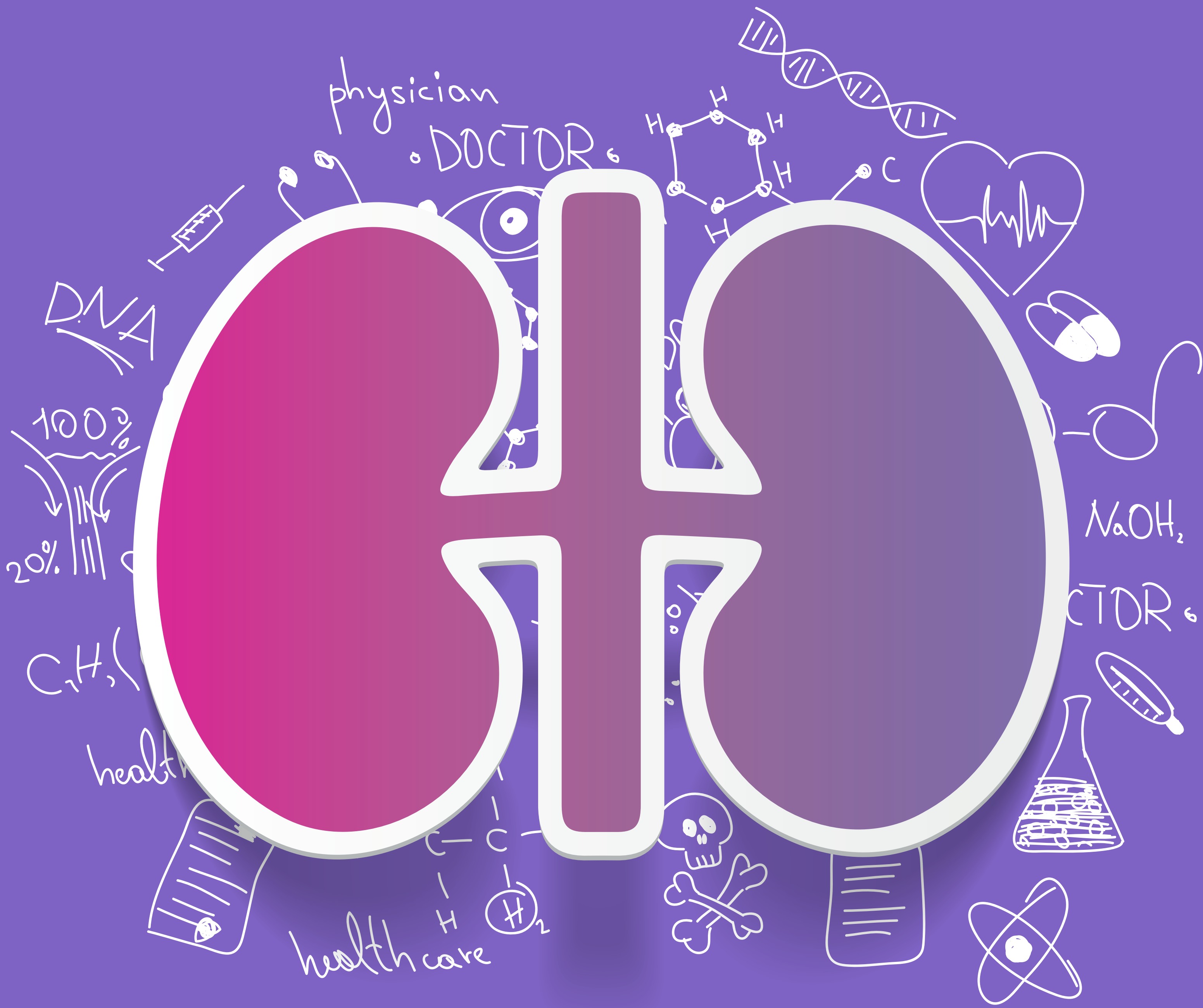
RENALITY

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

Newsletter October 2017



Featuring...

NEW CLINIC

100,000 GENOMES PROJECT

BRITISH TRANSPLANT GAMES 2017

RENALITY

Newsletter October 2017

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

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

In this issue...

The Renal Unit

The Kidney Fund

Kidney Patient Association (KPA)

REMEMBER...

Our website addresses are:

South West Thames Kidney Fund:
www.kidneyfund.org.uk

South West Thames Institute for Renal Research:
www.swtirr.org.uk

St Helier & Surrey Kidney Patient Association
www.shskpa.org

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

Better to Travel than to Arrive?

A trawl through the archives while seeking inspiration for this edition reminds me that this is the sixth year that I have been writing for Renality.

Over that time, many of the themes have recurred:


Dr Peter Andrews, *Clinical Director*

The Good

- Expanding dialysis and transplant numbers
- Excellent external and peer reviews
- Major contributions to research and to local and national renal bodies
- Major financial contributions to the Trust
- Improvements in dialysis infrastructure
- The pleasure of working with a team of committed, dedicated and hard working individuals, all of whom have patient care as their primary focus

The Bad

- The poor estates at St Helier (although these are being addressed)
- Increasing workloads with potential for burn out
- Inability of the NHS to work strategically to develop renal and transplant services in a coordinated fashion

The Ugly

- My office
- Wage freezes restricting opportunities to reward truly outstanding performance
- The profusion of management consultants infesting the NHS with little useful output

It remains a pleasure and a privilege to work for the NHS. Brief exposure to other healthcare organisations both at home and abroad reinforces how lucky we all are, both as providers and receivers. Healthcare remains one of the defining elements of living in the UK, and one that we should continue to celebrate.

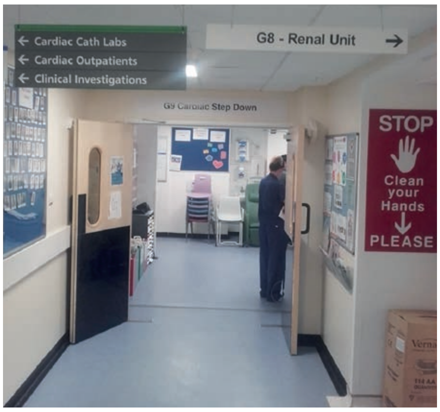
However, you may also detect more than a hint of frustration in the above, and you would be right. The frequent inability of the NHS to act in a coherent fashion is immensely frustrating for those at the coal face. Some of this is related to money, some to power and the lack of strategic control at the regional level, and a depressingly large amount to politics.

