results, letters and medicines, plus info about diagnosis and treatment. Set up alerts, monitor symptoms and download your records. You can view PatientView from anywhere you want and share your information with anyone you want.

If you want to sign up, it is simple, just

contact either Beverley Searles (0208 296 2587) or Jo Pope (020 8296 3199) or email them beverley.searles@nhs.net

For further detailed information about Patient View, please visit: https://www.patientview.org/

#### **Doing IT right**

In May of this year, the government will introduce new rules regarding data protection. Known as GDPR (General Data Protection Rules). We will be obliged to consider how we use information within the Trust. One significant change in relation to Renality is that we will only be able to send you a copy if you give us permission. It will no longer be sufficient for us to assume you want to receive the magazine just because you have not told us otherwise.

To try to make this process as easy as possible, we have provided three ways of letting us know if you want to receive future copies of Renality.

- Complete the form on the back cover of this edition and either hand it into your dialysis centre or St Helier Outpatient reception.
- Telephone either Beverley Searles (0208 296 2587) or Jo Pope (020 8296 3199).
- Email either beverley.searles@ nhs.net or joanna.pope@nhs.net informing them that you wish to receive future copies of Renality.

#### **Goodbye Jenny!**

Jenny has been my guide dog for eight years now. Through these eight years, she has become a special part of my life and to those at Epsom and St Helier that have



Jenny (right) with Steve and his new guide dog, Freeman.

#### come to know her. Sadly, even guide dogs have to retire and as Jenny has hit that age, she will no longer be spending time at our hospitals.

To celebrate Jenny's essential work as a guide dog over the past eight years, a unique retirement party was thrown for her in the Blue Room at St Helier on Friday 8 December. All of Jenny's friends joined together to thank her for her service and to send her off in style.

There was tea, coffee, cakes, but most importantly dog treats for Jenny. We also awarded her a special certificate, and she really deserves it! Now Jenny is retired, she will be looked after by my daughter Samantha.

#### **Message from Jenny**

Hey, Elsa, this being naughty thing is brilliant. Now that I am retired, I can get away with it. Also, my new owner, Samantha is my old owner's daughter and she is a bit of a rebel – so treats all round at Christmas!

The retirement party was ok but the young whippersnapper Freeman got some of the lime light. However, what he did not get was a Long Service award, given to me for 56 dog years in the NHS – that really does make me sound old!

Anyway, Elsa, I am sure I will still hear about your antics from my old owner so keep it up for non-working dogs all round the world.

#### **Message from Freeman**

Well, as this is my first message I perhaps should tell you a little about myself. I am a very handsome pure lab aged about 1<sup>3</sup>/<sub>4</sub>. My birthday is in April in case you are interested. I have not had a very auspicious start with my new owner as I developed a viral infection in my foot and had to have surgery just before Christmas. I am okay now, fit and ready to start my 8-10 years' service in the NHS. Jenny has told me much about life in Renal and has also mentioned in passing that there is another canine author who contributes to this magazine - apparently rather a naughty dog, eating documents, biting through phone lines and using the Christmas tree as a toilet!

Well, I hope to meet some of you over the next few months and will update you with renal news in the next edition of Renality.

In the meantime, I understand that Jenny used to tell you a dog-related joke, so here is my effort.

Q: What is it called when a cat wins a dog show?A: A CAT-HAS-TROPHY!

Steve Simper, Divisional General Manager

# Would you like to:

\_\_\_\_\_

- Find out your latest test results?
- Read online information about your condition and treatment?
- Read about diets?
- Check the transplant list?
- Enter your blood pressure and test results?



If you answered **YES** to any of these questions, you should take a look at **PatientView** 

#### www.patientview.org

If you would like to join **PatientView** please contact:

Jo Pope, *Renal IT and Admin Officer* 020 8296 3199 Joanna.Pope@nhs.net

# **Dear Kidney Fund Supporter,**

# All the boring jobs come around in January.

This evening I have had to apply to register with the Central Office of Information. This is now a Legally binding obligation for all of us that hold confidential information, whether for business of in our case patient records. A good safe-guard for the patient I suppose. It does mean that when you have a boring evening you can irritate your accountant or doctor or church to find out what information they are holding on you. Beware big brother is watching you. The next January task will be to fill in that form from the Tax man. Every year we vow to start and complete in April. Why does it always get left to the last minute?

