

WHISPERS

kidneysforlife.org

Spring
2021



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LIFE DURING LOCKDOWN

AN UPDATE FROM THE KFL TEAM – At the end of 2020, we said farewell to Carol Bonham as she retired from Kidneys for Life – we thank her for all that she has done for KFL over the past 8 years and wish her all the very best for a happy and healthy retirement. We were delighted to welcome Penny McKnight to our team and she looks forward to being able to meet out many of our supporters over the coming months. Although the start to 2021 has been difficult we continue to look forwards and to brighter days ahead. In this issue, we start by letting you hear from some of our Kidneys for Life Trustees, (all of whom are medics and who oversee the running and governance of Kidneys for Life in their very limited free time!) also from some of our researchers, Marcus Lowe.

As with everyone, we have had to make changes to the way that we work and have desperately missed being able to catch up with supporters at the hospital. We've also become very proficient in Zoom meetings and we were completely overwhelmed by the number of Christmas card orders that we received online!

RACHEL LENNON - The past year has been busy! We have all needed to be adaptable to fast moving situations. My role is split between being a Paediatric Nephrologist at the Children's hospital and a research group leader at the University. In April and May, I joined my clinical colleagues fulltime at the hospital to cover our department. In paediatrics we haven't seen many children with complications of COVID-19 but the major challenge has been to continue to monitor and treat children with kidney problems. From June we restarted research as most University labs closed during lockdown. We are now all back in the lab, although not at the same time to ensure we are able to distance and keep safe. We have also managed to meet on Zoom as Trustees for Kidneys

for Life. Overall, it feels as though there is lots to catch up but I'm so relieved that my clinical, research and Kidneys for Life colleagues are well and keeping safe and that has to be the priority in a pandemic.

AMRIT KAUR - I work as a paediatric nephrology consultant (children's kidney doctor) at Royal Manchester Children's Hospital. In addition to the day to day duties of a doctor I am also the departmental lead which means I am responsible for the running of the department. Ordinarily this role focuses on improving the service we deliver to our patients and their families, looking after the workforce and anything in between! During lockdown we have had to re-design the department so that children with kidney disease can still safely come to the hospital for clinic visits and receive dialysis treatment. Unfortunately children's kidney transplants were suspended during this period but since May I have been working closely with my department, RMCH managers and the adult kidney team at MRI to safely re-start the transplant programme in children. I'm pleased to say that all aspects of this service are now open. It's been an interesting few months both professionally and personally, I'm so grateful to work within such a supportive department and have been amazed at everyone's resilience and adaptive nature during such strange times.

AFSHIN TAVAKOLI – As with everyone, life has been very different for me this year especially during the initial months of lockdown. The way services ran at the hospital changed and as we are all aware the transplant service was temporarily put on hold. Those who know me, know that I am positive, happy person. So throughout this year I have done my best to stay cheery and upbeat and hope that has shone through on my social media posts and on the messages that I shared through the Kidneys for Life updates. While Manchester transplant services were suspended, the transplant team worked hard to transform the way we deliver care and redesigning clinics to safely look after and consult with transplant patients face to face or remotely. The Transplant Program resumed

in July and it was a great pleasure for our team to be able to get back to helping our patients with vital lifesaving transplants. I was lucky and privileged to be able to do the first transplant on my on call when we relaunched.

I can't praise enough the team and I am so proud of how we have managed to care for our patients in and out of the hospital, inpatient and outpatient.

I have missed seeing patients at the hospital and at fundraising events – it's now over a year since my last KFL challenge and that makes me even more keen to get training and ready for the 2021 Vietnam to Cambodia cycle.

