

WHISPERS

kidneysforlife.org

Spring
2018

**WHAT WE DO
WITH YOUR
MONEY?** Page 15

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**...AND MUCH
MORE**



OUR £10,000
FUNDRAISING CHAMPION!



HELP MAKE IT HAPPEN

Charity number 505256

WHISPERS

WE'D JUST LIKE TO SAY...

THANK YOU!

Your help and support enables us to continue with our life-changing research into kidney disease. A donation, of whatever you can give, brings us one step closer to making a kidney, for life, a reality, for our patients. Your time is also incredibly valuable to us, because, without you, we couldn't do all of the things that we need to. **Thank you.**

MMU

In February students from MMU organized a "Take me Out" Night in aid of Kidneys for Life. It was an extremely fun event thanks to great teamwork, a fabulous compere and hilarious contestants. **They raised over £700 for Kidneys for Life** as part of their Event Management course. Many Thanks girls and Well Done!



HALLOWEEN FANCY DRESS PARTY

We would like to thank everyone who came to our Halloween Fancy Dress Party in Oct at Houghend Centre. It was a great night, the kids looked as though they were really having fun, all the fancy costumes were amazing, everyone was dancing and having a go on the tombola, the DJ was good fun and played dancing games with the kids. We would like to say thanks to everyone who gave us some super prizes for our raffle which we did fantastic with and also thanks to the staff at Houghend who decorated the room and provided the lovely food. We would also like to thank Adele Adetoro, Annette Strong and Bernie Boruch for all their help in getting the party off the ground.

Finally we would like to let everyone know we actually raised £1,500 which was fantastic so thank you again to everyone who came and supported Kidneys for Life.





MILLIE MAE EMBARKMENT

Huge thank you to Millie Mae's Embarkment for their donation of £1,000 presented by Allison Sherrington. More amazing though is that over the past five years they have donated £22,683.63 to Kidneys for Life an amazing feat by all involved including Allison, Bev, Sharon, Ameer Burgess, Millie Mae, Lee and everyone who has supported the team over the years raising over £92k for good causes.

Well done from all at Kidneys for Life.

**£1,000
DONATION**

CHRISTMAS CARDS

**£7,350
RAISED**

A huge thank you to all those that purchased our Christmas cards last year which raised over £7,350.



DAVID EDWARDS

Took part in the Chester Marathon last year and **raised over £1,450** which will help support the Bladder Exstrophy Team's Children's Christmas Party last year.



CHRIS MORELAND

Organised a motorcycle ride from the Windmill at Blackpool to Whitby last year and **raised over £1,180** for which we thank everyone who took part.



SAZIA DESAI

Has supported Kidneys for Life by taking part in the Preston 5K as she says "my husband received a kidney transplant back in April 2017.

We're grateful for the care and treatment received at MRI, much of which is made possible by the research carried out by Kidneys for Life. This fundraising effort is a way to say thank you to the amazing staff at MRI and give something back to help even more patients. This was the first time, our son, Zayd joined me on a charity run along with team members, Sabina, Sahuda, Anthony, Salma and my niece and nephew, Khadeejah and Issy. Since the operation, many people have shared their personal stories about their condition and experience of dialysis and kidney transplants, so we're hoping that a pound or two towards this cause will directly benefit people with this condition, now and in the future.

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PETER BAINES

Once again transplant patient Peter Baines has **raised over £3,250** for Kidneys for Life by organizing a cycle ride from Buxton to Stockport, finishing at his car sales business, Banks Lane Car Sales. Supported by family and friends, Peter enjoyed another great day. Massive thanks to Peter and his donor brother Steve for all their support.



THANK YOU!

CEREMONIAL MAYOR OF SALFORD

Councillor Karen Garrido, the Ceremonial Mayor of Salford 2016-17 raised funds for Kidneys for Life (along with two other charities) and together with the Charity Committee raised **£16,000** for KFL for which we are extremely grateful. Part of the funds raised was to fund chairs to be used by patients and also family and friends of patients on the Renal Ward to enable them to stay by the bedside of their loved one.



£100 DONATION



COLIN SMITH

From Altrincham ran his very first run for charity on Sunday 24th September in the Macclesfield 5km running for Kidney's for Life. Colin knew about the charity as a friend of his Mike Kewley, is a renal transplant patient at Manchester Royal Infirmary and decided to donate any funds raised to the charity. He was supported by his daughter Kirsten and completed the run in 47 minutes. His target was 55 minutes. A regular gym attendee he had been practising for the run over the last few months both in the gym and on the pavement. When he asked a young personal trainer at the gym how best to train for the run the trainers answer was that he thought he was too old to do it!! Well he proved him wrong. In total he raised £100.00 for the charity but it proves it's never too late to do something new.



EMMA PARKER

On Saturday 21st October 2017, the 'Tour de 500' team set out to raise money for Kidneys for Life and Ronald McDonald House Manchester. We know these charities help and support a huge number of families at difficult times. Our team of 12 riders; Nigel Adams, Charles Cambridge, Tom Cambridge, Beth Cambridge, Max Lilley, Mark Davies, Scott Corbett, Richard Maddocks, John Timbrell, Ruairi Farrell, Dermott Tobin and Andy Parker began cycling 500 km over a four day period from the historic walled city of Carcassonne to the beautiful coastal resort of Les Issambres in the south of France. Supporting them on this epic adventure are Phil Maddocks, Paul Tomkinson and Burnup Cambridge. The 'Tour de 500' Team completed this gruelling challenge, which was tough but spirits are high over the four days and they had many laughs along the way.