That makes the next job of writing a letter to RENALITY a positively relaxing pleasure.

But wait, our treasurer is breathing down my neck to write a report for the Charity Commissioners to accompany the annual accounts. This really is important. We must safeguard the fantastic research directed and performed by Dr Mark Dockrell and his team.

The report (a mission statement) will go something like this...

From its foundation in 1980, The South West Thames Kidney Fund, renamed in 2017 as "The Kidney Fund", was set up

in the nineteen eighties shortly after I arrived on the Renal Unit at St Helier Hospital. The fund has been driven by the efforts of Kidney Patients and their relatives and friends. We have maximised the income from fund raising activities, from bequests and donations and established a healthy income from very wise investment of our out-going treasurer, Helen Green.

The Fund is here to promote and disseminate research that may ultimately improve outcomes for patients with kidney disease. The Fund has also taken a leading role in the education of clinicians and scientists interested in kidney disease. These funds are put to use in the laboratory,



training young Kidney specialists to have a scientific approach to solving the medical problems that the 21st century will bring.

One of the most exciting outcomes is that one of the Institute's first Graduates, Dr Hugh

Gallagher, has been awarded a Chair by Southampton University in recognition of his research. So now then, it is Professor Gallagher.

Helen Green is standing down as Treasurer to the fund at the end of the month. Elsewhere in this edition of RENALITY you will find a notice looking for her replacement. If you know of any friendly accountant do suggest that they could help the cause by taking over.

Very best wishes one and all.

Season's greetings,

Dr Michael Bending, Chair, The Kidney Fund

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

If your appointments at the Renal Unit drop to 2 or less per year, you will be removed from the 'RENALITY' mailing list and will no longer receive the newsletter.

You can receive a PDF of 'RENALITY' by email – just email Graham.Morrow@kidneyfund.org.uk and he will add you to PDF distribution list.

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

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



# **F**Too heavy a burden to bear?

#### Dear Renaliteers,

I know by the time you are reading this we will be well into 2018 but I am still going to take the liberty of wishing you a very Happy New Year. I do so because 2018 is a very special year for SWTIRR and for us at the Institute you might justifiably argue that the New Year starts in March - I always find it easier to win arguments if I make up the rules.

You may already know what I'm getting at here, do you? Yes, of course, I'm talking about the 20th anniversary of the Institute. Although I wasn't here at the time, I am reminded every day as I come into work by a rather handsome plaque that the Institute was opened on the 25th of March 1998. The discrete golden plaque may not be very large but what it marks is really something titanic. It certainly marks a wonderful achievement, perhaps three achievements! First, a group of patients, their families, their friends and their doctors dared to believe they could have something unique, a research Institute dedicated to improving the lives of kidney patients through research and education. Secondly, they raised all the money required to build it. Thirdly, they convinced their hospital to work with them in partnership to make it all happen. You had an idea, a dream, and you made it happen. How great is that?

If that weren't enough, that plaque marks something even more fantastic. It is a mark of hope and belief; hope and belief that together we can make things better, we can find a cure!

Now, don't tell anyone, but there are times, just now and then, in the dark loneliness of a sleepless night when I find those wonderful achievements of yours and the fantastic hope & belief you have a bit of heavy burden. I know you're not expecting a cure tomorrow but still, I mean it is quite a big ask. As the wind rattles my bedroom window, the street lights cast haunting shadows across my ceiling and the police car sirens play the lullaby of Brixton, I think, maybe I can't do it. I'm going to let all those fabulous fund raising Renaliteers down!