In this context, I hope you will be aware of the Trust's plans to develop a new £400M acute hospital co-located with the Royal Marsden Hospital at Sutton. I won't repeat the details here - please go to https://www.epsom-sthelier.nhs.uk/epsom-and-st-helier-2020-2030 for more background. Suffice to say that this is a once in a generation opportunity to resolve the planning blight in SW Thames and to develop acute services for the local population in a sustainable manner, but whilst retaining hospitals at both the Epsom and St Helier sites.

Please give this initiative your attention and your full support. You can most easily do so by providing your details on the website listed above. These plans have received the overwhelming backing of the Consultant medical staff, both in the Renal Unit and the Trust in general. We are doing the best we can and are very proud of our services… but think how much better things could be in a hospital fit for the 21st century.

Picking up on the title of this article, while I would agree in general that travel broadens the mind, we could all do with a bit of arriving. Small minded tribalism from politicians with short memories and vested interests will lead to small outcomes. How depressing if yet another opportunity to move things forward were to flounder.

By way of comparison, let us consider what can happen when interests are aligned, and when strong leadership



cuts through the red tape with the potential for long term benefit.

You will be aware that St Helier have been trying to develop a renal service in Surrey for nearly thirty years. At last, after false starts in Guildford (twice) and Chertsey, we recently opened a state-of-the-art eight bedded acute dialysis and kidney injury unit at Frimley Park Hospital.

The first renal inpatients were admitted to the new unit in September and the expectation is that more than 80% of patients who formerly had to transfer to St Helier will now be treated locally. This will improve patient satisfaction, support other acute services at Frimley Park, save money, and at the same time release resources for existing and future patients at St Helier.

We look forward to a long and fruitful relationship with Frimley Park, one of the outstanding Trust in the NHS, and to helping other hospitals in Surrey develop similar models of patient care. I commend the leadership teams of both hospitals for their constructive approach and their determination to just get the job done, whatever the difficulties. This is how the NHS should work.

Dog Days


Elsa


Stanley

Although this may be only a memory by the time you read this, I understand that you have all enjoyed an unusually hot summer. Spare a thought for those who are forced to endure the heat in a thick, glossy fur coat. This week's picture shows the only way I can keep cool, even if it comes at the expense of my usual good looks. If only the alpha male could have thought ahead and arranged a plunge pool in the garden!

One useful trick I have discovered is to hang around and to pant heavily when the pack is eating ice cream. The alpha female is a particularly soft touch and I usually end up with the chance to at least lick the stick. Another treat is to ask for ice cubes, which are cool and really crunchy. Yum!

Speaking of yum, you will be pleased (but not surprised) to hear that I was successful in this year's village fete 'catch the sausage' competition. Although it should really have been called 'eat the sausage' in my case. And the prize was… a dozen sausages! Now there's joined up thinking…

While on the theme of food, I thought I would share with you an anecdote about one of my good friends, Stanley. Stanley is a slightly eccentric character and many would say that he is one sandwich short of a picnic. The picture tells it all!

We often take our alpha females for lovely walks in the woods, but last week he was in disgrace. Apparently his pack had enjoyed Sunday lunch and had retired to the main kennel area for a siesta. After a couple of hours, the alpha male returned to the kitchen to do the 'washing up' but couldn't find the leftover chicken. On further inspection, he also couldn't find the roast potatoes, although he did discover a small pile of rejected spinach on the floor.

It eventually transpired that, feeling left out and a little peckish, Stanley had decided to help the 'washing up' process by cleaning some of the plates. And no one thanked him for it!!!

To add insult to injury, Stanley was apparently in trouble again the next day. By then, the chicken carcass and potatoes had worked their way round his digestive system and he was producing large volumes of highly noxious gas. But no one in that day's Book Club believed the alpha female's protestations that "It's the dog"!

Apparently, Stanley remains very much in the dog house.

I hope you all remain well, and free from unfair accusations.

Elsa xx

Better to Travel than to Arrive?

Dr Peter Andrews is being rather philosophical in this edition of Renality, referring to the trials and tribulations of working within today's NHS. I am using the same headline as Peter, but for a different reason.

The journey in this case is the one many of you have three times a week, getting to and from your dialysis sessions. We know that the journeys can be more arduous than the treatment and as such, we continue to seek ways to improve the service we provide.

Following the withdrawal of G4S and the subsequent interim provider ATS, we have almost completed a tender process to appoint to a new transport provider for the Trust and specifically for Renal Services.

We received nine submissions from a range of different transport suppliers, including some local taxi firms. The evaluation panel included managers, clinicians and a patient representative. One of the key requirements of the new service is referred to as '30-30-30'. This means that we will expect patients to arrive for therapy no more than 30 minutes early and have to wait no longer than 30 minutes following therapy before starting their journey home. Also, we would not expect your journey to be any longer than 30 minutes on the vehicle (unless you live more than 6 miles from the (unit).

We split the tender into several 'lots', which means we can choose the best supplier for each unit. We will be able to announce the preferred supplier(s) in the next couple of months with a proposed implementation date in the first quarter of 2018.

There is of course one way you can stop relying on transport altogether; you could bring the dialysis to your home. If you have ever wondered about home dialysis we would love to talk to you about the options you have available. It is not suitable for everyone, but can be clinically beneficial and give you much greater freedom as to when you receive therapy.

If you want to know more, please speak with your dialysis nurse, centre manager or consultant or simply drop me a line at **stevesimper@nhs.net** and I will ensure someone contacts you.

Does DNA stand for National Dyslectic Association?

Despite the joke above, DNAs (or Did Not Attends) is definitely no joke. If, for whatever reason you do not arrive for your dialysis session and do not cancel within 24 hours the Trust is still charged for your session but we of course receive no income. Therefore, we lose as much as £70k each year due to patients failing to arrive for their session without notice.

We understand that there may be many reasons for you being unable or unwilling to attend some of your dialysis sessions. We simply ask that you inform your centre manager in advance so that we do not incur an unnecessary charge. Just think what we could do with the £70k?

Sentenza (Angel eyes)

Angel Eyes was the 'Bad' character in the film referenced by Dr Andrews – The Good, the bad and the ugly.

The bad estates that Peter refers to is indeed one of the carbuncles on the otherwise fantastic complexion that is Renal Services. Nevertheless, not for too much longer. You will know that we have plans to move the dialysis units at St Helier and Croydon into different locations within the respective hospitals, providing fantastic new state of the art units for those of you who attend these centres.