They have raised over £5,000 for KFL with more to come.



DAVID WRIGHT

A massive belated Thank You to Jonathon, Ian and David Wright. In July last year they took part in the Hadrian's Wall event, a 2-day trek covering approximately 26 miles of walking over undulating hillsides. The Wall itself is a spectacular World Heritage Site, spanning sea to sea from Bowness on Solway to Wallsend, across some of the wildest and most dramatic country in England. As well as experiencing Roman life and epic history in stunning locations they raised over £1,250 for KFL taking on this trekking wonder.



CHARTELLE SCRAGG

Was Ipstones Agricultural Queen for 2016-17 and **raised £6,241** during her time and has **donated £500 to Kidneys for Life**. Both Charnelle's Dad, Barry, and his brother suffer from Alports which is why she wanted to support Kidneys for Life during her reign.



NAVRATRI FESTIVAL MCR

Dilip Modha from the Hindu Navratri Festival and also a kidney patient presented our Chair of Trustees, Professor Paul Brenchley, on the 9th day of the Navratri Festival with a **cheque for £1,001**. We would like to pass on our thanks to all concerned in helping raise these funds at the Festival.



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THANK YOU!

SANTA DASH

It was a bright, chilly Sunday morning in December when we were delighted to meet the 221 Santa dashers (and numerous dogs in Christmas outfits!) who were taking to the streets of Marple to participate in the 9th annual Romiley and Marple Lions Santa Dash.

It was a fantastically festive event with **over £4,300 being raised for Kidneys for Life**. One of our youngest Santa's was Ethan who is just 5 years old. Ethan took part with his mum and through fundraising at school and via an online page he raised an amazing £255.81. He has since taken his very well deserved fundraising medal and certificate into school to share his success story with his classmates.

Well done to all our Santa Dashers from all of us at Kidneys for Life and a very big thank you to Terry and the team at Romiley and Marple Lions Club for selecting us as your charity and for all the hard work in putting the event together.

Plans are already underway for a special 10th anniversary Santa Dash which will take place on Sunday 2nd December so keep the date free!





The family presented the funds last year during a routine check-up appointment. Pictured from left to right are: Beverley Whitnall – Urology Nurse Specialist, Dad - Ross Blackwell, Mum - Jenny Blackwell with newborn daughter, Esme Blackwell and Jacob Blackwell being held by Max Cervellione – Urology Consultant at the Royal Manchester Children's Hospital.

SCOTTISH FAMILY FUNDRAISE FOR UROLOGY RESEARCH

A family from Scotland have donated thousands of pounds to help fund research into Bladder Extrophy. Ross and Jennifer Blackwell handed over £2,530.40 to staff at the Royal Manchester Children's Hospital's Urology Department last year.

The couple's two-year-old son, Jacob, is under the care of urology specialist, Max Cervellione. The family regularly make the 600-mile round trip from their home on the West Coast of Scotland to attend Jacob's appointments in Manchester.

Mum, Jenny, said: 'We don't give the travel a second thought – it's just something we do for Jacob to receive the expert medical care he needs. Ross and I feel so indebted to Max and his team for the care our little boy received and will continue to receive. We both felt very strongly about raising funds for research into bladder extrophy in the hope it could find answers into the cause of the condition.'

The couple set up a JustGiving Page through Kidneys for Life and funds were raised through a gruelling 7-mile assault course, a summer fête held by their son's nursery and several anonymous donations.

VASCULAR NURSE – ALAYNE GAGEN

Kidneys for Life supports a number of different projects including research, nurse education, patient amenities and also equipment to enhance treatment of renal patients.



Kidneys for Life has purchased a number of pieces of equipment for the Vascular service at several of our renal wards and departments. To explain more about this Alayne Gagen has written the article below.

The gold stand of renal vascular access is considered to be a fully functioning AVF, constructed using a patient's own vein and small artery, this can be either at the lower end of the arm near to the wrist or in the upper part of the arm. There are many factors determining successful maturation of this particular type of access and it is the nurses on the renal unit alongside the patient to ensure that any problems with this access are captured quickly and dealt with appropriately.

Once a patient's renal function has dropped to below a certain level a decision needs to be made around what type of renal replacement therapy the patient wishes to choose. Haemodialysis being one of them for which good access is necessary.

There are four types of vascular access these being:

AVF - Arteriovenous fistula

AVG - Arteriovenous graft

CVC - Central venous catheter.

HeRo graft - Hybrid using a tunnelled catheter and graft.

Part of the monitoring of this access involves a sleeves up examination using the look, listen and feel approach, the nurse is looking for any signs of altered skin integrity, infection, scabs, bruising, swellings, aneurysms to name a few, the nurse also needs to listen to what is called the bruit, this is a whooshing sound made by the arterial connection to the vein. The patient is encouraged to feel for the 'Thrill' daily which is a buzzing sensation made by the arterial blood flow, the nurse will also feel for this on arrival to the units before commencement of dialysis.