Recently, Professor Bruce Hendry, the new chairman of the board of SWTIRR, asked me to put together a document summing up what the Institute does. It took a while but it gave me time to reflect. Time to reflect on the education and training that SWTIRR has delivered. Do you know that 5 of Epsom & St. Helier's consultants did their research at SWTIRR? That's only 5 out of the dozen or so we've trained and we're proud of everyone. The first graduate was Dr Hugh Gallagher – or should I say Professor Hugh Gallagher, as he now has an honorary professorship at the University of Southampton- and the most recent to get his PhD, Dr Simon Winn who is doing a marvellous, if almost impossible, job organising our Acute Medical Unit here at ESTH.

We may not yet have found a cure but we're working on it. We have made a number of discoveries that have helped us understand how the kidney works and how it fails. We have developed new diagnostic tools. Most recently this includes our patented K-Cad test that Dr Seema Jain worked on when she was at the Institute.



Dr Mark Dockrell

Sarah Yates continues that work and we recently submitted a grant application to a medical research Trust for just under £200 000 for Kam to take it further. This March we will have to say farewell to Dr Pritpal Virdee. Pritpal has been working on one of the closest things we have to a cure at the moment; a revolutionary new therapeutic approach that could divert the genes away from making the scarring that causes kidney fibrosis. By the time he finishes we should have the results of his pre-clinical trial.

To paraphrase Martin Luther King, I have decided to stick with hope as failure is too heavy a burden to bear.

So, when the sun comes up and I arrive at the Institute, I realise that I still can't do it, not on my own but I can when I work with great colleagues and a great team and your support. In fact WE are doing it. WE will not let you down! There is a cure and together we are going to help find it even if it takes another 20 years. If you're not ready to give up then neither am I. Chronic kidney disease is a tough relentless condition slowly wearing us down but I think it may have met its match in SWTIRR and the Renaliteers!

Funding = Research = Cure

# World Kidney Day 2018

**This year World Kidney Day** has the theme of Kidneys and Women's Health, an area that we don't often hear much about. In general, we don't tend to think about differences between men and women in kidney disease but there are some areas where it's particularly relevant, pregnancy is perhaps the most obvious example. Another area where it important is urinary tract infections (UTIs). Now I have to be honest and admit that this was not an area that I had given that much thought to, that was until I heard a really interesting talk at a Kidney Research UK Fellows meeting. The talk was by Dr Rachel Floyd from Liverpool. Rachel is a Kidney Research UK Fellow at the University of Liverpool in the **Cellular and Molecular Physiology** department and she has been doing some fascinating work. So, I thought I'd ask Rachel to share with us a little about what she has been doing.

UTIs are very common, but surprisingly, we understand very little about why some people are more likely to have



recurrent UTIs that are difficult to treat. There is growing evidence that hormones can have direct effects on bacteria, which may alter the severity of infection. Studies in our lab suggest that hormones such as oestrogen and progesterone, may play a key role in modifying the behaviour of bacteria such as E. coli, which enable them to survive and cause recurrent disease. These modifications are triggered by cryptic molecular conversations that occur between bacteria and the cells of the bladder. By translating some of



these conversations, the information can be used to design better treatments and also identify people who might be more at risk of UTI at an earlier stage. Dr Rachel Floyd.

As some of you may remember, here at SWTIRR we've also been thinking about infections and how to detect and diagnose them more rapidly. We're working Professor Bob Price from King's College London on his invention Grambacter. Grambacter will be able to detect whether an infection is bacterial or not within 10 minutes and if it is bacterial Grambacter will be able to tell us if the infection is Gram negative or Gram positive, important information when it comes to prescribing the right antibiotic at the right time. Bob is also now on the Board of SWTIRR. so expect to hear more from him in the future.

See you in around the Renal Unit at St Helier Hospital on Thursday 8th March for World Kidney Day.

# RENALITY

Adele, Amy Winehouse, 10CC Bob Marley, **Dusty Springfield** Kings of Leon, Tracy Chapman Cranberries, Van Morrison Chic, Fleetwood Mac, Soft Cell Jessie J, Modjo, Gabrielle Bill Withers, Norah Jones, U2 KT Tunstall...and many more!

> Featuring Maxine Wood Vocals

Appearing at Purley Social Club 60 Whytecliffe Road South Purley CR8 2AW

# Saturday 24th February Doors Open at 7pm

Entry is FREE via e-ticket in advance only. Tickets available from kidneyfundraiser@gmail.com or call 0208 296 3698.