The inevitable delays in preparing the sites does mean that we now have expected opening dates in July 2018, a few months behind schedule. However, this has given us more time to review and tweak the plans to ensure we have the very best configuration of clinical and non-clinical spaces. We are grateful to the staff and patient representative who have tirelessly and meticulously amended the layout to maximise this once in a generation opportunity to improve our environments.

We are also hoping to diminish the impact of Sentenza, turning Bad into Good by participating and taking a lead in a new Renal Clinical Network, including Epsom and St Helier, St George's, Guy's and St Thomas and King's College

Hospitals. This is with the aim to work far more collaboratively than ever before to improve existing services and to ensure we can continue to improve services within a changing healthcare landscape.

Keeping Warm

Several months ago, we, with the support of the KPA, provided some of you with your own fleece blanket to bring with you when you come for dialysis. All of you have welcomed this change so we have decided to roll this out to all of our dialysis units. So look out for an early Christmas present from the KPA.

The Great Renal Bake-off!

In September, renal staff were invited to enter a cake into the Great Renal Bake-off. We had many fantastic entries and managed to raise a tremendous £224 for the Renal Research Institute.

Please visit: https://www.flickr.com/photos/vipdesilva/albums/72157685686857991 to see photos of all the lovely cake designs.

Talking about Research, we are leading the way on £3.9 million research trial

Renal have had many good results recently! A team of researchers led by our very own Dr Hugh Gallagher have been awarded a prestigious research grant of £3.9 million to determine whether aspirin should be prescribed to people with kidney disease to help prevent heart attacks and strokes.

Thought to be the largest study of its kind, the team will look to recruit 23,000 people across the country in order to determine if a low dose of aspirin should be used to prevent a first heart attack and stroke in people with chronic kidney disease.

Dr Gallagher explained: "It is estimated that there are at least five million people with chronic kidney disease in the UK, and although only a minority will develop kidney disease of such severity that dialysis or a transplant is required, all are at increased risk of cardiovascular disease (a general term for conditions including heart attack, angina and stroke).

"Finding new ways to reduce cardiovascular risk is perhaps the most important task facing renal researchers internationally. Aspirin is a familiar and inexpensive intervention and there is some evidence that people with kidney disease may particularly stand to benefit, but there is also the potential for extra risks of bleeding. We believe that around one million people with chronic kidney disease who do not have cardiovascular disease are now prescribed aspirin to prevent a first heart attack or stroke whereas three million are not, reflecting the current uncertainty."

"To answer the question about the effectiveness and safety of using aspirin in this group, collaboration is necessary between Public Health, Primary Care and kidney specialists. We are working closely with Professor Paul Roderick (Public Health) and Professor Michael Moore (Primary Care) at the University of Southampton as well as other experts from Primary Care, Renal Medicine, Cardiology and Gastroenterology."

"This trial should give us the evidence required to prove one way or the other whether we should be offering aspirin to our patients with chronic kidney disease to prevent heart disease."

We are all so incredibly proud of Hugh and the research team for securing this vital funding. This debate around aspirin for patients with chronic kidney disease has rumbled on for some years, with doctors up and down the country taking a different approach. We hope that this clinical trial will give us a clear answer once and for all, and we are absolutely delighted that Epsom and St Helier staff will be at the forefront of that work.

Recruitment is expected to begin in the summer of 2018, and the trial is scheduled to finish in 2025.

Welcome to Team Renal

Since the last edition of Renality we have welcomed many new people to the team but I want to introduce you to two staff with whom you are likely to come into contact.

Firstly, a big welcome to Laura Garbett who has taken up a new role as Out Patient Supervisor. Laura has already made many behind the scenes changes to improve services and has now ordered uniforms for all outpatient staff.

Meheret Teferi has only just started with us at the beginning of October. She Joins Celia Eggling to provide a social work and counselling service. Meheret is a much needed addition to the service and we look forward to working with her.

I hope you all have a lovely autumn.

Message from Jennie

Well I start my discussion with you this time feeling rather jealous of Elsa who not only gets sausages for lunch but also has an ice desert. My owner tells everyone that I am a working dog (whatever that means) and I cannot eat treats! If working means no treats then I am rather excited by some news I recently heard about guide dogs being allowed to retire at age 10.

I am reliably told by a lady called Vet Anne Arian that I will be ten next February on another lady's birthday – someone call Val N Tine. I cannot wait if this means I get to go to country fairs and catch sausages – I wonder how fast they run. I hope I am not too old to catch one?

What confuses me is why Elsa is already retired, as she is still very young. I am still unsure what job she actually has, as it seems she spends most of her time walking, swimming and eating unhealthily.

I have started spending the weekends with my owner's daughter. She has her own dog. I think her name is Sue Luki or something similar. She is a big but rather scrawny looking thing, but harmless enough and lets me share her water bowl. I do not think she has ever worked before either and looks incredulous when she sees me wearing my harness!

Talking about working dogs, a police officer arrived outside the police station at the end of his shift and opened the van doors to reveal his K-9 co-worker.

A boy asked him: *'Is that a dog you have there in the back of your van?'.*

'It sure is' replies the policeman.

Looking puzzled, the little boy asks: *'what did he do wrong?'.*

Byebye for now.

Steve Simper,
Divisional General Manager

NEW CLINIC for patients with Autosomal Dominant Polycystic Kidney Disease!

Lead by Dr Rebecca Suckling and Dr Anne-Marie Habib

We have started a new clinic at the Renal Unit for patients with Autosomal Dominant Polycystic Kidney Disease (ADPKD). This inherited condition causes small, fluid-filled sacs called cysts to develop in the kidneys, as well as in some other organs such as the liver. The kidneys get bigger and can cause problems due to their size and the space that they occupy. For most people, this will occur when they are between 30 and 60 years of age. Less commonly, children or older people may have noticeable symptoms as a result of ADPKD.

As the cysts develop the kidneys are not able to function as normal. They can deteriorate until so much function is lost that kidney failure occurs. Until recently, other than treating high blood pressure, there was no treatment to slow down the development of kidney failure. However in ADPKD the kidney is very sensitive to a hormone naturally present in the body called vasopressin. A new medicine called Tolvaptan can block this effect. This slows down the growth of kidney cysts and reduces the progression of kidney failure. Tolvaptan is the first therapy aimed directly at slowing down the underlying processes leading to kidney enlargement. The treatment is effective in people where kidney blood tests show that there is a high risk of progressing to kidney failure but who do not have very advanced disease. There are very strict criteria for prescribing the medication and it is only available from the hospital, not your local doctor or chemist.