A stethoscope is suitable for the purpose of listening to the bruit, but in recent years a small hand held Doppler machine has proven to be more sensitive, allowing an experienced nurse to detect changes in the quality of fistula blood flow. This facilitates the early detection of fistula problems and allows for the instigation of more timely interventions. Kidneys for life have very kindly donated 3 of these machines to the renal unit over the last year, one of which has gone to the Renal Vascular Access Nurse Specialist to use in daily work and the others to a satellite unit

They have proved invaluable for detecting non-functioning AVF resulting in a timely referral for necessary intervention and have been used to cannulate (needle) new fistulas after listening for the bruit to map the vessel before undertaking cannulation. It is hoped that with improved use of technology such as the Doppler machines renal vascular access problems can be detected and acted upon much quicker, therefore ensuring longevity of a patient's life line.

For further information you can visit the following sites:

<https://www.thinkkidneys.nhs.uk/kquip/magic/>

<http://britishrenal.org/>

Alayne Gagen
– Vascular Nurse at MRI



Sister Gagen the Renal Vascular Access Nurse Specialist would like to extend her thanks to Kidneys for Life for giving the units this very useful piece of equipment in order to improve on monitoring and surveillance of a patient's AVF/AVG.

Kidneys for life have also funded Sister Gagen to attend conferences with the British Renal Society Vascular Access special interest group (BRS SIG) of which she is vice chair. This group was set up in 2015 to look at developing and improving aspects of renal care, the BRS sig joined forces with Vascular Access Society of Britain and Ireland (VASBI) in 2016 and as a result The MAGIC Group (Managing Access by Generating improvements on Cannulation) was set up to look at developing a set of national clinical practice recommendations for Cannulation of Arteriovenous (AV) Fistulae and Grafts. This was to ensure that there was best needling practices nationally, being specifically aimed at those directly responsible for patient's care of AVF/AVG. KQUIP have also now teamed up with the working group in order to support and create a quality improvement through the cannulation recommendations.

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ALBERT'S PATIENT STORY

Albert was born in Feb 2015, he was born with a very rare condition called Autosomal Recessive Polycystic Kidney Disease and this is a summary of our journey. The full journey can be found on the Kidneys for Life website under Patient Stories.

I can honestly say it never crossed my mind that we would have a baby with health problems, I am guilty of being one of those people that thinks it will never happen to them. Sadly, I couldn't have been more wrong. We had arrived at hospital and Albert was ready to come but on examination they discovered he was breech and advised an emergency caesarean section.

Once he arrived there were concerns about his breathing, so we were quickly introduced to our baby, able to give him a kiss and then he was gone. Before we could see Albert again a Consultant sat us down and explained that Albert had deteriorated over night and was now requiring 100% ventilation, they also had concerns because his urine output was extremely poor, and his abdomen was very distended. He went on to explain they needed to transfer him to Manchester Children's Hospital as he required specialist care and we needed to prepare ourselves for the worst.

We all went down to see Albert before they transferred him, and that moment will stay with me forever, even sat here writing it out I have tears rolling down my face. Albert was taken to Manchester in an ambulance and we weren't allowed to travel with him, Walking on to NICU at Manchester was a scary experience at first, seeing your baby hooked up to all the machines with them alarming like a musical orchestra and medical staff running around him using medical terms you are not yet familiar with takes some getting used to. The following morning, we met with two members of the fantastic renal team that have now looked after Albert along with the rest of the team since that very day, its funny looking back now how two strangers would go on to play such a significant part in your life and you didn't realise it at the time. We were taken in to a room and it was explained to us that they didn't yet know what they were dealing with, it was clear he had complications with his kidney function, but further tests were required to find out what exactly was going on.

They ran through two possible scenarios with us:

1. A problem with the valves to his kidneys
2. A disease which caused cysts to develop in his kidneys, a condition known as Polycystic Kidney Disease (PKD) and with this condition it comes in two forms
 - a. Autosomal Dominant Polycystic Kidney Disease (ADPKD) which is the worlds most common inherited kidney disease and is relatively well treated
 - b. Autosomal Recessive Polycystic Kidney Disease (ARPKD) which is a rare condition that affects the kidney and the liver, it occurs in about one in every 20,000 live births in the UK and is a severe disease. With this condition one in three babies die from breathing problems during the first four weeks and it also causes extremely high blood pressure

Within the next 24 hours we had an answer that our baby had PKD, they were still not certain which of the two forms he had but the signs were encouraging that it may be the less severe form. Day by day his breathing improved but he had started to retain fluid, in fact he retained over 1 kg in fluid in just three days which was extremely concerning and was also not going to help his breathing. After 5 days they had managed to get his fluid retention under control and Albert came off ventilation, he was breathing on his own!! He was on a high amount of oxygen but was breathing without assistance and continued to do well over the next few weeks.

We finally brought Albert home after 4.5 weeks with our first clinic appointment 10 days later. It was amazing to have him home and was so nice to have some normality, from day one though Albert had struggled with his feeding and this had continued at home.