In support of

Please support the event via our RAFFLE which will be drawn on the night.

dontasktheband.com

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idney

# **Kidney Fund Clinical Research Fellowship**

Many of you will be aware that the Kidney Fund has supported several Clinical Research fellows over the last twenty years. The first of these was Dr Hugh Gallagher, (1998 to 2001). Since he was awarded a PhD degree for the scientific work he performed, Hugh has been appointed Consultant Nephrologist at St Helier, and the Royal Surrey County Hospital. Finally, at the end of 2017 Hugh was appointed Professor in recognition of Nationally Important Kidney Research. You may have been present at the AGM of the Kidney Fund, last autumn, to hear Hugh talk about his work.

Since then many more nephrologists in training have passed through the unit, Dr Mysore Phanish, Dr Ramaswamy Diwakar, Dr Mangalakumar Veerasamy, Dr Reza Motazed, Dr Michael Lam, Dr Kanwal Sandhu, Dr Simon Winn, Dr Katie Lane, Dr Nilesh Shah, Dr Seema Jain, and currently Dr Pritpal Virdee.

Simon Winn is currently lead Consultant Physician for Medicine at St Helier. Dr Phanish is consultant nephrologist at Croydon University Hospital and St Helier. Phanish is also Dr Mark Dockrell's right hand man as Medical Director of the Institute and Lead clinician for Live Related Transplantation. The achievements of these young men and women epitomise the objectives of the Kidney Fund. That is what we do.

The cost of training a medical student in the UK is approximately £250,000 over six years. The cost of a threeyear PhD studentship for a Senior Registrar in training comes to a staggering £300,000. Most of this cost is in laboratory fees, equipment and biochemicals.

Would you like to fund or contribute to our next Fellowship which will commence in September 2018? The funds raised are put in a restricted account for the purpose of funding this post and its research only. Anyone who wants to donate to endow the work would get the opportunity to meet the fellow at the start of the project and would get bi-annual letters updating you on progress. There will then be the chance to celebrate the massive achievement and award of a degree at the end of the project.

If you would like to donate for this specific purpose then just let Sarwat Ahmad, our administrator, know that the donation is for the Research Fellowship post.

#### Sarwat's Contact is: SWT Institute for Renal Research, The Renal Unit, St Helier Hospital, Carshalton, SM5 1AA or: 0208 296 3698 or: satwat.ahmad@nhs.net

In the meantime, we must be thankful to those Nephrologists in the present generation who have sweated through this arduous training to become the Consultants who look after us with such dedication today.

Keep up the magnificent fund raising that has made this all possible in our own Renal Unit.

With best wishes

Dr Michael Bending Chair, The Kidney Fund

## The Kidney Fund Quiz Night was held at the Purley Social Club on Saturday 20th

**January 2018.** With a mixture of TV Quiz themed rounds using buzzers, a large screen and even A4 playing cards, the participants were entertained for  $2^{1}/_{2}$  hours. It was well supported and there was a great atmosphere. With entry fees and donations, £600 was raised and special thanks are due to Nick Ford and Cakes by Olivia Rose for their invaluable contributions. Unfortunately the event was so busy I forgot to take any photos.

My next event is a **Music Night on 24th February** again at the Purley Social Club. Please see the Kidney Fund Facebook and Twitter pages or call Sarwat at St Helier on 020 8296 3698 for full details.

#### **By Anthony Vidler**

# **Our London Marathon Runners... please support**

#### Richard Trowbridge

I am 42 years old and work for an insurance company. This will be my first ever marathon so wish me luck. I chose to run for the Kidney Fund as not only are kidney issues close to me due to my



father needing dialysis 3 times a week, but also for my work colleague who has a very close relationship to this charity due to the treatment his wife is having at Epsom and St Helier hospital. I hope I can do the charity proud and earn some money for them to go toward their research in to this under rated health problem.

#### **Adam Farrant**

The reason I would like to run for the fund is because my Grandpa passed away last year. He had kidney problems for many years and was on Dialysis for around 12 years. To raise over £1500 for the Kidney Fund would be amazing for me and the family.