The clinic is held in the Renal Unit at St Helier Hospital and we are happy to see anyone if their usual nephrologist feels that they may benefit from this new therapy. We will confirm that you are suitable for treatment and monitor of the effect of Tolvaptan including side effects. Please ask your nephrologist about the clinic if you think that you may be suitable for this clinic.

The 100,000 GENOMES PROJECT

This is a national, NHS funded project which will sequence 100,000 genomes from around 70,000 people. This project is looking for people who have rare diseases and this will include most people who have an inherited kidney disease.

100k Rare Disease Team

Your genome consists of all your genes (about 20,000) and all the genetic material surrounding the genes, for which there is, as yet, no known function.

The aim is to create a new service for the NHS which will be called genomic medicine and will transform the way people are cared for. People may be offered a diagnosis where there wasn't one before. In time, there is the potential of new and more effective treatments. In addition we hope to be able to provide advise on the risk of recurrence of a condition and this will help people to understand the options for their family.

The project will also enable new medical research. Combining genomic sequence data with medical records is a ground-breaking resource. Researchers will study how best to use genomics in healthcare and how best to interpret the data to help patients. The causes, diagnosis and treatment of disease will also be investigated. We also aim to kick-start a UK genomics industry. This is currently the largest national sequencing project of its kind in the world.

St Georges Hospital has a leading genetic department which covers the same area as the renal unit part and are looking to include patients from South London, Surrey and Sussex.

If you have been diagnosed with any of the following conditions you may be able to join in this project.

- Proteinuric renal disease
- Familial haematuria
- Atypical haemolytic uraemic syndrome
- Primary membranoproliferative glomerulonephritis
- Cystic kidney disease (Adult or Juvenile Polycystic Kidney Disease and some other conditions)
- Congenital Anomaly of the Kidneys and Urinary Tract (CAKUT) which includes conditions such as posterior urethral valves, vesicoureteral reflux
- Renal tubular acidosis
- Renal tract calcification (or Nephrolithiasis or nephrocalcinosis)
- Extreme early-onset hypertension
- Unexplained kidney failure in young people

To take part a member of the team would need to meet with you to go over the consent form and to obtain a blood sample. The team are coming to the Renal Unit to the Progressive Adult Polycystic Kidney Disease clinic but also can see you close to home as we go to St George's, Worthing, East Surrey and Frimley Park Hospitals. Occasionally we are able to offer home visits.

If you think you might be a suitable candidate you can contact us directly on the details below or ask your consultant to refer you to us or to ask Dr Suckling and Dr Habib to pass on your contact details as they are in contact with us.

Our contact details are:

Glen Bric
glen.brice@stgeorges.nhs.uk

Alena Marynina
alena.marynina@stgeorges.nhs.uk

Gaya Connolly
gaya.connolly@stgeorges.nhs.uk

Telephone - 020 8672 1255 Ask for Bleep 6170

Dear Kidney Research Funder,

The Annual General meeting of the Kidney Fund, Chaired by Dr David Makanjoula, will have passed by the time that this edition of Renality is published.

I do hope that many of you knew about the meeting beforehand and were able to attend. Last year, in October we enjoyed an inspirational talk from our General Manager, Steve Simper. This year we were very pleased to get Dr Hugh Gallagher to speak to us about his National work in helping to identify those people at risk of renal insufficiency.

2018 will see the 20th anniversary of the opening of Our Renal Research Institute at St Helier. We are planning several events to mark this milestone. Peter Andrews has arranged that St Helier will host the annual meeting of kidney doctors and nurses from the South East of England. That will attract our colleagues from Brighton and Portsmouth and Canterbury and St Thomas's, St Georges, Kings and Guys.

In the morning we are inviting all the graduates of the Institute to attend and present a summary of their clinical and research work since the left the Unit. The afternoon will comprise a clinical and scientific meeting. This is always a great forum for all to exchange ideas about new trends in Kidney Failure diagnosis and management and treatment.

Those of you who visit St Helier regularly will have noticed scaffolding everywhere and the investment of very considerable sums in our infrastructure. Management at St Helier is now directed by two of the Unit's bright stars, Dr James Marsh and Dr Simon Winn. Major improvements in National waiting time targets have earned our parent hospital National attention and will, we hope, go a long way to helping our future stability.

This last period has seen the usual fund-raising efforts by many supporters. We are so grateful as always for this. We have also welcomed new blood onto the Executive committee. Chris Howard has injected many new ideas and organised excellent Magic evenings. Nick Ford and his family have organised two Gala Dinners boosting income.

More recently we have welcomed Councillor Jean Crossby to the committee. This is rather a boost to the Fund as Jean is the Mayor of the London Borough of Sutton this year. Jean is very well known locally as Councillor for St Helier Ward, LBS, and she has done much to support the whole hospital over many years.

Very best wishes to all our supporters.

Dr Michael Bending
Chairman, The Kidney Fund

Prudential Ride 100

We had six riders competing in the Ride 100 this year. Five men and one woman all of whom were members of the Crowborough cycling club.

We went to watch and to cheer them on at the point where the Boxhill Road meets the Headley Road at Tadworth, right on a hairpin bend. It was very exciting to watch them all coming down the hill and around the bend. However due to the road being wet very soon after our arrival we saw the first of many spills with cyclists going too fast and they and their bikes parting company. Fortunately they all got up, dusted themselves down and with a quick check of the bike were off again. One cyclist had a puncture and a very kind onlooker quickly gave him a spare inner tube and helped him affect the repair, it was very speedily done, rather reminding us of the Formula 1 pit stops.

We have eight places for the 2018 ride and are hoping to fill them all, GET CYCLING.

Maggie Sammonds

I have the pleasure of sending a cheque for £785.00 the result of the Lucky Bags stall my friend Pam Hibbert and I ran at Rowledge Village Fair (near Farnham) on Spring Bank Holiday Monday.

The sum reflects the generosity of those who have donated prizes to fill our bags and the interest and demand from our regular 'customers' who have supported us over many years and which has been reflected in the sums we have managed to raise specifically for Kidney Research Projects.

Kate Shipton

Staying Connected at SWTIRR

It probably won't surprise many of you that I am not a great fan of shopping but I have enjoyed the recent re-emergence of small specialist shops. Many many years ago when my father ventured south from the cold wet and wild lands north of England to what he considered the civilised world in London he would always visit a particular shop in Germyn street. Hilditch & Key made and sold only shirts. They were experts in their trade and well respected for it.