Our very first clinic appointment! When Albert had been discharged we still didn't have a definite diagnosis, they had sent bloods off to genetics to get a final diagnosis, so I was also hoping these results may have come back. Let's just say Albert started his first appointment as he meant to go on, we had gone through after being weighed and his blood pressure checked, it was 164 and in that second my heart dropped, we were told he needed to be admitted to try and get his blood pressure under control, not what I was expecting from his first clinic appointment. He was in for 3 weeks trying to get his blood pressure under control and I can honestly say this period in hospital was one of the scariest times in Albert's journey. Albert seemed to deteriorate in a matter of half an hour to the point we had a consultant from intensive care talking though the possibility of ventilating him and his own consultant sat on the floor in his room telling us he was really worried about him, he was struggling to breath and again he had retained a lot of fluid. The condition Albert has causes cyst to grow in the kidneys making them extremely large, this means they take up a lot of room in the body causing other organs to become squashed so when he comes down with a cold he doesn't have the room to fully expand his lungs and it impacts on his breathing massively. This became a trend throughout his life that he struggled with simple things like colds, it also became a trend that whenever he was poorly he retained a lot of fluid. He was monitored extremely closely

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over the next few hours and he began to turn a corner, his breathing improved, and we avoided having to ventilate him. Over the next three weeks they managed to get his blood pressure and fluid retention under control, he was finally allowed home and he was on 12 different medications. We had been told it was now looking likely that he had ARPKD due to the high blood pressure and this was confirmed during that stay as the genetic results came back.

The next 12 months consisted of many clinic appointments and too many to mention hospital admissions, within this time we had extreme low points but also some very happy moments. Within that time Albert had his first kidney removed at 6 months old, this was one of my extreme low points. Another personal issue was his sleeping, Albert wouldn't sleep longer than 20-40 minutes through the day and night meaning myself and John were exhausted as this had been going on since he was born, we had put this down to the fact the kidneys were so big so thought he must be uncomfortable. I made the fatal mistake of putting all my eggs in one basket so to speak and thought having the kidney out would solve all these problems, this was a mistake I would never make again. As time went on his feeding deteriorated and he was vomiting more than he had been prior to surgery, this was disappointing, but I kept telling myself to give it time and it may get better. His sleeping also hadn't improved, we had also hoped it may help reduce his blood pressure and we could drop one of his medications, but this didn't happen either.

We had been home a couple of months when we were attending one of his clinic

appointments, during the appointment they asked if his sleeping had improved. It hadn't improved at all, this was a lightbulb moment, his consultant looked down his list of medications and one of the blood pressure medications he was on had a side effect of sleep disturbance, at this point I would have tried anything, it definitely couldn't make it any worse. So, we made the decision to stop the medication the following day and that night Albert slept through from 9pm to 5am!!! I think I cried with happiness and he has continued to be a fantastic sleeper ever since. My advice after this is always go with your instinct and question things if you think they aren't quite right because there is always that one child that likes to do things differently and guaranteed it's probably yours.

Another area that hadn't improved was his feeding, although he was steadily putting on weight he had been fed completely via a nasogastric (NG) tube since he was about three months old and would vomit with almost every feed. I fought for a long time about him having an NG tube full time and didn't want to be "defeated" so persisted trying to feed him with a bottle which caused both Albert and myself a lot of tears and stress. It was the same with using the pump to feed him, once we started using the pump I instantly thought I can't believe it has taken us so long to try this, it was the best thing we ever did and made life so much easier.

As Albert spent most of the first year in hospital I wanted to ensure the time he was home was good quality time so made every effort to go to as many baby classes as I could, take him swimming and do all the other activities that a healthy child would do. I was also keen for him to go to nursery and my family also encouraged this to give me some time to myself, so he went

to nursery just after he turned one, this was one of the best decisions I ever made.

The decision was made to take the second kidney out when he was 2, his blood pressure had become increasingly difficult to manage and his weight and breathing were again a concern. To me dialysis was quite a daunting prospect and I thought once the second kidney was out it wasn't like we could put it back in if he didn't cope well with dialysis, so it was a massive decision. We were given time to think about what we wanted to do and given all the facts about haemodialysis, the doctors were keen for us to take our time coming to a decision as haemodialysis can have a huge impact on families. Once we had made our decision we were shown round the dialysis unit and a date was set, I would need to bring Albert 3 or 4 days a week and I would have to leave the house at 6.30am and would only be getting home around 2pm. I got home and thought about it realistically, people do that journey and get up at that time five days a week to go to work and that's all I was doing, yes, I was going to be sat on a hospital ward and there would be times that he may be unwell, but I was going to treat it as a job and that seems to have worked for me.

The day soon came around that his second kidney was coming out, they were also putting in a central line for his haemodialysis. It never gets any easier taking your child down for surgery no matter how many times you take them. 3 hours in to surgery we received a phone call to say they couldn't complete the surgery because Albert had spiked a temperature, they had managed to get his central line in, but they couldn't remove the kidney. Initially I was devastated but I had no doubt the right decision was made, I wouldn't want them to proceed if

there was any risk. It was quite a shock when he came back from surgery, we had been shown what the central line looked like but to see it in Albert was quite upsetting. The second attempt was successful, and Albert was making a fantastic recovery. Children never cease to amaze me at how resilient they are, and Albert was certainly no exception, the second kidney weighed nearly 1kg and was approx the size of a bag of sugar, bearing in mind at this point Albert only weighed 8kg.