I am a chef and I do intend to bake lots of cakes to raise money also my husband owns a tattoo shop *"Mr Gordon's Tattoo Emporium"* he has agree to help me raise money by raffle a tattoo.

Running for Kidney Trust will be a way to raise money for a worthy cause.

#### **Keir Charles**

I wanted to run for The Kidney Fund because my friend, Jo Bending, who has also run the London Marathon for you, told me of the fantastic work that the charity does and how the research of the scientists that you work with resonates



not only in this country but internationally, changing people's lives for the better.

I am also aware that, as a smaller charity, it is important to highlight it's fantastic work as much as possible.

#### **Scott Reeves**

I want to run for the Kidney Fund as my mother sadly passed away in September 2015 after being diagnosed with Anti-GBM disease. She spent many months at St Helier where the doctors and nurses were amazing. Any



### money I can raise to say thank you and enable future research to stop anyone else suffering from kidney disease would be amazing. Thank you for the opportunity!

#### **Yvette Adair**

I served just under 10 years in the regular army as a chef, I am now on my fourth year as a reservist.

Running is a hobby and it also gives me an opportunity to raise money for charity.



#### **Amy DuToit**

For years as a keen spectator of athletics I finally hopped into a pair of trainers and hit the road about 5 years ago. I accomplished 7 half marathons over the years. In March last year I set the trainers aside for medical



reasons. Now 10 months later I am ready to pound the pavement and challenge myself again. With this potential opportunity to run the London marathon – I set out to take the dream of running my first full marathon but I fill my biggest dream of physically taking part in the London marathon. No longer would I be cheering from the side lines (in happy tears), in awe of people from all backgrounds pushing themselves to their goals and the betterment of others but I will be there doing the same. A fellow runner friend suffers from Berger's disease and I thought this would be a great opportunity to run in her name. With a little research, I now know, around 1 in 8 people will develop Chronic Kidney Disease and every day 19 people will develop kidney failure in the UK. This means many more people I know, and likely someone you know, may be affected. I am honoured to support awareness and fundraise for much needed research to help those struggling with this disease have the best chance to live a full and happy life.



# OUR LOTTERY STILL GOES FROM STRENGTH TO STRENGTH!

#### Our lottery is still going strong as we approach 400 weeks with £47,549.50 being paid out in prizes!!

This means over £50,000.00 being paid to The Kidney Fund from your subscriptions and donations.

We'd love to welcome any new members or welcome back anyone who had to stop participating for a while.

Come and join in the fun whilst contributing to a cause that's so dear to all of us and GOOD LUCK!

Just complete the mandate or e-mail lottery@ kidneyfund.org and we'll send you a mandate for completion. The winners since the last issue of Renality are:-

06/10/2017	101073	Wallington	£159.50
13/10/2017	101009	Camberley	£159.50
20/10/2017	101034	Streatham	£160.00
27/10/2017	101266	Swansea	£159.50
03/11/2017	101200	Rayleigh	£159.00
10/11/2017	101014	Caterham	£164.50
17/11/2017	101101	Frensham	£161.50
24/11/2017	101237	Camberley	£162.00
01/12/2017	101245	Byfleet	£162.00
08/12/2017	101076	Wallington	£162.00
15/12/2017	101297	Camberley	£161.00
22/12/2017	101002	Guildford	£160.50
29/12/2017	101113	Bognor Regis	£161.00
05/01/2018	101161	Wallington	£161.50

# The Kidney Fund 2 Trustee vacancies

## Would you like to be a Treasurer for the Kidney Fund?

We are seeking a qualified Accountant to become Honorary Treasurer for the Kidney Fund.

If you or your relatives/friends have had problems with your Kidneys this will give you a good insight into the role already (giving you a natural affinity with the Charity).

Board meetings are approximately 6 times a year.

Duties include: Producing Final Accounts and the annual return for the Charity Commission and liaising with the Auditors. Be the first point of contact with the stock broker. Provide the board with financial and investment updates at meetings.