SMEETA SINHA - A lot has changed since March 2020 and last year really was a whirlwind of change. Just before the first lockdown, I had stepped down as the Clinical Director of Renal Services at Salford Royal and was looking forward to spending more time with patients, working with Kidneys for Life as a new trustee and leading the North West Renal Network to share good practice from around the region, particularly around transplantation, dialysis and early detection of kidney disease. As a new KFL trustee I was really excited about fundraising and supporting projects that would benefit patients in Greater Manchester and beyond. Instead, I found myself seeing less of my patients as clinics rapidly moved to virtual or telephone clinics. I still miss the face to face contact and hope that this is something we can bring back in some shape or form but for the time-being I understand how important it is to keep everyone safe. As well as trying to do my clinical work, albeit differently, my North West role needed me to support intensive care units. You will all have heard how unwell some people became and how they needed support in intensive care, sadly many of these people also developed kidney failure. We had to quickly develop ways of delivering kidney dialysis treatments amidst a national shortage of machines and fluids. It hasn't been easy but the intensive care and renal communities came together and ensured that no

one went without kidney support. As a network, we also had to ensure that patients' voices were heard, particularly around shielding and access to home therapies. I can't thank Rob Finnigan from Kidney Care UK enough for his support and guidance. As part of the North West Network I've seen colleagues and patients from Greater Manchester, Cheshire, Mersey, Lancashire and South Cumbria come together to keep our services going and our patients as safe as possible. We've learnt an awful lot which I hope will help us over the next few months but also the years to come.

MARCUS LOWE also gives an update on his research project which he initially outlined in Whispers back in Spring 2019 (If you missed this and would like a copy do get in touch) 'Since last year, UK Biobank has provided some extra data which has been very useful. I have used eGFR as a measure of kidney function, as well as a number of clinical indicators such as end-stage renal disease and chronic kidney disease. This has led to the discovery of 33 HLA types which appear to be associated with kidney function in white British subjects (11 of these genes are linked to worse kidney function, and 22 linked to better function). This has been written up into a paper which is currently undergoing peer review.

There were also four HLA types linked to renal function in African subjects, and this has been submitted to a different journal for peer review. Unfortunately, no associations were discovered in other ethnic groups, possibly because there were not enough subjects included in the analysis. Future work with bigger groups of people might reveal new associations.

Finally, UK Biobank have provided data on subjects with covid-19; I am currently using this to test whether there are any HLA genes which might be linked to increased or decreased risk of contracting the disease. Although this isn't related to kidneys, without KFL's grant I would not have access to this data so could not conduct this research.'

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



LANE END PRIMARY SCHOOL

Thank you to Lane End Primary School who organised an own clothes day for Kidneys for Life on World Kidney Day. The children (and staff and parents!) very kindly donated an amazing £204.84!! Thank you to Liz Edwards and her daughters, Emily & Grace for putting the idea forward at the school.

£204.84
RAISED

JAMES PARRIS-KING

Living in Aylsham, Norfolk, James Parris-King signed up for the Norfolk 10k Run to raise funds for Kidneys for Life. His niece, Kira, has been battling kidney issues since birth.

James describes Kira as “a very determined and inspirational little girl. Every day she has the biggest smile. Fighting through the pain and constant infections and currently on the transplant waiting list, Kira still manages to attend school and has a bright future ahead of her”.

If you'd like to support James and Kira you can donate on his fundraising page by going to: <http://www.justgiving.com/James-Parris-king1>



JANINE WINFIELD

Janine Winfield held an online raffle for a stunning piece of art to raise funds for the two Charities close to her heart – the NHS and Kidneys for Life.

The colours used in the art piece are both blue NHS colours and purple KFL colours.

Janine explained, “After having a life-saving kidney transplant 3 years ago I can now live my life to the fullest. If it wasn't for all the wonderful staff working for these two causes I wouldn't be here today”.

She was hoping to raise at least £500 to split between the 2 charities but actually raised an amazing £ 561.25 including Gift Aid.

A HUGE Thank You to everyone who bought a raffle ticket!

The winner was picked by Janine's beautiful football-mad 9 year old cousin, Lucy, who at the time was waiting for a life-saving kidney transplant.



PETER ROWLINSON'S ISOLATION GAMES!

Peter Rowlinson first contacted me in January 2020 - before we'd heard of COVID19.

He was letting me know that he and some family members and friends would be running in the Manchester 10k in aid of Kidneys for Life.