So, the next chapter of our journey had started..... haemodialysis. They had started him with short sessions whilst he was in hospital and he had tolerated these sessions well. I had been quite anxious about starting dialysis for many reasons, there was the early starts and driving to Manchester, keeping a two-year-old toddler occupied for 4 hours and expecting them to stay still on a bed was a huge ask. It all started really well, Albert was an absolute super star and to this day has never been difficult to keep on his bed (keeping him still is another story), for the first few weeks he was quite suspicious of the nurses but now he knows they aren't going to hurt him he absolutely adores each and every one of them and there have been times it has been a task getting him to leave. Albert had issues with low blood pressure initially but once his blood pressure evened out Albert started to thrive on dialysis, he has put 5kg on in twelve months and is so much happier, his development has come on leaps and bounds and has so much more energy.



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We are now at the stage where we are waiting for a date for transplant, he has been seen at Birmingham Children's Hospital as his condition affects his liver as well and a month after returning from Birmingham I received one of the best phone calls I've ever had, the results were back and they didn't feel at this point it was necessary to transplant his liver and hopefully it will last him a few more years so we were given the go ahead to do an isolated kidney transplant. Myself and Albert's dad were keen to be tested and see if we were able to donate one of our kidneys, we are both a match but John was a slightly better match than myself and John is going to donate his kidney.

I remember being at the beginning of our journey thinking how are we going to get through the next few years and the point of transplant is so far out of reach but in the blink of an eye we are here. It has by far been the hardest few years of our lives and we have experienced some of the darkest moments we will probably ever experience but we have also had the privilege of going on this journey with the strongest and most amazing little boy who has surprised us at every hurdle and fought every step of the way. I am so thankful to have had some amazing support and I can honestly say I wouldn't have coped at times without my mum, she has been my absolute rock. Even though your world is turned upside down when you find out you have a poorly child it will turn back over and its just working out how everything goes back, some pieces don't go back where they were, but it may actually work better putting them in a different place. My friendships have changed,

my work life and my home life but I have learnt so much. I have learnt to laugh more even when you are sat in A&E at 3am trying to catch a urine sample with a bowl, I have learnt to smile even when you would rather cry, and I have learnt to be positive even when you want to give up. Our journey is not over yet and there will be hard times along the way, but we are going to ride it and see where it takes us.

— Erika



WHAT WE DO WITH YOUR MONEY...



RESEARCH GRANTS – awarded in Nov 2017.

Kidneys for Life has funded the following 10 research projects with a total amount funded of £95,382.57

- Elucidating the effect and role of hypoxia on differentiation of stem cells to kidney progenitors
- The impact of abdominal wall closure technique on incidence of incisional hernia in kidney transplantation
- Investigating FGF23 as a modulator of renal hypertrophy
- What is the significance of shortening Acute Kidney Injury Recovery Time? A clinical outcome and biomarker study.
- A Pilot Analysis of the Changes in the Oral Microbiome Associated with Kidney Transplantation.
- A zebrafish screen for chemicals to delay chronic kidney disease
- Investigation on the impact of Chronic Kidney Disease(CKD) on hepatic drug metabolising enzymes and use of Physiologically Based Pharmacokinetic Modelling(PBPK) for precision drug dosing in CKD
- The use of Microdialysis catheters to assay the interstitial fluid in kidney allografts immediately after transplantation. Proof of Principle.
- Using the Speckle Doppler to Quantify Perfusion Quality in Kidney and Pancreas Grafts on vascular reperfusion. A Pilot Study.
- Why do mutations of ACTB, coding for B-actin, cause kidney malformations?
- Assessment of Pancreas Allografts Using Novel Magnetic Resonance Techniques.

You can find more information including Layman's Summaries for each project on our website.

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FUNDRAISING AT SALFORD ROYAL

It's been a fantastic few months for me as the Kidneys for Life fundraiser at Salford Royal.

The staff and patients have been really welcoming and it has been so lovely to speak to so many kidney patients and their families and hear their kidney journeys.

If you would like to share your story or would like to fundraise for us then please let me know when you are going to be in clinic and will make sure that I come to see you!

We have an ambitious amount of money to raise to fund various projects over at Salford Royal so it has been great to have Salford staff eager to sign up for some of our events – we have a Renal dietician taking part in the Manchester Marathon in April and a Renal Doctor preparing to trek the Grand Canyon in September.

Spaces are still available on most of our fundraising events for this year and whatever you raise will help us reach the Salford Royal fundraising target so if you would like to get involved then let me know.

— **Victoria**



FAR INFRARED MACHINES

Pain and discomfort associated with the use of AV fistula can be a major cause of anxiety for patients. It can result in patients reducing dialysis time or even refusal to dialyse or to have AV fistulae cannulated.

Kidneys for Life has supported the funding of two Far Infrared machines which have been supplied to Wigan and Salford dialysis units. The machines, funded by Councillor Karen Garrido, the ceremonial Mayor of Salford in 2016-17 and our Venice to Rome Cycle Challenge Team, work through far infrared rays which help mature the arterial-venous fistula and reduce clotting due to the release of chemicals from the vessel wall.

Far infrared is given for 40 minutes whilst the patient is on dialysis and this reduces inflammation at the fistula. It is a safe and effective treatment, low-risk and non-invasive, that helps to improve fistula maturation after surgery. It is also of benefit to those patients with very severe bruising and those experiencing fistula pain during haemodialysis. The patient experience has been positive and this has been a welcome development in fistula care.

OUR £10,000 FUNDRAISING CHAMPION!



One of our volunteers who certainly deserves a special mention is Karen Ainsworth.