In 2002, when I first came to the Institute Dr Phanish started looking at a molecule called Connective Tissue Growth Factor - CTGF. It was a relatively new area of research in the field of kidney disease. He and I worked together on it for three years; we published couple of landmark papers and the subject matter became Phanish's PhD thesis. We were both aware that we only just scratched the surface. We continued over the years to learn more, increasing our knowledge and developing our expertise. Later Phanish and I supervised another junior renal doctor's PhD work on CTGF in the kidney. By the time you read this Dr Simon Winn – the current Acute Medicine lead at Epsom & St Helier- will have been examined on the work by 2 leading professors working in the field. As time went on it became clear that CTGF was one of a family of molecules, some with very different effects. In 2014, in recognition that SWTIRR had become the leading research centre in the UK investigating CTGF in kidney disease, we were awarded at £175000 grant to study CTGF, now called CTGF/CCN2, and its sister molecule CCN3.

We had hypothesised that CTGF and CCN3 had a kind of Ying Yang relationship and whether kidney scarring developed or not might be because of a change in the balance between the two. The work started well but after just under two years the research assistant working on the project left to seek his fame and fortune elsewhere. It is really difficult to bring someone new in at such a late stage and hope to keep the work flow going. In one of those unlikely strokes of extraordinary good fortune that have happened from time to time at SWTIRR we found Abi. Really I should say she found us. When I advertised for someone to come in for the final year of the project I received over 80 applications. Only one showed the initiative to come down and visit us at St Helier, find out what we do at the Institute and discuss the project. Abi wasn't unemployed or a graduate looking for her first job; she already had a job. I think it may have been the day of the interview that I offered her the job with us and I haven't regretted the offer for a single moment. Abi has been superb in verifying the earlier work and taking the work forward. In fact, considering that 12 months ago I was fretting that we might not be able to finish the project and now I'm planning a follow-up application to Kidney Research UK; I should say Abi has done us proud. On the subject of CTGF, I should also tell you that Phanish and I have just been involved in submitting a formidable 5 year project grant application to the MRC; keep your fingers crossed for us.

Funding = Research
Research = Cure

When I entitled this article "Stay Connected at SWTIRR" I wasn't just talking about Connective Tissue Growth Factor. As much as I admire the small specialist really in the world of21st century scientific medicine success lies in bigger networks. Indeed, the follow-up application to the work Abi's currently doing would be a collaboration led by us but including Imperial College and a nephrologist in Taiwan; two other members of the international consortium I was involved in setting up to investigate new therapies for diabetic kidney disease. And the big MRC grant application Phanish and I are involved in is in partnership with Professor Christer Hogstrand from the Department of Diabetes and Nutrition at King's College London. Become specialist, develop expertise at home and then share it far and wide to form networks, collaborations and consortia. (*After all you may buy your shirts at Hilditch & Key but you need to go to Gieves & Hawkes, if you want the trousers and jacket to make the whole outfit.*) This is how I believe we can carry out good research, address the big questions in medical research and find treatments and cures for problems like kidney disease. I still firmly believe:

Dr Mark Dockerall

The Renton Dance School in Farnborough held a show at the Princes Hall Theatre Aldershot back in May.

Lorraine Willis a dance teacher whose husband has recently gone back on dialysis was part of the show that was made up of 3-18 yr olds. A great success a cheque for £1000 was presented to the Kidney Fund.

Renton Dance School, Farnborough

Scott Wright Morrow

22 November 1978 - 12 April 2017

As reported in the June edition of Renality we sadly and suddenly lost our son Scott.

The family requested no flowers for Scott's celebration.

Scott was the most amazing, loving and thoughtful son, brother, uncle and friend to so many it was with so much pride that on 10 August at a gathering of his family and friends we were able to present cheques to SW Thames Kidney Fund and Juvenile Diabetes Research Foundation, each for £3,045.37. This will make a huge difference to the research funded by both charities and will affect the lives of many for years to come.

BARCLAYS

Pay South West Thames Kidney Fund

Date 10 August 2017

Three Thousand+Forty Five Pounds 37 only

Only

£3045·37

In Memory of Scott Morrow

22·11·78 – 12·4·17

Cheque No. Sort Code Account No.

The Proud Morrow Family

(NB. The actual money and associated Gift Aid was transferred directly to each charity bank account by Virgin Giving)

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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.

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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.

British Transplant Games 2017

For many years I have reported on the Transplant Games but this year the Games Report/ Experience is provided by a competitor, Moray Laing, and a volunteer, team supporter and partner of Jonathan Douglas-Green, Hannah Dick.

For a flavour of the Games a short film of BTG 2017 is available for you to view and download on the link below, may I urge everyone to watch it – it is informative and inspiring:

https://drive.google.com/file/d/0B273dJ-s4zlqbVZPVUdjNm1aU1k/view

And if it encourages you to participate either as a competitor or supporter, the 2018 Games will be held in Birmingham 2-6 August – plenty of time to train and book time off!

Thank you SH&SKPA for the tremendous support the Team receive each year, I know it seems automatic, but we ALL really do appreciate your support each year.

Graham Morrow – *Team Manager*

A Competitors' Perspective

The small but intrepid St Helier Transplant Games team made a longer than normal trek to this year's British Transplant Games which were held in North Lanarkshire, Scotland. With fairly predictable weather, this was a far wetter weekend than normal however the enthusiasm of the team was not dampened with what is becoming a regular high standard of commitment to representing the hospital, ably and vocally supported by families (including our one amazing live donor Vanessa Douglas-Green) and friends who braved the elements.

The Games are an annual event open to post Transplant patients and now live donors. It represents many things, a celebration of life and achievement in recovering from serious illness, a chance to promote organ donation nationally and an annual re-union with other similarly impressive athletes and competitors of all ages from 3 to 82 who have become firm friends over the years.

Sports range from archery, darts, bowls, snooker, cycling and fishing to all racquet sports and a full schedule of athletic events. You don't have to have been a serious athlete pre-transplant to take part although those who do perform to a high standard at the British Games are eligible for selection to the Great Britain team in the World Transplant Games. We currently have a World Champion athlete in the St. Helier team!

Back to the Games this year, the team kept up its impressive record of all team members winning medals.

The total medal haul was 7 gold 3 silver and 5 bronze. If the ratio of medals per competitor were a factor in deciding the overall winning team at the Games we would certainly be up there somewhere.

