

WHISPERS

kidneysforlife.org

Spring
2019

IN THIS ISSUE...

Thank you's

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...AND MUCH
MORE



CIRQUE DU SOLEIL
PAGE 22

 **KIDNEYS
FOR LIFE**
HELP MAKE IT HAPPEN

Charity number 505256

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. Without you, we couldn't do all the things that we need to. **Thank you.**

O2 / RITZ

Thanks to O2/Ritz for supporting Kidneys for Life at the Jilly's Rockworld tribute night. It was a great night and some fab music from all the DJs. Our thanks also to Chris Mann, Marcus and Cassie Brzoza and our volunteers on the night.



ANN BOOTH

Ann Booth's family made a donation to Kidneys for Life in her memory to support the Afternoon Teas which take place on the Renal Ward as Ann loved these so much.

KEVIN'S RUNNING SUCCESS

Thank you so much to Kevin Donovan who took part in the Great North Run and the Great Birmingham Run in Autumn 2018. Kevin shared his story of why he took part in the events and chose to raise funds for Kidneys for Life: 'Our little story started when my daughter was diagnosed with a kidney disease when she was 3 years old. She was in GOSH for about six months and was an outpatient there until she became an adult and was then referred to Addenbrookes, which is where she still attends today.

Carolyn managed on reduced kidney function for 29 years, her kidney function was and had been getting worse over the previous years and we always knew they would stop eventually.

When we arrived at this point I decided to put myself forward for donation, fortunately we matched well and in January 2016 Carolyn received one of my kidneys. It has not been plain sailing, there has been some minor rejection but on the whole her health is much improved.' **Kevin has raised £137.50 for Kidneys for Life – thank you for supporting us Kevin and for sharing yours and Carolyn's story with us.**

PAULA STOTT

Paula Stott went sober for October and raised £1,255, Paula wanted to do this as her husband suffers from polycystic kidney disease and has been on dialysis for over 2 years. Recently a living matching donor came forward. Unfortunately at the last minute his transplant was cancelled. Everyone was devastated.

Paula said "I'm doing this to raise awareness and to raise money for such a good cause." – **Well Done from all at Kidneys for Life**

**£1255
RAISED**

JO JONES PHOTOGRAPHY

A really big thank you to photographer, Jo Jones, from Jo Jones Photography who has been our official photographer at our Circular Cycle Ride and also at the Santa Dash. Jo explains why she has chosen to support Kidneys for Life: 'This is a charity that is very close to my family as my dad had a kidney transplant and although he's not with us anymore he benefited from the transplant for an extra 10 years'

Jo's photos can be seen on our website and on our Facebook page. Jo has also generously offered to make a donation to Kidneys for Life for all bookings that are made this year.

Very sincere thanks to Jo for your fantastic photos and support!

Joanneandrewsjones@hotmail.co.uk



NORTHWEST SCOOTER RIDERS

Thank you to the North West Scooter Riders from North & Central Manchester and Salford Knights Scooter Clubs who took part in an event on Remembrance Sunday in central Manchester and Salford War Memorial. The Clubs raised £1,078 for Kidneys for Life for which we are really grateful. Our thanks particularly goes to Graham May, Paul Levy, Colin Geary, John Abbott, Paul Ardern, Dave Swift & Mike Lennon.

WHISPERS

NEW YEAR, NEW HAIR!

Tilly and her Mum, Natalie, contacted us in Autumn 2018 to let us know that Tilly was doing some fundraising for Kidneys for Life. After seeing one of her good friends, Pippa, go through treatment for a Wilms' Tumour and lose her hair, Tilly decided to grow her hair and then have it cut off and donated to the Princess Trust – a charity who make wigs for children who are undergoing cancer treatments and other illnesses. Tilly decided that any sponsorship that she raised by having her hair cut should be donated to Kidneys for Life. The big hair cut day was 2 January. Both Tilly and Natalie were a bit nervous on the day but thankfully Tilly (and her mum!) love her new hair – Tilly admitted to feeling a bit sad that her long hair had gone but over the moon to have raised over £500 for Kidneys for Life. We all think that Tilly's new hair style is beautiful and it really suits her. **Thank you so much Tilly for being so brave and for raising so much money!**



CHRISTMAS RAFFLE

Huge thank you to Iain Milligan for providing a headline prize – a gold and diamond necklace - for our Christmas raffle.

With such a stunning prize it comes as no surprise that the sales of tickets amongst patients, staff and supporters went really well - thank you to everyone who purchased tickets.

Over £1,500 was raised.

The raffle was drawn in clinic by Dr Mike Picton on Friday 14th December. Tricia Heavyside was the winner of the necklace which she now wears with pride! 2nd prize, a night at The Principal Hotel, was won by Jane Bakash and 3rd prize, a Christmas hamper, was won by Marieanne Fishwick.

SPOOKY HALLOWEEN FUNDRAISING!

In our last Whispers we were delighted to share Caroline Williams story with you – in this issue we can tell you about a spooky event that Caroline organised alongside her mum, Linda Rowe. Caroline and Linda worked incredibly hard to put on a wonderful Halloween party at the Leesa Vain Dance Academy in Middleton. It's no exaggeration to say that the guests went all out with their Halloween costumes – judging the best costumes really was a tricky job! Caroline and Linda had contacted local shops and businesses and had a huge array of raffle items. The evening was full of pies and peas, games and dancing - great fun was had by all.

THANK YOU!

An astonishing £1,442 was raised on the night and in the words of Professor Phil Kalra: 'Events like this are so important, and together we can make life better for the many people living with kidney disease.' Special thanks to Caroline and Linda for all the effort and time that they put into this fundraising party – and of course, **massive thank you to all those who supported the event!**



£1442
RAISED



GLOW IN THE PARK!

Thank you to Janet Dickinson who completed the 5K Glow In The Park at Heaton Park on Saturday 27 Oct 2018 and **raised nearly £100 for KFL**. The event looked like great fun and we are very grateful for Janet for raising funds for us.

WHISPERS



THANK YOU!