Those of you who attend the Renal Department will no doubt have met Karen but you may not be aware that through all her hard work and dedication **Karen has raised an amazing £10,000 for Kidneys for Life.** Karen's journey with Kidneys for Life started 11 years ago with the arrival of her youngest son, Sam.

Sam was born with dysplastic kidneys and then went on to spend four and a half years on dialysis. Thankfully Sam had a successful transplant from his Dad on 10 Feb 2011 and is now a healthy, happy young man who also likes to support Kidneys for Life and took part in the Santa Dash last year.

Karen really does work tirelessly to raise funds and awareness for Kidneys for Life. As well as hosting her own fundraising events, raffles and tombolas Karen has also taken part in several Kidneys for Life fundraising events including the China Trek, Vienna to Salzburg Cycle Challenge and Liverpool to Manchester Cycle Ride.

This year Karen is taking on our Challenge the Wild event and the London to Paris Cycle Challenge. Karen is supported in her fundraising by her family and local companies including Sainsbury's, Morrison's, Costco and the Chandos Club who have kindly provided the venue for various fundraising events.

It is thanks to all of the above and Karen's kind donors that she has raised in excess of £10,000.

Karen, in true form, is not stopping at this amount though so if you would like to read more about her story or donate to her please visit her fundraising page. <https://uk.virginmoneygiving.com/KarenAinsworth1>



RENAL PATIENT QUESTIONNAIRE



Last year we asked our patients to complete a Renal Patient Questionnaire to find out what Kidneys for Life, Hope KPA and MRI KPA could do to help renal patients and we were pleased to receive over 50 replies.

We have now gone through all the suggestions and looking to see what we are able to implement following your suggestions and hopefully you will see evidence of this next time you attend hospital or clinic. One suggestion was the availability of leaflets on various aspects of kidney disease which we are now looking at compiling and making available but it will take some time to get this together.

We also asked if you would be interested in being part of a Patient Support Group(s) to help local kidney patients and their carers and we have now been in touch with those that were interested to set up initial meetings in Manchester and Salford at the end of March / beginning of April.

If you have not received anything and would like to be involved please get in touch with Irene Chambers by email: fundraiser@kidneysforlife.org or telephone 0161 276 6671.



TERESA JERÓNIMO – ALGARVE HOSPITAL, PORTUGAL

Teresa Jerónimo currently works at the Department of Nephrology, Centro Hospitalar do Algarve. Teresa does research in Nephrology. Their current project is 'Empowerment in dialysis patients'. Teresa was offered the opportunity for a three month fellowship with the Haemodialysis Team here at the MRI with the support of Kidneys for Life.

Teresa said “the opportunity to be in Manchester for a 3-month fellowship was of great importance to expand my knowledge in the field of haemodialysis (HD), especially to understand how to develop a home HD programme. The main message to retain is that Empowerment in dialysis patients allows to improve their quality of life and can help them to achieve better outcomes. I am very grateful about the experience with a wonderful team and I’m working to be able to offer the best to all the patients who would like be more in control of their own disease.”

REMEMBERING...



Hilary Compston (1951 – 2017)

A gift of £2,500 has been made to Kidneys for Life. This is from individual donations in lieu of flowers in remembrance of Hilary following her sudden death in hospital on 22 Nov 2017. Hilary was a supporter of the charity since her husband Evan had a kidney transplant at MRI in September 1999. Hilary had worked in the NHS for over 40 years. After qualifying as a Nurse she worked in

Sheffield and Oldham as a Health Visitor. She moved into a management posts in Salford and became the Director of Clinical Services. Prior to her retirement Hilary worked as an Associate Director of Supportive and Palliative Care in the Greater Manchester and Cheshire Cancer network. Hilary had an excellent work reputation and was always proud of being a Nurse. She is sadly missed as a very good friend to many, not least her husband Evan.

John Ferguson

Doreen Hall

Hayden Harrison

Kathleen Heaton

Kevin Johnson

David Kay

Barbara Key

Christopher Lack

Bob Law

David Leith

Kelvin Prince

Wendy Rowland

David Smith

Frank Smith

Patrick Thorne

Jean Wright

EVENTS DIARY



25 March 2018

AFTERNOON TEA TO CELEBRATE 50 YEARS OF KIDNEY TRANSPLANTS AT MRI

22 March 2018 is the 50th Anniversary of the first kidney transplant at Manchester Royal Infirmary.

To celebrate this occasion and the 6,000 plus transplants that have taken place since then the Manchester Transplant Team has organised an Afternoon Tea and we hope that you are able to join in the celebrations. Kidneys for Life is organising this event on behalf of the Team.

Date & Time: Sunday, 25th March 2018 at 2-4pm

Venue: The Grand Ballroom, The Principal Hotel, Oxford Road, Manchester M60 7HA

Cost: £22.50 per person

28 & 29 April 2018

CHALLENGE THE WILD

An exhilarating and uplifting outdoor experience. Under the watchful eye of highly trained experts you'll be encouraged and empowered as you take on a series of challenges. You don't have to be fighting fit or as strong as an ox to take part.

A positive mental attitude and a good sense of humour are far more important! Activities include: Grade 1 Scrambling, negotiating tunnels and cave systems, abseiling 150ft, trekking, cliff jumping, wild camping, outdoor cooking, ghyll scrambling, waterfall jumping, problem solving

Registration: £50

Minimum Sponsorship: £300



2018



12 May 2018 TANDEM SKYDIVE

Taking place at Cockerham Airfield, Lancaster. Enjoy an 11,000 ft. adrenalin rush Tandem Skydive, freefalling to 5,000ft.