Review the SWTIRR budget for Trustee approval (The Kidney Fund provides the South West Thames Institute for Renal Research with funding for original research).

The current Treasurer, Helen Green will be moving over to Helier Scientific Ltd – who sell the products created by this research.

## 2. Legal/Corporate Governance Trustee/Adviser

The Charity is growing. Having taken on a new fundraiser we are reviewing the way the charity work and would like to ensure we have best practice that fits current standards.

We currently have no legal or corporate governance expertise on the Board. We would welcome advice from those with a legal/corporate governance background.

If either of the Trustee roles interest you please send a CV and covering letter outlining your suitability to hmegreen@btinternet.com

More information on the Kidney Fund can be found at: www.kidneyfund.org.uk



The Chairman of the Kidney Fund Dr Michael Bending, MA, MSc, FRCP and The Worshipful the Mayor Councillor Jean Crossby London Borough of Sutton cordiallly invite you to

A dinner celebrating the 20th Anniversary of the SWT Institute for Renal Research, raising money for the Kidney Fund

The Grange Restaurant Beddington Park, London Road, Wallington SM6 4BT On Wednesday the 21st of March 2018 at 6.30pm

# A night of entertainment and fine Indian cuisine

Vegetarian and other options available, but we will need to know prior to the event

Raffle

Tickets  $\pounds 40$  per person or  $\pounds 370$  for a table of 10

Tickets available from Ms Ahmad T: 020 8296 3698 E: admin@kidneyfund.org.uk

Cheques made payable to "The Kidney Fund" should be sent to the Kidney Fund, c/o SWTIRR, The Renal Unit, St Helier Hospital, Wrythe Lane, Carshalton, Surrey SM5 1AA

# A message from your Chairman

#### I hope that you had an enjoyable Christmas and New Year and that you are looking forward to 2018.

2018 will see the opening of the new Dialysis units at both St Helier and Mayday.

Following re-election at the AGM in November, I have now started my twelfth year as Chairman and the Committee and I will continue to provide every possible support to our KPA members and the patients and staff at St Helier and its Satellites. A full list of your Committee members appears in this edition.

The KPA AGM was held on 14th November 2017 and was attended by a disappointing total of only 12 people, 10 Committee Members and only 2 KPA members. All the Officers and Committee Members were re-elected and 2 co-opted members became full Committee members.

Our 2 new members are both renal patients, there's Sarah-Louise Harwood who works as a Patient Involvement Co-Ordinator for Kidney Research UK and Kevin Carter who volunteers on the KPA's St Helier servery counter.

As there's no longer a KPA Christmas patient lunch at St Helier (as the

numbers were falling year on year), we now sponsor local patient parties at St Helier and all 8 Satellites and this year we raised the level of financial sponsorship for these individual parties to £4.00p per patient, we also gave every renal St Helier in-patient a Christmas card containing £10.00p.

The Grand Christmas Draw took place at St Helier on Tuesday 12th December, the winning tickets being drawn by the Dialysis nurses. Details of prize winners are published separately. The draw showed a surplus of £1713.00p which was similar to 2016. My sincere thanks go to everyone who purchased tickets despite the uncertain economic climate and Brexit, to Jackie Moss for sorting and folding thousands of counterfoils and to Ghansham Patel and Jackie for recording and banking all those individual £5 cheques, notes and coins, a job I know they both loved doing!!!!!

#### **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 15th June 2018. 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, Purley and Crawley.

The KPA has over 800 patient members so hopefully representatives from those 3 units would consider joining Committee to represent your fellow patients.

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 Tuesday 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.

Finally, may I, on behalf of the Committee, wish you a happy and healthy 2018.

**Best Wishes** 

#### Dave Spensley Hon Chairman

# St Helier & Surrey KPA Christmas Draw

Following the Grand Christmas Draw at the Renal Unit, St Helier hospital on 12th December 2017, we are pleased to announce the winners were as follows:

	Winner	Total Prize Won
First Place	Ticket 11033 – Worcester Park	£500.00
Second Place	Ticket 04042 – Greatham	£200.00
Third Place	Ticket 06525 – South Croydon	£100.00
Fourth Place	Ticket 07785 – St Helier	£50.00
Fifth Place	Ticket 10495 – Egham	£50.00

The tickets were drawn by the Dialysis nurses at St Helier. We would like to congratulate all of those people above and say a big thank you to all of you who once again, despite the current economic climate, purchased the draw tickets.