Thanks as always must go to Graham, Angie and Craig Morrow who together keep the team going despite some dwindling numbers in recent years. They are collectively the rock behind the team and particularly this year in light of the tragic loss of their son and brother Scott deserve the utmost praise and gratitude of the whole team. I can safely say one behalf of the team that all medals won this year are dedicated to Scott's memory and also to our former team member and friend Ewa Skonecka who sadly passed away recently.

Despite being a small but successful team, we are very keen to increase our numbers for next year's Games which are being held in Birmingham. If you are interested in competing at the Games and joining what is a very friendly and welcoming team, please arrange to contact Graham Morrow through your consultant or the Transplant staff nurses at St. Helier when you are next at a clinic. Who knows, you could be in Team GB before you know it!

This year's team comprised Craig Morrow, Kevin Trimming, Moray Laing, Jonathan Douglas-Green and Louise Cook and our competing donor member was Vanessa Douglas-Green.

Moray Laing

And a Volunteer & Supporter's View

This was my second year volunteering at the Transplant Games and as last year, I thoroughly enjoyed it. My partner, Jonathan, has competed for the last three years and I can see that he really benefits from participating - both in terms of motivating himself to do more exercise throughout the year, but also by meeting people who have been through similar health experiences as he has.

I volunteered at the virtual triathlon first, which was great fun, cheering on people of all ages and abilities, and as a social event, those who had not had transplants were also able to compete. It was the first year this event was held and I hope they continue it. The next day I volunteered at the children's obstacle relay, which is an amazingly uplifting experience, seeing children who have been through so much, running around really enjoying themselves, and celebrating that they were able to take part, no matter how fast slow they were.

I shall be volunteering again next year, as it is a fabulous event to be a part of.

Hannah Dick

Kidney Fund

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Ewa Skonecka

24 December 1963 - 23 August 2017

It is with great sadness that I have to inform you that after a stay in St Helier Ewa was transferred to Kings ITU where she passed away 23 August.

Ewa was already a member of the Team when Craig, Angie and me attended our first Transplant Games in Liverpool in 1997 and she continued to represent the hospital until 2006 when work and health issues took over.

She organised fundraisers for the Team at her local, The Ship, Croydon and continued to support SW Thames Kidney Fund by making and selling jewellery.

After dialysing for a number of years, Ewa received a kidney this year donated by her friend but had been unwell for some time with an infected gall bladder.

Ewa's funeral took place in Poland - our sincere condolences to Ewa's family and partner Tony.

Graham Morrow on behalf of St Helier Transplant Team, current and past

If you would like to volunteer some of your time to assist with the event, please send an email to info@kidneyfund.org.uk or call 020 8296 3698

DRAGON BOAT RACE 16th July 2017

I arranged to pick up Sarwat at 7.30am on Sunday morning to set up for the Dragon Boat race. I looked it up the internet and saw it was in East London – phew I was going to have to turbo drive to get there for 8.30am so I pitched up at her house at 7am – how to spook an efficient person – be more efficient than them. At this point I found out that the boat race was at Kingston – opps!

We set up the stall and waited for our two finely chosen teams to arrive. We had two boats – one headed by Dr Mark Dockrell and the other by Dr Pauline Swift.

In the mean time we gave out balloons to children with the Kidney Fund logo on it – every single child had such a look of delight as they received their balloon – if only us adults were so easy to please. The tombola stall had a steady stream of people out for a stroll on a Sunday afternoon. Dr Makanjoula's wife – Carol was at the helm, calming organising the stall.

For the first time we did henna tattoos painted on people's hands – Sawat's daughter Sophie drew a range of designs for whatever people wanted.

Nimmy (St Helier Renal nurse) arrived with home cooked food to sustain us.

Our boat teams were called and we all pilled in – 16 to a boat. – Doctors, Research Scientists and patients and relatives. Anna's (Renal nurse) husband volunteered to be the cox on one of the boats. As he was over 6ft he perched himself on a very tiny seat looking like a giant leprechaun. Dr Phanish's daughter was the other much more traditionally sized cox.

We gave it our best – but I don't think that is saying much, but we did have a blast.

The team of burly men who won it, did it in half the time and as they would make a pack of rottweiler dogs look cute and cuddly we had to just be grateful we did not capsize.

As the day was coming to a close our volunteer, Mary, was selling some of the fine goods to some of the Doctors. Now, as she is a midwife she is used to finely timed deadlines and she was focused on her task. I waited as I watched the Doctors realise it wasn't IF they were going to buy these goods but just WHAT they were going to buy.

They walked away with delightful goods for their better halves, Mary had met her deadline and the Kidney Fund coffers had been increased - perfect result.

Our thanks go to Carol for her unflappable organisation, Nimmy for her superb shopping skills, Anna for pitching in and Mary for helping from dawn to dusk.

Next year we will have 2 boats, 32 spaces in July– so if you interested we will give out details via the Renal group email.

Helen Green
Treasurer for the Kidney Fund

Camberley Car Show

Saturday 19th August 2017

Right in the heart of Camberley, hundreds of beautiful vintage vehicles - cars, bikes, trucks and spectacular vehicles were displayed - all for the public's delight.

Glenise Bonner had a successful kidney transplant many years ago, donated by her sister. Her husband Ken, a vintage car enthusiast organises this car exhibition every year with the proceeds going to The Kidney Fund.

The event was on from 10am to 5pm. We were overwhelmed to see so many vehicles. It was the car equivalent of an exquisite box of chocolates.

There were beautiful cars from the turn of the century to the fifties - that oozed glamour and elegance. Just driving around the block in one of those cars would be an incredible experience.

There was a Chitty Chitty bang bang car - the squeals of delight from children and adults was about equal. Sarwat lived in Germany and has never seen the film Chitty Chitty Bang Bang or Mary Poppins - I have never met somebody who has never seen those films - she doesn't realise what a gaping experience in her life this is!

A Jordan Grand Prix EJ11 racing car was being showed and you can sit in the seat and have your photo taken. Well there was no way my hips were going to get in that snake hipped pit - but strangely this car, worth six figures, was a child friendly height and parents popped their bewildered bundles of delight into the seat for a photo opportunity.

Two 6ft burly lads drove around the streets in a tiny circus act car entertain all. A couple walked around the town in 1940's outfits - the man had a spivy outfit and rattled out jokes faster than Bruce Forsyth to entertain us and his wartime dressed girlfriend looked divine. Cars that have a place in history breaking speed records sat quietly next to modern day Porsche's, Ferraris and BMW's.

There was an aqua/land car. Funny cars such as Mutt Cutts - covered in Fur.