Registration fee: £50
Minimum Sponsorship: £345



20 May 2018 MANCHESTER 10K, HALF MARATHON AND JUNIOR & MINI RUNS

The Manchester 10k Run, the largest 10k in the UK will take place for the 16th time next year and on the same day the Half Marathon will take runners of all abilities on a 13.1 mile tour of the city. The route passes by two of the UK's most iconic football grounds, the Etihad Stadium and Old Trafford, as well as the Imperial War Museum and Albert Square. In addition there is also the Junior Run (9-15 years) and Mini Run (3-8 years). There's lots of music and entertainment along the course and no shortage of support.

It costs just **£44 for the Half Marathon** and **£38 for the 10k** to register your own place.

More information can be found online at www.greatrun/great-manchester-run

EVENTS DIARY



27 Aug – 1 Sep 2018

LONDON TO PARIS CYCLE CHALLENGE

Do you fancy a weekend in Paris? That's what you get when you take part in the Kidneys for Life London to Paris Cycle Challenge. You finish at the Eiffel Tower in the most amazing way possible as you celebrate the 50th Anniversary of the first kidney transplant at MRI having already celebrated the centenary of the end of the First World War as you pass through Arras and Compiègne. So much to get excited by and so much not to miss.

Registration: £100

Minimum Sponsorship: £1,600

15 to 22 Sep 2018

GRAND CANYON TREK

Join this fantastic trekking challenge as we explore in and around one of the World's most magnificent natural wonders – the Grand Canyon. Experience breath-taking scenery, camp under the moon and stars, and learn about the fascinating history of Northern Arizona and Utah whilst on this iconic challenge. This exciting trek will see us hike through Sedona's Red Rock State Park, along the famous Bright Angel Trail and the South Kaibab Trail...to name a few! We assure each day of this charity challenge provides a different perspective of this breath taking wonder, so join us on this iconic challenge and tick it off your bucket list!

Registration: £449

Minimum Sponsorship: £3,500



2018



7 Oct 18
50 MILE / 50K CYCLE FOR KIDNEYS FOR LIFE

A new bespoke event for Kidneys for Life to celebrate 50 years of transplants at Manchester Royal Infirmary. A one-day Cycle – two distances – 50 km and 50 miles, suitable for all abilities.

Cycling from MRI to MRI please check the website for more details. Coming soon!

2 Dec 18
SANTA DASH AT MARPLE

A fun run for all the family starting at 12 noon from Marple Memorial Park. This is being organised by Romiley & Marple Lions on behalf of Kidneys for Life, more information on how to register will be on our website soon.

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If you are interested in any of these events please get in touch or visit our website www.kidneysforlife.org/events

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CORPORATE SUPPORT

EAST CHESHIRE CHAMBER OF COMMERCE



East Cheshire Chamber holds two Clay Pigeon Shoots a year both at the beautiful Cloudside Shooting and Sporting Club, Macclesfield. Great days but very different weather. In June we were slapping the sun-cream on and in October the wind was slapping us. A hearty steak pie dinner soon warmed us all up. This was followed by the Christmas Lunch at Peck's restaurant. Fabulous Peck's hospitality and seasonal cheer.

The last event in the Chamber's fundraising calendar will be the Awards Dinner in April when Kidneys for Life's year comes to an end. The support from the East Cheshire members has been amazing and they're hoping to raise even more funds for Kidneys for Life with some awesome auction and raffle prizes at the Dinner. I can recommend this sharing, friendly Chamber.

A massive Thank You to you all!



CATAX

Tax Advisors Catax, based in Altrincham, continues to raise funds for Kidneys for Life and are now recruiting for the Challenge the Wild event in April when their fundraising year will, sadly, come to an end. Staff have embraced Kidneys for Life and have taken part in the Skydive, the Manchester Run and the Liverpool to Manchester Cycle Ride. I hope they've enjoyed their time with us as much as we've enjoyed receiving their much appreciated support. (see photo on cover)

Good Luck in the Lakes!



WILKINSON STAR

A Big Thank You to Wilkinson Star in Worsley for **raising £ 2,750 for Kidneys for Life** from a promotion offered to their customers in November. Please watch this space for even bigger, even more exciting news. Can't wait!

WE VALUE YOUR SUPPORT

If you are a business and would like to help fundraise for Kidneys for Life, please get in touch today.

**Irene Chambers on 0161 276 6671
or fundraiser@kidneysforlife.org**

THE RENAL PSYCHOLOGICAL SUPPORT SERVICE



Dr Nicola Reid
Consultant Clinical Psychologist



Katie Leicester
Specialist Renal Counsellor

I would like to introduce myself, my name is Nicola and I am the Consultant Clinical Psychologist who alongside our Specialist Renal Counsellor, Katie Leicester, makes up the renal psychological support service. I joined the team in May 2017 and am thrilled to have become part of such a committed and energetic bunch of people.

For most of my career, I have worked with people who are living with physical health conditions and I continue to be amazed by the strength and resilience patients and their families demonstrate, often in the face of significant challenges. I enjoy working as part of a large multidisciplinary team as I feel that through each member's unique contribution we can offer the most holistic approach to care.