ZUMBA MARPLE FIZZ AND FASHION SHOW

In November last year, Sarah Dalby hosted a Winter fashion and fizz show at Marple Cricket Club. Clothes were provided by SOS Bramhall and models were recruited from 'Zumba Marple'. Strutting their stuff on the dancefloor at Zumba is quite different to taking to the Catwalk but the Zumba girls did a fantastic job and once over the nerves, really enjoyed it!

Sarah and Hannah had a really busy afternoon setting up for the event and making sure everyone enjoyed their fizz as well as the fashion!

100 tickets were bought for the event and everyone had a great, fashionable evening with lots of new stylish winter clothes being bought! The event was a super success and raised over £500 for Kidneys for Life. Sarah, who also supports Kidneys for Life by running the Zumba warm up at our Santa Dash, is planning another fashion show in Spring 2019 – details of which will be posted on our website and Facebook page.

Thank you so much for your support Sarah and Hannah and we're really looking forward to your next event!



50K/50M KIDNEY CIRCULAR CYCLE RIDE

The Circular 50k/50m Cycle was on Sunday, 8 October last year which seems ages ago now. The One-Day Cycle route was changed to a circular ride enabling us to have two routes – 50 miles for the more experienced cyclist and 50 kilometres for everyone else – and it worked brilliantly!

There was a great atmosphere at the start with over 50 cyclists gathering together to support Kidneys for Life. There were transplant patients, dialysis patients, families, friends, researchers and medical staff.

Setting off from MRI the longer route went as far as Knutsford, cycling through beautiful Tatton Park and back through Lymm to MRI. Whilst the 50km cyclists followed the same route but cut out Tatton Park.

The weather was mixed; sunny spells interspersed with a cold wind but it was a lovely scenic ride with a stop at the Green Dragon at Lymm where refreshments were provided to keep those, by now, weary legs going.

Cyclists were greeted back at MRI by supporters and volunteers cheering them in.

The whole day was captured on film by Jo Jones Photography for everyone to download from the website. Tesco provided the bananas and Archers Caterers, from Altrincham, donated nibbles for the half-way stop and Karen & Nigel volunteered on the day. At MRI Karen, Judy, Lisa, Joanne, Janice, Nina, Paul & Jane manned the start and finish and served some welcome refreshments.

The Cycle Ride was organized by Chapeau Events and everyone arrived back safely. The incredible “Two Guys” on their tandem finished at Knutsford but they had already cycled from Knutsford to the start at MRI so could be excused.

Another great Kidneys for Life event! You can register now for this year’s Cycle Ride, Sunday, 8 September.

ELLIOTT FAMILY STORY

In the summer of 2013, while playing with her big brother Ben on holiday in the US, Natalie (aged 9) had an accident on a hammock and knocked out two of her adult teeth. Following a frantic 70 mile dash to the nearest hospital, the two teeth were forced back in at the hospital without anaesthetic. At that moment, we thought that was the worst of it but just before we left the hospital the results of a standard blood test done on arrival came back.

The American doctor treating her took us to one side and asked us if we were aware of any kidney problems. Natalie had never been ill and we thought it must be some mistake. He urged us to get her kidneys checked when back in the U.K. Six months later after numerous tests and hospital visits, Natalie was diagnosed with nephronophthisis, an incredibly rare genetic disorder of the kidneys which affects children and causes the kidneys to start to fail from age six. The only treatment was a transplant and both Joanna and Chris were tested; with Chris being the best match. Natalie was monitored regularly to ensure that we were able to optimise the timing of the transplant to avoid dialysis.

In the run up to the operation in 2015, we decided to raise money for Kidneys for Life as a small thank you for all the amazing staff who had helped Natalie at the Manchester Childrens' Hospital.

Natalie's mum, Joanna, decided to run the Manchester 10km, furthest distance that she and all her friends, family and Astrazeneca work colleagues that took part had ever run!! They've run the race every year since to raise additional donations.

Natalie's dad, Chris and 15 of his colleagues from M&G Investments did the Three Peaks Challenge (it was the week before Natalie's transplant and so Chris was only allowed to do one peak!). Chris also took on the challenge to run the London Marathon – training and running on that very hot day was gruelling – great achievement but never to be done again.

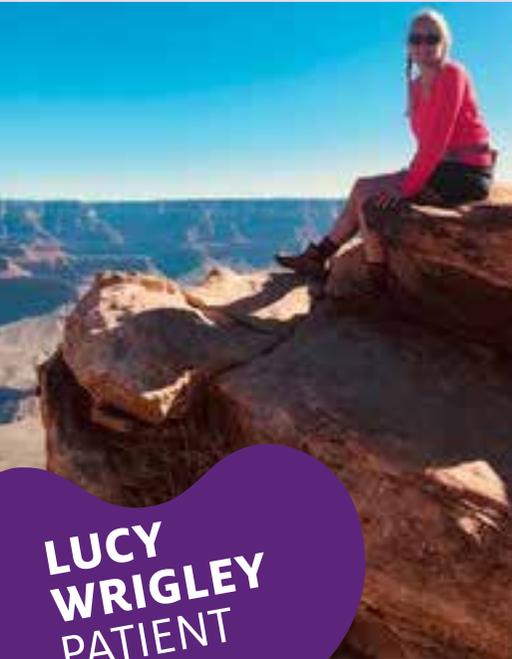
Other events have included Chris's bands gigs and the 50 year anniversary 50km cycle ride.

Natalie and her family have been truly humbled by the sponsorship received from friends and family and have raised over £70,000 to date.

Natalie had her transplant in October 2015 and has gone from strength to strength since. She regularly competes in the British Transplant Games and loves catching up with other competitors and supporters. She is now able to live a very normal teenage life!! She is now and will forever be very grateful to all surgeons, doctors and nurses that helped her manage her disease before her transplant and who post transplant ensure that she is fighting fit to ensure her amazing new kidney last as long as possible -

Thanks to all!!! Natalie XX





LUCY WRIGLEY PATIENT STORY

I was diagnosed with kidney failure shortly after I was married at 28 and on dialysis by 32, I was extremely lucky to be the recipient of a life saving kidney transplant in 2011 when I was 36, donated altruistically.