# St Helier and Surrey KPA Golf Day

In Aid of St Helier and Surrey Kidney Patients Association



(Registered Charity Number 266391)

# Milford Golf Course (Surrey)

# Friday 15th June 2018

## Cost — £50.00 Per Person

The day will comprise of:

- A shotgun start
- A Singles Stableford Competition (Full Handicap)
- Prizes for "Longest Drive" and "Nearest the Pin"
- Bacon Roll on arrival
- 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

# Kidney Sharing Scheme (KSS) Concert

Our Christmas charity event took place on Sunday 10th December 2017 at the Carshalton Girls High School. I would like to thank our sponsors the St Helier and Surrey Kidney Patient Association, the staff at the renal unit at St Helier's Hospital, my family and friends for their unfailing support over the past year.

This event sought to engage local residents and patients with lived experience of kidney disease or having had transplants, their relatives and carers. Providing a voice for both equally. The event aimed to showcase the improvement in the quality of life for the recipient and their relatives as well as celebrate Christmas with local churches and community groups.

To all the volunteers and performers for this event who came out despite the rain and snow some with long journeys as far as Cheshire we appreciate you.

To the evening's moderator (Dawn Rhys-Taylor), the stage manager (Mark Carnegie), the staff at the door and the volunteers serving refreshments; who brought calm, fresh energy and vitality after the fire alarm sounded, I give you special thanks.

It became overwhelming for some patrons when both, Dr Phanish



(Consultant) took to the stage to enlighten and bring attention to the KSS and how quality of life improves, for many individuals and Transplanted Patient Kevin Carter delivered his thoughts about the kidney-sharing scheme from a recipient perspective, with Bertram Jones giving vote of thanks.

The Christians in action praise and worship team (who were able to support the event by opening the afternoon's proceedings, to cover artists who were unable to attend owing to train cancellations on the day), the Carshalton choral society, and the St Mary's church all filled the event with joy and deep feelings, while bringing smiles to many faces.

To the venue manager (Adam Nauth) you handled yourself with grace and good humour, I say thank you.

Finally to the attendees, you have





ignited in my wife and I a passion for what this event has meant for us both, to give back, we hope that, if given the opportunity, we'll do our best to make the event bigger and better next year.

#### Until then...

Bertram Jones KSS Christmas Charity Event project co-ordinator

# **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
- John Lawrence

# KPA Memorial Donations...

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

- Amithra Ilangantileeke
- John Boden
- Hilary Pannell
- Sylvia Lee Smith

# St Helier & Surrey KPA Committee Members – 2017/2018

Hon. ChairmanDavid SpensleyL'Alise, Guildford Road, Godalming, Surrey GU7 3BXTel:01483 426276Mobile:07836 750 433Email:daspensley@btinternet.com

Hon. Treasurer Ghansham Patel 7 Waterer Rise, Wallington, Surrey SM6 9DN Home: 0208 395 8037 Mobile: 07967 387 474 Email: gknp989@gmail.com

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

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Satellite Liaison – Epsom Leo Kelliher 37 Sopwith Avenue, Chessington, Surrey KT9 1QE Tel: 0208 397 3059 Mobile: 07702 045 703 Email: flk20aa@aol.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

St. Helier Patient Liaison/Stock ControllerDavid Theobald10 Doveton Court, Doveton Road, S. Croydon, CR2 7DHTel:0208 680 1821Mobile:07585 536592Email:d.theobald@btinternet.com

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Committee Representative Kevin Carter Mobile: 07732 952169 Email: kevcarter8715@yahoo.com

 Renal Social Worker/Amenity Subcommittee

 Celia Eggeling

 Renal Unit, St. Helier Hospital

 Tel:
 0208 296 2940

 Email:
 c.eggeling@nhs.net

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