A bit about our service...

Living with renal disease can be stressful and further problems can sometimes be caused by emotional reactions to illness. Clinical Psychologists and counsellors often work with people who have physical health conditions to help them cope with the stresses and demands of managing their health.

Emotional support is available from many other members of the renal team. Much of the time you may find that talking through your problems with your care team, or your own friends and family, will be enough to help you to cope. If, however this does not resolve things our service may be able to offer some further support and advice.

What we offer...

We work with people through 'talking therapies' which means practical problem solving techniques are used as well as counselling and psychotherapy approaches. The reasons for people seeking support can vary, but the aims of this work are usually:

- To help people make changes in the way they think, feel or act.
- To help people understand and cope with their problems more effectively.

If you feel you would benefit from accessing our service, or you would like to find out more about what we do, just talk to a member of your care team, or email us on: **renal.support@mft.nhs.uk**

SALZBURG TO VIENNA CYCLE CHALLENGE 2017

Well, where do I start?After having decided to do this challenge I had to think about getting myself a bike obviously.



Thanks to some fantastic friends, I didn't need to as they actually bought me one. They'd seen that I had already done a number of challenges and instead of sponsoring me they wanted to get me a bike! Well, you can imagine... I was over the moon. But this meant I couldn't back out of it. (Oh, what have I done?).

So I tried to cram as much training in as possible (6 weeks in all). A group of us would meet up and cycle along the canals in Manchester and I have to say that after not being on a bike for over 20 years I found I actually enjoyed it. I wasn't very good at it but got better each day, although the backside was being to feel it and not in a very nice way if I'm honest. I stuck at it and then before I knew it, it was the night before we were due to fly out and, my word, there was no way I could back out now.

We set off from Manchester Airport on the morning of the 26th Sept 2017 to Vienna and then we took a train to Salzburg where our cycles were waiting for us to start on the morning of the 27th.

The nerves had already set in but I knew I was with a great group of people who would keep us all going and make sure that we were all ok and, of course, we had the lovely Afshin Tavakoli (Renal Transplant Surgeon) along with us. Both his music and his dance moves (let me tell you he definitely has the moves) made him a fab member of our team.

The lovely Janine Winfield was with us too with her brother Joe and work colleague Andrew. The first day of the cycle ride was actually the first anniversary of Janine's kidney transplant. What a way to celebrate!

We cycled along the lakes and rivers of Salzburg and into Passau on the German/Austrian border. The scenery was amazing, an absolutely beautiful place. We joined the Danube cycling along the river banks through ancient vineyards where the locals were out picking grapes. It was definitely a sight to see. Some of the little towns and villages were gorgeous with lovely quaint little shops and cafes which we did manage to stop at at times to enjoy a long, refreshing, cool drink and take in the scenery.

For me, I don't think I would have got through it without the fantastic support from everyone on the challenge. Everyone was great, even when I needed to be pushed up the so-called flat (ha, ha) hills and even when I got off and walked because I thought I couldn't do it someone would come along and get me through it. They even shared their chamois cream because, let me tell you, after spending all those hours in the saddle each day.....

We cycled for 4 days and altogether covered on 275 miles. You can't imagine how we felt, especially me, when we got to the last day, and the finish was the Stunning Hofburg Palace in Vienna. We'd actually done it! We'd actually finished! Oh my word, I couldn't believe it! An emotional moment for everyone.

Before going we were told that it was fairly flat so we would be fine. Mmmm.... well let me tell you what I describe as flat is definitely not what they describe as flat but we did itall of us. There was lots of laughter, plenty of tears at times too.....but definitely fun times.

Would I do it again? Every possibility I would but I would make sure I did plenty of training and especially on the hills and definitely well before the event.

Just knowing that I'd done something that I never thought I could do and to know I'd raised money too for Kidneys for Life made every mile I cycled and every hill I tried to get over (without being pushed) so much more worthwhile.

— Wyn Gregory



MAKE A DONATION AND HELP MAKE KIDNEYS FOR LIFE A REALITY

Kidneys for Life raises money to enable research into kidney disease, transplantation and dialysis and the Research Teams at the MRI, Salford Royal and the Children's Hospitals have a proud history of being at the forefront of many acclaimed scientific discoveries and internationally celebrated successes. The research work undertaken by the teams offers real hope for patients both new and in the future. **Please help us by making a donation...**

To make your donation please fill in your name and address below and return to Irene Chambers, Kidneys for Life, The Renal Unit, Manchester Royal Infirmary, Oxford Road, Manchester M13 9WL

Don't forget to Gift Aid to make your donation worth more (see below).

Name

Address

Postcode

Email

Tel

Signature

Date

Please tick an amount below or let us know how much you would like to donate.

 £25 £50

Other amount

Please make cheques payable to Kidneys for Life

I want to Gift Aid my donation*

* I confirm that I am a UK Income or Capital Gains taxpayer. I have read this statement and want Kidneys for Life to reclaim tax on the donation above, given on the date shown. I understand that if I pay less income Tax/Capital Gains Tax in the current tax year than the amount of Gift Aid claimed on all my donations it is my responsibility to pay the difference. I understand the charity will reclaim 25p on every £1 that I have given.

To donate: text KFLS22 £5 to 70070 or visit kidneysforlife.org