Having spent many years being treated at the renal unit in Manchester Royal Infirmary (MRI) I knew I wanted to do something to show my gratitude. When I heard that the charity Kidneys for Life were organising a trek through the Grand Canyon to raise funds, I knew it was a perfect way for me to show my gratitude and celebrate my good health.

I have a busy home life; with a husband, two young boys and also work so I was excited and anxious to set off on an adventure on my own from our local train station, I was waved off by family and treated to first class tickets to Heathrow where I boarded the plane to Phoenix!

Having arrived in Phoenix later that evening, I met my fellow trekkers for the first time and we travelled together to our first destination – a travel lodge for the night which I was delighted with I was so tired. We had our first taste of the Arizona heat, it was literally like standing in front of an electric fire! This was going to be tough....

The next day we went for an “acclimatisation trek” in Red Rock State Park near Sedona, it was hot, over 100 degrees Fahrenheit. All the months of training in North Wales over the British summer could not prepare me for that heat. During our first gentle 3 hour walk, one person was sick due to the heat and 2 people fainted! It was a shock to us all....

The next night we camped; as I went to bed, in my own 2 man tent one of the locals said if you hear a “yip yipping” in the night, it’s the coyotes making a kill! I woke at 3am to the sound of yipping and dying for the loo! There was no way I was walking across the campsite on my own in the dark with coyotes around, so I decided to quietly go next to my tent! Only to be told the next day that other people heard the coyotes and were up going to the loo at the same time.... hope no one saw me!

The next day was to be the hardest trek of the week; Hermit trail. We were up at 5.30, ready for breakfast, packing up camp and filling our water bottles. We’d be trekking 8 miles in total, 4 miles down into the canyon and 4 back out again, in over 100 degree heat, carrying all 5

litres of water required and food for the day. The heat is draining, it took an hour to walk one mile. Canyon trekking is the opposite to what us Brits are used to; in the morning when it is coolest and you are feeling refreshed you trek down, the easiest in my opinion, the air getting even warmer as you descend. All the time thinking you have to get yourself back out of this, there is no rescue out there and you barely pass another person!

We were rewarded on this trail with stunning views across the vast 18 mile canyon to the other side and a beautiful spring of fresh cold water at the bottom, aptly named Dripping Springs as it really was just a drip. But it was heaven for us, we washed the ice cold water over our heads, wet our clothes and drank from it. It was idyllic.

That was my first experience of canyon trekking, it was tough, exhausting, beautiful, vast, breath-taking and extremely memorable. The next few days trekking were just as memorable; especially to Ooh Ahh point, which really was Ooh Ahh; our late night swim under the stars in the turquoise waters of Lake Powel; Bryce Canyon with its amazing "HooDoo" rock formations and the Zion National Park were all just stunning. Nothing prepares you for the vastness of the canyons, the wilderness, the amazing scenery and the absolute stunning beauty.

I achieved all my initial goals taking on this challenge; to raise as much money as I could for Kidneys for Life who directly support MRI (over £11k) and to show my thanks to all the staff at MRI who have supported me over the years.

But I accomplished so much more; I was especially lucky on my trek to meet so many wonderful people, who had all been touched in

different ways by sadness & tragedy in theirs or their friends or family's lives. It sounds like we must have been a depressing bunch, but there was such amazing comradery and team spirit. We all shared our stories and helped each other along, even physically pushing people up rock sides at one point! I haven't laughed so much for a long time, all this made it an experience to remember for the rest of my life. It just shows the old adage what doesn't kill you makes you stronger is true and I am stronger for all my experiences good and bad.

I wanted to challenge myself & show my thanks and I am very proud of myself for accomplishing these things, but I am especially thankful for all the support I have received from my friends and family (especially the 70+ who joined me hiking Snowdon!), I couldn't have done it without them and we had such fun along the way! **Lucy**



WHAT WE DO WITH YOUR MONEY...



My name is Marcus Lowe and I am a PhD student at the University of Manchester. Kidneys for Life have been essential to my project – without their funding and support I would not have been able to even get started.

The title of my project is “HLA Class I and II Associations with Renal Dysfunction in an Aging Population”. I am trying to discover whether there are any genes which might cause renal failure. I am working on this project part-time – I also work as the Data & Audit Manager for the Renal Transplant Unit at Manchester Royal Infirmary. The project will take six years in total to complete. I’ve done two years already, and have made some interesting findings.

I am using data from UK Biobank, a company based in Stockport which stores health records and other information on over 500,000 volunteers. All the subjects are from Britain and are aged between 40-70.

The first tests I performed looked into whether there are any HLA types which are linked to kidney failure. HLA (human leukocyte antigen) is a set of genes in the immune system. There are many different HLA types – similar to the different blood types, but with thousands of possible types. They are inherited from parents, and have an effect on transplantation and other immune responses.

My first results suggest that there are some HLA types which lead to kidney failure. People with these types are more likely to have high creatinine, which is a sign of renal dysfunction. They may also be more likely to need kidney transplants than people who have different HLA types.

There may also be some types that protect against kidney failure. Patients with these types tend to have lower creatinine, which suggests that their kidneys are functioning well.

The next step in my research will be to investigate these genes further. Instead of using creatinine as a measure of each person’s kidneys function, I will use eGFR (which is the same test that doctors use). This will give a more accurate idea of how well the kidneys are working.

I will also look at whether any non-HLA genes are linked to kidney function. HLA is only a tiny part of human DNA – there might be other genes in other parts of the genome which lead to good or bad kidney function.

This work has the potential to change clinical practice and benefit patients. It could be used to help diagnose renal failure as early as possible. If there is a gene that is linked to kidney failure, people could be tested to check if they have the gene so that kidney failure can be caught as soon as possible. It could also change the way organs are allocated for transplant – priority could be given to patients who have the gene in question. That's all a long way off but anything that helps patients would be a great result!

Kidneys for Life has provided money to pay for my tuition fees and the data from UK Biobank, as well as a computer powerful enough to perform the tests. I am incredibly grateful to Kidneys for Life for giving me the opportunity to carry out such interesting work which has so much potential for patients. It would not have been possible to do this study without Kidneys for Life.