The reason for taking part and running for Kidneys for Life was that he would be celebrating the 30th Anniversary of his kidney transplant in June 2020 and he wanted to mark the occasion with several members of his family and friends. Peter wanted to use the opportunity to raise some money for Kidneys for Life, so he contacted me because he was wondering if he would be able to get some T- shirts for the team and he was thinking that he would probably set up a donation page for the team on JustGiving or Virgin Giving.

He explained, "At the age of 21 I was diagnosed with kidney failure and just a few months later in February 1983 I started on dialysis. After 7 years dialysing 3 times a week for 8 hours at a time (with a 10 month break in 1985 after an unfortunately short-lived transplant) I had a successful kidney transplant at the MRI in June 1990 - I remember it well as it was during the World Cup!!

This transplant totally transformed my life and I am now able to eat and drink (just like a normal person!) and go on holiday where and when I want. But better even than that, 18 months after my transplant, my wife Maria, gave birth to our beautiful daughter, Amy.

Completely unexpectedly, also at the age of 21, Amy too was diagnosed with kidney failure and after a tough couple of years on CAPD and then haemodialysis, Amy had a kidney transplant in January 2016 with a kidney donated by my amazing younger brother Ian and and their operations were carried out by Mr Tavakoli.

Amy is now fit and healthy and is married to Grant, who was inspired to take up long distance running to raise money on Amy's behalf and, after winning several local events, completed the 2016 London Marathon in a stunning time of just 2 hours and 25 minutes.

The next day I received notification that Peter had set up his fundraising page. Sadly, almost two months later I had to contact Peter to say the Manchester Run had been postponed to



September due to COVID19.

Then I received a second fundraising page notification – and I was mystified! It said, “Due to the postponement of the Manchester 10k the team, along with even more family and friends, are holding the “Isolation Games”. The Games will be a series of challenges to complete while we are in lockdown and the entry fees will go to Kidneys for Life.

I had been looking for an idea that would capture the imagination of kidney patients, shielding at home and here it was – ready-made for me! The Games were a series of challenges to complete while in lockdown and the entry fees would go to Kidneys for Life.

The challenges included the Teabag Challenge, Toilet Roll Keepy-Uppy, Dance Routines and the Isolation Games Bake Off. The videos were excruciatingly funny – it was hard to watch some of them with tears running down my face!

Such an extraordinary group of families and friends – Thank You all so, so much for sharing your skills, triumphs and defeats and I look forward to meeting you all at the next Manchester 10k!

Now let me introduce **JCS CONTRACTING** – a new enterprise that was also set up during lockdown - by John who is just 9 years old! John has been busy weeding and gardening (using his own mower and peddle tractor) and putting out bins for his neighbours. John is donating the money that he makes to Kidneys for Life and has already sent us £150. Awesome work John and you definitely earned your Kidneys for Life Hero medal!

THANK YOU!





MUGGERIDGE MARATHON

My name is Aaron Muggeridge and I ran my very own (made up) “Muggeridge Marathon” or a Muggathon if you prefer. I was prepared to run the full Manchester Marathon on the 5th of April and had raised over £400 but sadly because of recent events it was delayed until October.

One of the reasons I was running this was to be able to say, “I ran the distance of a Marathon BEFORE my 21st Birthday” (August) and the other reason was because my Nanny has been going to Dialysis 3 times a week for the past 11 years. The pain and burden this has caused throughout my family has affected the way I appreciate every day and never take a moment for granted. Very sadly, my Nanny passed away in Autumn 2020.

I decided to run for 24 hours straight and run at least 1 or 2 miles each hour, completing the distance of a Marathon in a day.

I started at 6pm on Friday 22nd May 2020 running 2 miles for every hour until 2am -it went by very quickly with very little pain. I slept for 3 hours until 5am then smashed

Around 7am with another 10 miles to go I got some breakfast down me and went to sleep until 10am. I ran for the next 3 hours and then a final 3 miles took me to the front of my house for the goal of the Muggathon!