Ed China, TV presenter had his photo taken with car enthusiasts.

There was a whole section for vintage bikes and trucks.

All the owners sat with their beautiful cars all day and were happy to answer any questions. It was like watching a whole tribe of perfect marriages - whilst your other half may take up a ridiculous amount of your money, break down at the most annoying time and use up all your time and energy - you still think they are the most fabulous thing going!

We were so captivated that we stayed to the end. The cars drove out in a procession at around 5pm. Ken shook the hand of every car owner as they drove past. The cars that so patiently stood to attention all day roared like a pride of lions as they left the town.

The whole Bonner family so brilliantly organised this day and they had so many great volunteers helping out.

So thank you to one clan - the Bonners, one tribe - the Vintage car owners, and all for one charity - The Kidney Fund.

Helen Green,
Treasurer of the Kidney Fund

Camberley CAR SHOW 2017

Raising Funds for Kidney Research

The sixth annual Camberley Car Show took place on Saturday 19th August 2017 with over 200 vehicles, of many makes, types and eras on static display in and around Camberley Town Centre's streets which, to host the Event, were closed to all other traffic for the day.

Since it's inception the Show has grown year on year and is now hailed as 'Camberley's Event of the Summer' attracting huge crowds to the town. Initiated by Ken and Glenise Bonner the Event is organised to raise money for Kidney Research following Glenise's very successful kidney transplant in 2010 and is simply an attempt 'to give something back'.

The total raised this year amounted to £11,804.51 of which £9,279.51 went to 'The Kidney Fund'. The additional £2,525.00 raised by 'Sporting Bears' at the Event went to 'Kids Kidney Research'. This brings the total collected over the past six years to £41,912.93 with every penny raised donated to kidney research.

Many friends and family members and a number of kidney patients and their partners/relatives once again gave up their day to help out at the Show, these included Martin and Cynthia Banton, Chris and Clare Barrett (and Chris's parents), Angie Morrow, Jackie Magness, Annie yuk ying Tse, Alexia and Christopher Ross-Lewin - so grateful thanks is due to all for their very valued help!

In addition to the fantastic selection of vehicles, there were street entertainers, roving musicians, free face-painting for children and of course, being a town centre location, lots of shops, restaurants, coffee bars and pubs on hand making it a great, free, family fun day out with a real carnival-type atmosphere.

For further information or for images from previous years, see - www.camberleycarshow.co.uk or e-mail kenbonner@btinternet.com

THE KIDNEY FUND LOTTERY

The last 6 months winners are:-

07/04/2017	101105	Horley	£160.50
14/04/2017	101183	Guildford	£160.50
21/04/2017	101234	New Haw	£160.50
28/04/2017	101083	Guildford	£161.50
05/05/2017	101071	Weybridge	£162.00
12/05/2017	101309	Merstham	£161.50
19/05/2017	101080	Fleet	£161.50
26/05/2017	101012	Farnborough	£161.50
02/06/2017	101276	Kenley	£160.50
09/06/2017	101335	Selsdon	£160.50
16/06/2017	101338	Tolworth	£161.00
23/06/2017	101055	Carshalton Beeches	£158.50
30/06/2017	101286	New Haw	£159.00
07/07/2017	101192	Bracknell	£160.00
14/07/2017	101104	Camberley	£160.00
21/07/2017	101156	Caterham	£160.50
28/07/2017	101238	Addlestone	£161.50
04/08/2017	101212	Sutton	£162.00
11/08/2017	101131	Farnham	£164.00
18/08/2017	101226	Cinderford, Glous.	£161.50
25/08/2017	101016	Wallington	£161.00
01/09/2017	101279	Farnborough	£161.50
08/09/2017	101038	Walton on Thames	£161.50
15/09/2017	101118	Farnborough	£161.50
22/09/2017	101130	Aldershot	£161.50
29/09/2017	101316	New Malden	£159.50

We have now paid out well over £45,000.00 in winnings since we started in July 2010 and have been able to contribute even more than that amount to The Kidney Fund.

If you're not already a member then for just £1.00 a week (you can have more than 1 entry if you want!) you can join in the fun while contributing at the same time by sending me the completed mandate from the back page.

A message from your Chairman

I am nearing the end of my eleventh year as Chairman and I am more than happy to continue for another year. I hope that the KPA members, patients and the renal unit staff are pleased with the work that the KPA's Committee has done on your behalf over the last year. On a personal note I would like to thank all of the Committee members, all of our Volunteers including those on the Servery together with the Renal Unit staff all of whom provide invaluable support to the KPA throughout the year.

St Heliers HD dialysis unit will move to a brand spanking new unit in the main hospital in the spring of 2018 and the new Mayday dialysis unit should open by late summer of 2018 so patients of both units can look forward to much more comfortable surroundings in the not too distant future with some nice air conditioning and TVs!!!!

The KPA has over 870 members so we're kept pretty busy dealing with the many and varied requests which we receive from both patients and the renal unit. As in previous years I thought it would be good to show how we have distributed our funds during the past year. These include

- 5 Profiling beds for St Helier and Satellite units
- 16 new TVs for Kingston Satellite & 2 TVs for St Helier together with aerial and power installations.
- ECG machine for St Helier.
- Renal Overlays for St Helier and its Satellites.
- Exercise Equipment and Stress Balls for dialysis patients
- Fleece Blankets for Dialysis patients
- 6 Laptops and cows for St Helier wards and Specialist Nurses
- 8 Dripstands
- Renal bedside folders and shared care pamphlets
- Financial assistance with Holiday Allowances, Travel Benefits and Amenity payments to a higher level than any previous year.
- Financial support of the participants in the St Helier Team at the Transplant Games
- Supporting buffet lunches and PEP's

This has all been possible due to the generous donations that we have received and fund raising events reported upon in previous editions.

With this edition you will find our Grand Draw tickets and whilst I know that times are really tough for some of you could I please urge you to purchase them if possible as this is one of our main fundraisers and makes a huge difference to our funds and our ability to continue to help the Unit, it's Satellites and its Patients.

If you feel that you are unable to purchase them can I please ask you to return them to the address printed on the tickets as we had requests for additional books last year?

As there is no longer a St Helier patient lunch, the draw will be made at the renal unit on Tuesday 12th December during our Committee meeting; we'll be asking the renal staff and dialysis patients to draw the winning tickets.

Committee/Patient Representatives

The KPA Committee has gained a couple of new members over the last few years but it would be lovely to have every Satellite represented. We still need reps for Kingston and Sutton.