SANTA DASH

We were really excited to be working with the Romiley and Marple Lions on their 10th annual Santa Dash. It's always such a great way to start the Christmas festivities and this year was certainly no exception with an astounding 232 Santa dashers taking part in the event

The festive Zumba warm up was led by Sarah Dalby of Zumba Marple and really provided a great way to start the event.

We had some really enthusiastic fundraisers at the event – Lily-Mae and Pippa held a cake sale at their school which was incredibly successful and raised £70. Another of our young fundraisers, Logan aged 9, shared his account of the day:

'I wanted to do Santa Run 2018 so people in the world with kidney problems would

get well and have a better life. My friend is waiting for a new kidney and I wanted to run for him. I raised over £150 by asking the staff at my school-Warren Wood Primary. My Dad asked all his friends at work (Robins and Day Stockport) to sponsor me. Friends and family also sponsored me. My favourite part of the day was when I sprinted to the finish line with my Grandad and I liked getting a selection box at the end.'

£2,500 was raised from the event and we would like to say a huge thank you to everyone who took part and of course, special thanks to Terry and his team at The Lions for putting the event on for Kidneys for Life. We are already looking forward to this year's event which will take place on Sunday 1st December!

Photos – Jo Jones Photography

DAVID WRIGHT'S CHESHIRE WALK & DISCO PARTY

Thank you to David Wright for organising a 5 mile Cheshire Walk. We registered and had coffees at the Claret Jug at Mottram Hall before getting together for a group photo and heading off on the 5 mile walk.

It was a cold and crisp morning – absolutely perfect weather for a country walk. The walk was suitable for all ages and it was lovely to see so many families taking part.

The walk finished back at the Claret Jug where hot drinks and bacon butties were waiting for us. The hospitality from Mottram Hall was fantastic and David was delighted that the day raised £340 for Kidneys for Life.

David is also organising a Disco Party on 9th March at Mottram Hall, Cheshire SK10 4QT Join David Wright to celebrate at his fundraising it will be a fun night of surprises including a very special version of bongo bingo and dancing until 1am.

Tickets are £48 each - for tickets or to book a table contact David on 07545 421 381.

For those of you who've been to David's parties before you'll know that they sell out very quickly so don't delay.



BOOK NOW!

DISCO PARTY

9TH MARCH 2019 | 7:30PM TIL LATE

MOTTRAM HALL, WILMSLOW ROAD, MOTTRAM SK10 4QT
DRINKS RECEPTION FROM 6:30PM | 3 COURSE MEAL FROM 7:30PM

£48 PER TICKET - £480 PER TABLE OF 10

MEGA DJ LLOYD THOMAS • BANJO BINGO • PRIZES

DRESS CODE : A HINT OF GOLD

ALL PROCEEDS WILL GO TO 

EVENTS DIARY



4-6 MAY 2019

COAST TO COAST CYCLE

Join us on this 2 day iconic cycle event from Whitehaven to North Shields, as we conquer the infamous Coast to Coast route. Pedalling from west to east, we encounter the glorious countryside and scenic views of the District National Park and North Pennines. As demanded by tradition, you will get to dip your back wheel into the sea at the beginning of your epic journey and your front wheel at the end, then celebrate your achievement as you tick this challenge off your list!

Registration fee: £ 60

Minimum Sponsorship: £600



11 May 2019

TANDEM SKYDIVE

You're balanced on the edge of an open doorway of an aircraft flying at approx. 11,000 feet. Now imagine leaning forward out of that doorway into the beckoning blue sky, diving down through the air as you freefall at over 120mph. Taking place at Cockerham Airfield, Lancaster. Enjoy an 11,000 ft. adrenalin rush Tandem Skydive, freefalling to 5,000ft.

Registration fee: £50 Minimum

Sponsorship: £350



2019



19 May 2019
MANCHESTER 10K, HALF MARATHON AND JUNIOR & MINI RUNS

The Manchester 10k Run is the largest 10k in the UK will take place for the 17th 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

27 – 30 Jun 2019
LONDON TO AMSTERDAM CYCLE CHALLENGE

Cycle approx 160 miles over 2 days from London to Amsterdam, finishing with a free day to explore this vibrant city! Join us on this awesome challenge as we cycle together to raise vital funds for Kidneys for Life

Registration: £100
Minimum Sponsorship: £1,000

EVENTS DIARY



12 to 20 Sep 2019

CHINA TREK

Stretching 6000km in a dotted line across China, the Great Wall was begun in the 5th Century BC. As it snakes across the mountains it conjures up a sense of history which is difficult to grasp until you have had the opportunity to experience it. Our trek is very varied, as we pass through woodland and terraced farmland, and follow the contours of the beautiful hills and mountains in remote areas north of Beijing. We follow old sections of the Great Wall, as well as restored sections with smooth flagstones and lots of steps! This challenge is physically demanding and offers fabulous scenery and a fascinating insight into a rich culture and history.

Registration: £349

Minimum Sponsorship: £2,880

SUN, 8 SEP 19

50M /50K CYCLE FOR KIDNEYS FOR LIFE

Cycle either 50 miles or 50 kilometres through beautiful countryside going south west from the MRI, eventually cycling along flat Cheshire lanes as we pass through Dunham Massey and Ashley. The 50 mile loop continues through Mobberley and Ollerton before taking the path through the delightful Tatton Park, Bucklow Hill as both routes join again near High Legh before the celebration finish at the MRI.

Registration: £ 30

– Early Bird until 19 Jul (£35 afterwards)

Minimum Sponsorship: £50



2019



Sun, 8 Sep 2019 GREAT NORTH RUN

Starting in Newcastle upon Tyne the 13.1 mile route takes runners through the city centre towards the River Tyne where thousands of people will cross over the iconic Tyne Bridge, where if you're lucky, you might get a glimpse of the Red Arrows passing overhead. From there runners will travel through Gateshead while being entertained by our Bands on the Run. The route, lined by thousands

of supporters, leads runners to South Shields where at the top of Prince Edward Road the view of the sea is one of the most welcoming sights along the whole course. From that point there is just over a mile to go and the crowds get louder as runners make their way down the final straight towards the finish gantry.