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 normally on the first Tuesday of the month.

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

I think that is all I have to report on so may I be one of the first to wish you all a very Happy Christmas and a happy and healthy New Year.

Best Wishes
Dave Spensley, *Hon. Chairman*

ST HELIER AND SURREY KIDNEY PATIENTS' ASSOCIATION

10TH ANNUAL GOLF DAY

What a fabulous day, warm, dry, really well attended and we made lots of money to help patients.

On Friday 16th June 62 golfers took to the fairways of the lovely 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 £4300.00p excluding Gift Aid.

We had some fabulous auction lots but undoubtedly the 2 star lots were golf vouchers to play Sunningdale & Walton Heath, the bids for these two raised £1650, amazing bids, I'm sure you'll enjoy your days at 2 fabulous courses.

Thanks to Alex Stead for providing a fabulous range of golfing equipment for our auction and raffle.

The overall winner of the day was Jake Olekszy with scoring 39 points (playing to 3 under his handicap). Mike Sealey took the Congu trophy (for players holding an official club handicap) with 39 points, 3 shots better than his handicap, well done to all. I just have to give a special mention to Alex Gurney who scored a spectacular hole in one on the 12th hole.

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

- Paul Connolly and Fay Eves for organising the event and the auction prizes.
- Di, Anna, Rachel and Kevin for helping on the day and,
- Ghansham Patel, our Treasurer for keeping track of our finances.

In addition my thanks must also go to the following:

- Every player on the day who turned out despite some dodgy weather forecasts, boy did those forecasters get it wrong!
- The members of the Becketts Barn Golf Society and the SandM Golf Society who attended
- Ivor Connolly who collated the score cards and handled our auction and squeezed almost every last penny out of people!!!!
- Milford Golf Course, its members, General Manager Steve Harrison and the Catering & Waitressing Staff for their welcome and hospitality

Everyone went out of their way to help and we've already booked next year's event, Friday 15th June 2018.

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

Members and Friends of the KPA would like to offer condolences to Mrs June Arnold following the death of her husband Vic .

Mr and Mrs Arnold has kindly donated numerous hand made characters over the years to the KPA.

Thanks and appreciations are sent to Mrs Arnold for all their hard work.

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
- R Collyer
- I Murrey
- S Choudhury
- Roffe Swayne Chartered Accountants

KPA Memorial Donations…

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

- Brian Rutherford
- Dakshaben Patel
- Joyce Austin
- Lisa Hill
- Victor Lewis
- Ronald Rance
- Yiu-Ting Kuet

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The Kidney Fund

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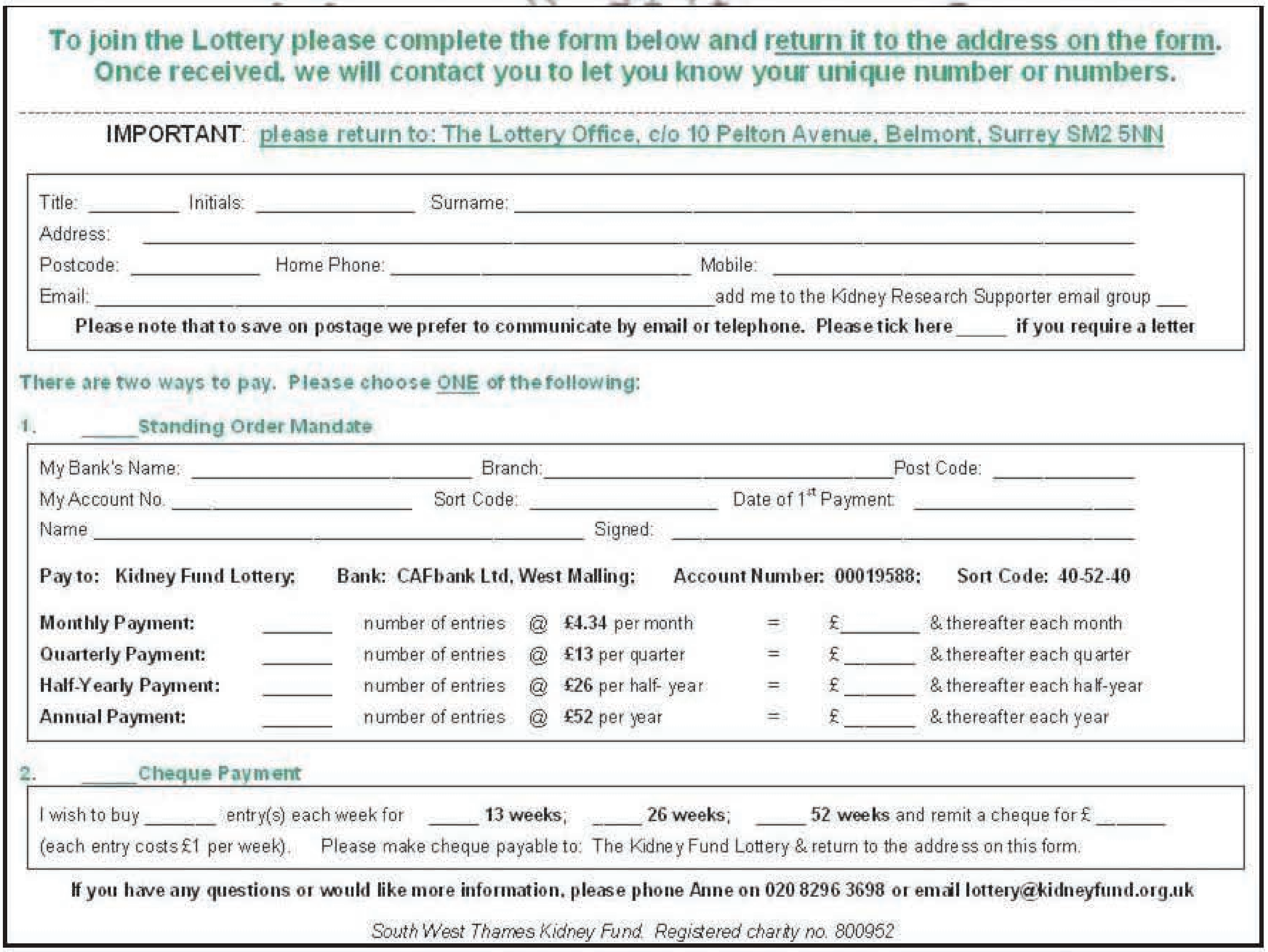

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