If you were successful in your ballot entry for the Great North Run and would like to support Kidneys for Life whilst taking part please get in touch and join our KFL Team and we will send you a Sponsorship Pack including a Tshirt or running vest.

We also have a limited number of charity places for the run and if you were unsuccessful and interested in participating for Kidneys for Life. The registration fee is £75 and minimum sponsorship of £225. Please get in touch if you are interested in one of these places.

EVENTS DIARY



Sun, 1 Dec 2019

SANTA DASH AT MARPLE

Date for your diary more details later in the year.



Sun, 8 Mar 2020

AFTERNOON TEA

Date for your diary more details later in the year.

21 & 22 September 2019 HELL VALLEY EXPERIENCE

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

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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Mobile: 07714 864833

victoria.thomson@kidneysforlife.org
Mobile: 07507 001829



CLIP 'N' CURL

We always love to hear from shops and businesses who have chosen to support Kidneys for Life and it's always especially nice when we can go over to meet our fundraisers.

We were invited to Clip 'n' Curl in December to be presented with a cheque for an amazing £700 (one of many donations made by the Salon!)

The morning at the hair salon in Bolton was brilliant – the welcome and hospitality were both so warm, it was clear why they have so many repeat, loyal customers! Whilst there we were able to chat to the salon proprietors, Deidre and Hayley, who regularly run raffles and coffee mornings at the salon.

We also met a loyal customer, Barbara, who has been coming to the salon for many years and is also a kidney patient and we heard from salon co-owner Deidre whose grandson, Jacob Ogg-Bleakley, is also under the care of the Renal team at the RMCH. Jacob is now 8 years old, he had nephritic syndrome from the age of 1 and was very poorly. Jacob has now been in remission for the past 2 years and is doing very well growing up fast with a wonderful life.

Thank you so much to all the staff and customers from Clip 'n' Curl for supporting Kidneys for Life and for such a warm welcome at your lovely salon!

WHISPERS



CIRQUE DU SOLEIL

Back in September Kidneys for Life were extremely lucky to receive some complimentary tickets to the Cirque du Soleil OVO show at the Manchester Arena. Here is what one of our lovely young dialysis patients, Kim, said about the show!

'Cirque du Soleil Ovo was an amazing night, the performance was an incredible sight I won't forget. The acrobats were incredible from their detailed costumes to their daring tricks, and the hilarious stage acting. Everyone was amazed at how they were able to perform such wonderful things. An amazing night out thanks to Kidneys for Life.'



DAVID WALLIAMS - SPECIAL VISITOR ON THE CHILDREN'S DIALYSIS UNIT!

It was no ordinary day for the children on the dialysis unit back in November when the fabulous David Walliams called in! He spent time lots of time chatting to the children and also handed out copies of his new book. He is pictured above with Pippa and Maisey.

Maisey said that David was really friendly and asked her about how she gets to the hospital - when she said that the traffic is often a nightmare his response was 'I'll have to get Simon Cowell to lend you his plane!' Pippa said 'It's the second time I've met David and he's lovely. He's also my favourite judge on Britain's Got Talent!' Following the visit David very kindly arranged for the girls and their families to have complimentary tickets to Britain's Got Talent. An amazing treat that the girls are definitely looking forward to!

GREEN FAMILY FUNDRAISING PARTY

A huge thank you to the whole Green Family who hosted a fundraising party at The Laurels, Charnock Richard back in October. The room was decorated and looked stunning, the disco lights were flashing and everyone was definitely ready to party! 160 people attended the evening, a mixture of adults and children, and it's no exaggeration to say that the party was a huge success in every way.

Fun was had by all, a lot of sausages and chips were eaten, raffle tickets were sold along with specially designed Kidneys for Life keyring bottle openers which were a complete sell out! The young members of the Green family added that their favourite part of the evening was going round and collecting all the money in the buckets and all the dancing! **The result was a truly outstanding £6078 raised for Kidneys for Life.**



£6078
RAISED



IN MEMORY OF ROBERT HARRISON

On a VERY wet Sunday morning Katie and Steve set off on the Manchester Half Marathon to raise funds for Kidneys for Life as a tribute to their Grandad Bob who, after many weeks of being cared for on the Renal ward at Manchester Royal Infirmary, sadly passed away on 28 July 2018.

The route took them along Washway Road in Sale, where we waited to cheer them on. Whilst they were busy running the loop through the local roads we 'raced' to meet up with them again, because the route was also going to take them past Sale Cemetery where Grandad Bob's ashes had just been placed alongside his beloved wife, Lily. This time we handed Katie and Steve a bunch of flowers each and they made a quick detour to place them with Grandma and Grandad - a fitting tribute to what would have been Grandad Bob's 90th birthday two day's previously. It was a very emotional moment. Then Katie and Steve were on their way to rejoin the race.....

Having cheered them on their way, we headed into Sale for a coffee and pastry at dad's favourite place - Costa! On the way, we passed Sale Salvation Army Band, huddled under a tiny garden gazebo, playing to the runners and spectators - brave lads! And as dad had been a lifelong member of the Salvation Army, playing in the band at Sale until into his eighties, that somehow seemed a very unexpected fitting tribute.

Katie and Steve went on to finish the race in an incredibly good time of 1hr 56mins. Great going, a proud moment. **They raised around £487.50.**

Another proud moment was when Jessica, who, in her first few days at at Flixton Girls School, asked if she could bring some cakes in to sell to her classmates to raise funds for Kidneys For Life, in memory of her Great Grandad Bob. The school

went the extra mile and asked Jess's class to donate cakes to sell to the whole school, and they raised £188.50. Well done Jess (and mum), Class 7FH, and huge thanks to the school !

We are so grateful to all our friends and family who have sponsored and donated so generously to MRI's Kidneys for Life fund, raising just over £1,000.

Words cannot express our appreciation for all the care my dad received, from the Pre-dialysis team, the staff at Altrincham Dialysis Unit for over 5 years, and special thanks to all the staff on Ward 37 at MRI for their excellent care and dedication in looking after him through his final weeks and last few hours.

And the one who would have been most appreciative of everyone's efforts would be our Dad, Bob...

Sincere, heartfelt thanks to you all. God bless,
Jean Cairns & Ken Harrison'



REMEMBERING...

Margaret Ashton

Sylvia Austin

Ann Booth

Audrey Brown

John Buntin

Vivien Clarke

Maurice Wilfred Earlam

Shaun Fethers

Robert Firth

Alan Gotts

William Gratton

Robert Harrison

Patrick Joseph Long

Jessie MacKinnon

Susan Myatt

Jeffrey McKeever

Jedd McKeeves

Anthony Needham

Isobel Nicholson

Joseph Priestley

William Rickard

Anthony Riley

Elizabeth Worsnip

Charles Youngson





BRS YOUNG ADULT CONFERENCE 2019

Kidneys for Life were really happy to join forces with Hope KPA and Kidney Care UK in providing funding for the 2nd BRS Young Adult Conference which took place at Salford Royal Hospital on 28th January.

The day started with a welcome from Dr Tina Chrysochou and then first up was Maddie Warren – AKA Queen of Dialysis – whose talk on how she dialyses to live rather than living to dialyse was nothing short of inspirational as she spoke about skydiving and running the London Marathon.

As the day continued we heard from other young adult speakers as well as from medics from across the country whose topics included the health effects of sleep deprivation and ongoing renal research projects for young adults. Feedback on the day was incredibly positive and we look forward to being part of the Conference in future years.

GIFT CARDS

Kidneys for Life now has a range of gift cards designed for free by Danny Cameron whose son has chronic kidney disease.

There are six designs, four birthday cards and two general cards. They are £1 each and you can buy all six for £7.50 (inc P&P) online via our shop: www.kidneysforlife.org/shop. Alternatively they are available in clinic – just let us know when you will be attending.



KAREN'S SALFORD FUNDRAISING STALL

We would also like to say a really big thank you to Karen Ainsworth who continues to run a stall at Salford Royal on alternate Tuesdays – whether it's a tombola or a raffle that Karen is running she always puts 110% effort in!

Karen's dedication and enthusiasm to Kidneys for Life's fundraising is outstanding and we are delighted to report that her fundraising total to date stands at over £14,000. Thank you Karen and also all those who support her stalls at Salford Royal!

VASCULAR ACCESS REPORT

The 2017 PREM (Patient Reported Experience Measure) survey, co-ordinated by Kidney Care UK and the UK Renal Registry, had good and bad news for kidney units.

While most of the 11,027 kidney patients completing the survey highly rated their overall care, many haemodialysis (HD) patients were dissatisfied with their experience of needling—i.e. how often the kidney team inserted needles with as little pain as possible. Satisfaction with needling also varied widely between kidney units.

“This highlights that vascular access is one of the most important—and challenging— aspects of kidney care. Vascular access is a patient’s lifeline because good dialysis depends on it. Access must be ready for the start of dialysis, and then looked after to make sure that it’s functioning correctly,” says Alayne Gagen. Renal Vascular Access Nurse Specialist for Manchester Royal Infirmary, and recently became Co-Chair of the British Renal Society Vascular Access Special Interest Group (BRS VA).

Alayne recommends discussing vascular access as soon as possible — certainly when eGFR is declining towards 15 — and it should at least be broached in the pre-dialysis or low-clearance clinic.

The prospect of dialysis can be unnerving, and Alayne believes that every patient deserves a great deal of empathy.

“Health professionals need to take a step back and understand each patient as an individual. Some people may not want to talk about access. This applies especially to those with acute kidney injury (AKI) or who have been diagnosed without warning with kidney failure and need to start dialysis immediately, as they have so much to absorb. And some patients do not feel ill even with very poor kidney function, while others see access as a step towards dialysis and feeling better. And every patient has lots of other concerns, such as the future of their family, job and other commitments,” she says.

Fistula First - There are four types of vascular access, but an arteriovenous fistula (AVF) is the gold standard. One reason is that it gives a good blood flow, which increases the effectiveness of dialysis, in turn improving health and wellbeing. Alayne adds: “Since a fistula is made from your own blood vessels, you do not have a foreign body permanently inside you. Compared with other types of access, there is less risk of clotting and infection, so you are less likely to need hospital stays and antibiotics. A fistula also enables you to continue most of your daily activities. You can have a deep bath or a

long, hot shower, and go swimming—none of which are advisable with a central venous catheter (CVC) or line.”

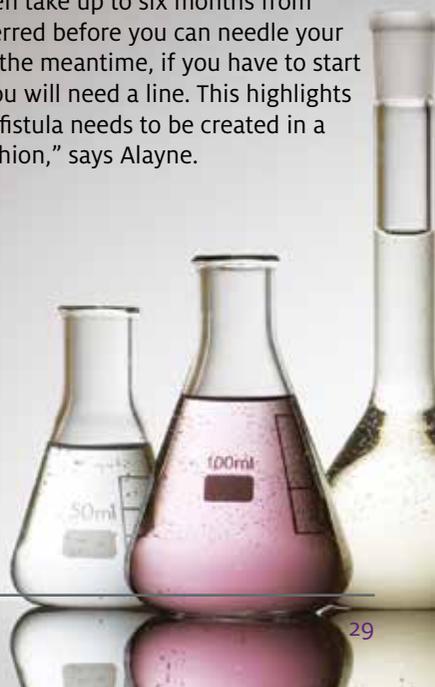
According to Alayne, the main drawback with a fistula is that it might not work, or can stop working: the vein can become narrow (stenosis) or it can clot and become blocked. It can also be difficult to balance the restrictions of a limited fluid allowance against maintaining the hydration needed for a good blood flow—a problem in very hot weather, or during any illness that causes diarrhoea or vomiting.

Some people also worry about the fistula’s appearance. “Patients tell me that they do not want ‘those lumps’ on their arm. The usual cause of lumps or aneurysms is area puncture—i.e. the fistula is needed or cannulated in the same place every time. ‘Rope laddering’ or the needling along the length of the fistula is recommended and will help to reduce the likelihood of aneurysms,” says Alayne.

Buttonholing is a newer method of needling that is less likely to cause aneurysms. Instead of sharp- pointed needles, blunt needles are inserted at the same two positions each time to create a tract or tunnel into the fistula—like the hole in the skin created by a piercing. It takes about six sessions to form buttonholes suitable for dialysis.

“At MRI, we train all our home HD patients to buttonhole. It can be difficult to use buttonholing in a dialysis centre unless the staff have received specific training. However, patients can learn the technique and do their own needling within the main unit—something we do encourage at MRI. This is because, in order to form the tracts, the same person must do the first six initial cannulations with the sharp needles, and we cannot always guarantee this in a busy dialysis unit,” explains Alayne.

Fistula Surgery - When you are ready to go ahead with your access, the usual procedure is to be referred to a vascular surgeon for a consultation - at MRI the wait is 4-6 weeks. “It can then take up to six months from being referred before you can needle your fistula. In the meantime, if you have to start dialysis you will need a line. This highlights why your fistula needs to be created in a timely fashion,” says Alayne.



WHISPERS

At the one-stop appointment with the surgeon, your veins are 'mapped' with ultrasound to see if they are suitable for a fistula, either at the wrist (radial fistula) or at one of two positions at the elbow (brachial fistula). One of the latter may involve a second operation called superficialisation, which should be discussed during the consultation.

At MRI, the fistula operation takes place 3-4 weeks after the one-stop appointment, lasts for 30-45 minutes and is usually done under local anaesthetic. A general anaesthetic is possible if you cannot face being awake, but this means a longer wait for surgery because of the need for pre-operative assessment and possibly an overnight stay in hospital.

You can go home after the operation when the surgeon is happy with your recovery, usually after 4- 6 hours with local anaesthetic. After your operation, you should not drive or lift heavy objects for two weeks. Your kidney unit should advise you when and how to start exercising your fistula arm to improve blood flow and help your fistula to develop.

From now on, check the appearance of your fistula and feel for the thrill (the buzzing sensation under the skin) every day. Contact your kidney unit at once if the thrill stops, or the fistula feels hot, looks red, or is painful.

"I strongly advocate that patients learn to be experts about their fistula. Sometimes I suggest that buying a cheap toy stethoscope so that you can get used to listening to sound of the thrill or bruit, " says Alayne.

Starting dialysis - At the follow-up appointment 6-8 weeks after the operation, an ultrasound scan checks the depth, diameter and flow of blood of your fistula to see if it can be needled (called maturation). Should a superficialisation be needed, it will be booked after the follow-up appointment, and is generally done under a general anaesthetic. Pre-operative checks should have already been done, but if not, an appointment will be sent before the operation date is given.

The early days of needling a fistula are often a worrying time for patients. According to Alayne: "We sometimes cannot avoid infiltration (when a needle goes into the fistula and out the other side, or nicks the vein wall). If the vessel wall is still fragile, the fistula may blow - i.e. the area will swell and pressure needs to be applied quickly, as it will cause bruising under the skin. It is the job of professionals to support patients through this experience".

"Vascular access is a patient's lifeline because good dialysis depends on it"

Alayne stresses that pain should never be a problem when needling a fistula or graft. "I always advocate that patients should have some form of local anaesthetic if they wish (at MRI we offer three types). Health professionals would not have dental treatment without anaesthetic and it is unacceptable to needle a fistula without offering pain relief, especially at the first of needling of the fistula," she says.

Unfortunately, fistula surgery sometimes fails and not everyone is suitable for a fistula or

graft. Your artery walls may have become hardened due to deposits of calcium, while your vein can be too narrow. And sometimes blood vessels are too small or have been damaged due to other diseases like diabetes. This will be explained when you see the surgeon, who will then discuss your options for access.

According to Alayne, it is possible to dialyse long-term with a line, providing it is well cared for and is checked carefully at every dialysis. She also sees no objection home haemodialysis with a line as long as you have been thoroughly trained to identify and cope with any problems.

Improving vascular access care - The BRS VA are working with colleagues to improve vascular access care across the UK. Initiatives include clinical practice recommendations to improve needling technique, tools to improve safety, and a national survey of the structure of vascular access services.

“By optimising vascular access services throughout the UK, our aim is to raise standards, which will in turn improve patients’ wellbeing and the safety of their kidney care,” concludes Alayne.

Janet’s story - Janet Loftus, 59 lives in Manchester, and has been dialysing for 5 years. She dialyses at a hospital unit for four hours three times a week, and has started to self-care. At present, she sets up her dialysis machine and dressings table and is hoping to start inserting her own fistula needles. Three months after starting dialysis with a line, Janet underwent her fistula surgery at the one-stop vascular clinic in Manchester.

She says: “I hated dialysing with a line and could not wait to have it out and use my fistula.” After her operation, Janet exercised with a squeeze ball to strengthen her fistula, and still uses one every day to maintain the blood flow. In the early days of dialysis, Janet’s fistula blew a few times, but since then there have been no problems.

Janet says: “My fistula is amazing: it gives me a higher pump speed, so I feel much better than with a line. I can also do more. Before my kidneys failed, I used to go swimming with my granddaughter and she was devastated when she found out I could not swim with a line. Now I have my fistula, she is happy that we are back in the pool.

Alayne Gagen

Renal Vascular Access Nurse Specialist at MRI



WHISPERS



WILKINSON STAR JASIC CLASSIC GOLF DAY

Wilkinson Star hosted the inaugural Jasic Classic Golf Day on 29 August at the Worsley Marriott.

The event was truly an unforgettable golf day.

So much thought, energy and effort had been put in to the organisation of the day from Tina Wilkinson-Bell and her team at Wilkinson Star. The golfers had everything that they needed - from welcome coffees and bacon butties through to Jasic branded golf accessories. The sun even shined! Nothing had been forgotten, nor could any part of the day or evening have been any better, with exception perhaps of one or two of the golf shots, something that was all captured on camera and shared with the guests at the evening dinner by golf entertainer, David Edwards!

In the evening Dr John Wilkinson OBE, Chairman of Wilkinson Star welcomed more guests for the fundraising dinner. We also heard from Professor Phil Kalra and transplant patient, Iain Milligan.

We had a wonderful video message from Mr Pan Lei, President of Jasic, who generously donated \$5000 to Kidneys for Life. We were thoroughly entertained by comedian Mick Miller and wowed by signer Lauren Waterworth. The evening concluded with a very successful auction and raffle.

The inaugural Jasic Classic Golf day was an enormous success on every level – one guest described it as the ‘the best golf day they have ever attended’ and a whopping £17,126 was raised for Kidneys for Life. Thank you to the Wilkinson family, all those at Wilkinson Star who put so much into putting the day together and to all those who were so generous on the day.

The 2019 event has already been confirmed – Friday 6 September. It will be another sell out golf day so if you’d like any info contact us sooner rather than later!

STEPHEN & TRICIA HEAVYSIDE

What a year 2018 was for Steve and Tricia Heavyside. Not only did the couple from Barrow-in-Furness celebrate their Ruby wedding anniversary but it was also the year in which Tricia donated a kidney to Steve!

In Steve's words: 'In April 2018 when my kidney function was down to 6% and I had been on Peritoneal Dialysis for 12 months, I finally received a kidney transplant lovingly donated by my wife Tricia. This was after three failed visits to Manchester for transplant that unfortunately didn't go ahead. This was a very distressing time for myself and my family, but due to the fantastic work and science my transplant finally went ahead! After which my kidney function has reached 50% allowing me freedom from the dialysis machine, energy, and most importantly allowing us to make plans for the future.'

Steve certainly hasn't wasted any time in making future plans – he will be taking part in our Portugal Spring Cycle Ride in March this year – an event which he is using as a training event for his big cycle event which will take place in November this year – Vietnam to Cambodia!

Fundraising for the cycle events has also been in full swing – Websters Fish and Chip shop based in Baildon held an incredibly successful fundraising evening in the run up to Christmas which **raised an amazing £1400.**

A special thank you to Ann and the team at Websters for putting the event on!

Steve and Tricia finished the year on a high as they formed part of The Gifted Organs Choir – an incredibly special choir which was formed by James Tottle and is made up of patients who have either received a transplanted organ or have donated an organ. The group released a single called "Tomorrow" in the run up to Christmas and were featured in The Sunday Times and invited on to The One Show to promote both the single and organ donation. The single can be heard on Youtube - <https://www.youtube.com/watch?v=5jz1v-CM1bU>

To top it all Tricia also won first prize in our Christmas Raffle. Steve and Tricia have more fundraising events planned for the year details of which will be posted on our website and social media pages.



DIFFERENT WAYS TO GIVE TO KIDNEYS FOR LIFE

Amazon Smile

AmazonSmile is a simple and automatic way for you to support Kidneys for Life every time you shop, at no cost to you. When you shop at smile.amazon.co.uk, you'll find the exact same low prices, vast selection and convenient shopping experience as amazon.co.uk, with the added bonus that Amazon will donate a portion of the purchase price to Kidneys for Life.

To shop at AmazonSmile simply go to www.smile.amazon.co.uk from the web browser on your computer or mobile device. You will see eligible products marked "Eligible for AmazonSmile donation" on their product detail pages.

You use the same account on amazon.co.uk and AmazonSmile. Your shopping cart, Wish List, wedding or baby registry, and other account settings are also the same.

To support Kidneys for Life on your first visit to www.smile.amazon.co.uk you need to select a Kidneys for Life to receive donations from eligible purchases before you begin shopping. Amazon will remember your selection, and then every eligible purchase you make will result in a donation of 0.5% of the net purchase price (excluding VAT, returns and shipping fees) of your eligible AmazonSmile purchases.

Please support Kidneys for Life – every little helps.



Regular Giving

A regular gift, perhaps just a few pounds per month or whatever you can afford, helps us enormously. With a regular gift we can plan ahead far easier and you'll not only be making a difference today, but every day. So how can you make a regular gift? Please see the enclosed Regular Giving leaflet and complete the form to start your regular gift and return it to Kidneys for Life.

Alternatively, if you use Internet Banking, you can set up a Standing Order, payable to Kidneys for Life online using our bank details:
Sort Code: 16-30-15 Account Number: 11424879.





Facebook Fundraisers

We've seen a real increase in people setting up Facebook birthday fundraisers for Kidneys for Life – it's a great way to raise money for Kidneys for Life and also to spread word about the charity! The fundraisers are easy to set up and can generate a significant amount of money without too much effort.

Georgina recently had a page which went on to raise £215. This is why she decided to support us: 'Approx 5 years ago I was diagnosed with FSGS a chronic disease of the kidneys. I only knew through doing a routine urine sample at my GP.

At the time of diagnosis I was pregnant with my first child and was told I may not be able to carry a child to full term due to the strain on my kidneys. Now 5, almost 6 years on I have 2 beautiful girls who I am thankful for every day and to have been able to carry to almost full term myself. This organisation is a close one to me as I am personally affected with kidney disease and I know many others who are too. It's opened my eyes at how important kidneys really are and how I went undiagnosed for years and never knew there was anything wrong.

I hope by raising money and awareness of Kidneys for Life it may open others eyes on kidneys and how we need to keep them as strong and healthy for as long as possible.'

Along with Georgina Swann we would like to thank Danielle Aspden, Gillian & Alan Barnes, Emma Bicknell, Natasha Collum, Alan Dodd, Rebecca Hampson, Chris Hulme, Ashleigh Michaela, Sarah Mitchell, Adelle Morrison, Kelly Richardson, Alison Shute, Nicky Tierney, Penny Wood & Simon Yates who have raised nearly £2,000 between them.

If you would like any help in setting up a fundraising page then please get in touch and we'll be more than happy to help you!



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.

£10

£25

£50

Other amount

Please make cheques payable to **Kidneys for Life** I want to Gift Aid my donation*

We would like to keep you informed from time to time about what we do and how you can support us. Please let us know how you would like us to contact you (tick the relevant boxes)?

By Email

By Phone

By Post

Signature

Date

Your details will only be used by Kidneys for Life, we will never give your information to other organisations. We will keep your details safe and you can change your preferences at any time by contacting our Fundraising Team at fundraiser@kidneysforlife.org or on 0161 276 6671

To donate online visit www.kidneysforlife.org

* 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.