On Saturday 23rd May 2020 at 1:26pm I completed it! I ran 26.2 miles over a 24 hour period. I was extremely proud of myself and I achieved something bigger than me. I had completed the Muggathon!

Some of you may have noticed I had a few hours until 6pm and so did I. My body was well enough, my mind was strong. So I pushed myself through the pain and the clicking knee 4 more miles to round it up to a total of 30 miles.

Having completed this challenge, it has changed my mindset and the way I approach parts of my life. I am content that I concluded something I set out to do. I am so grateful for the money I have raised for the Kidney for Life charity and will continue to train for the full Manchester Marathon.

A huge thank you to everyone who supported me and kept me going over those horrid 24 hours. Thank you to my girlfriend, Alex, who kept me laughing throughout the night and to my family, who made sure I was alive and well from start to finish.

You can donate on Aaron’s fundraising page by going to: <https://uk.virginmoneygiving.com/AaronMuggeridge>

CHAPEAU SOCIALLY DISTANCED CYCLE RIDE

It was a lovely sunny Sunday this year for the cycle ride. Caroline Clark who works in the transplant team at UHMN completed the 60km bike ride along with her partner Mike, her daughter Katie her very good friend Jacqui and Jacqui's husband Lyndon.

3 years ago Jacqui donated her kidney to Lyndon which made completing the bike ride super special particularly as it's the furthest they have ever cycled!

This fantastic team raised £200 for Kidneys for Life which we are extremely grateful for. We look forward to hearing more from them – maybe for our socially distanced Spring cycle.....?



LESLEY DUNN, transplant patient, took up sewing during lockdown and thanks to a generous donation Lesley was able to donate some face masks to kidney patients.

IAN WALLWORK'S EPIC SWIMMING CHALLENGE

In 2019 Ian retired from his opticians business and set himself a new and incredible challenge – becoming an altruistic kidney donor. In the April 2019 I donated a kidney to a lady in London and after a couple of weeks of soreness I gradually moved around more and after 3 months was back to swimming training. ‘

I had planned my next challenge to be a very taxing swim one year on from surgery, but Covid put paid to that. On 18 July I did a 10K swim in Salford Quays (in 2 hours and 50 minutes!!) with support from Matt and Emma Tonge.

My intention was to raise awareness of kidney donation and to show that after a relatively short period you can be just as fit and strong as before, you are sharing your health and well-being with someone and not giving away something that limits you in the future.’ Ian raised an amazing £2500 for Kidneys for Life and did so much to raise awareness of living organ donation.

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THANK YOU TO ANNIE AND HER SEWING FRIENDS!

Annie Thompson's son, Adam, is a kidney transplant patient which is why late last year Annie decided to hold a sewing workshop and invited her sewing friends to join her. Annie says, "They needed little encouragement as we are always up for a day of sewing and they were absolutely delighted when I told them that their workshop fees were being donated to Kidneys for Life".

These lovely ladies made table centre decorations, many with Christmas themed fabric which were then given as gifts. They used the church hall which is fairly small so they could only accommodate 10 ladies but we had a great day and raised £225 in the process. They were hoping to do another workshop this year but like everyone else their plans were scuppered.....never mind perhaps next year!

The patchwork quilt in the background is an example of the quilts Annie makes. This particular quilt is obviously made with a child in mind and backed with a warm snuggly fleece which makes laundering much easier.

Not only has Annie offered to make one of her beautiful quilts for Kidneys for Life but also some of her fabulous washable face-masks.

A BIG, BIG Thank You to Annie and her talented sewing friends!

KAREN AINSWORTH

Shhhhhh! I'm on a TOP SECRET mission....

Karen Ainsworth is one of Kidneys for Life's most consistent, regular supporters. Her reason for being so consistent is because her son, Sam, was born with dysplastic kidneys and he had to go straight on dialysis.

Luckily, Sam received a kidney transplant from his Dad but Karen knows a transplant doesn't last forever. Karen wants her donations to fund ground-breaking research projects to improve the lives of not just Sam but every kidney patient.

She holds table sales, raffles, tombolas, sells football cards and joins in Kidneys for Life events. Karen's walked the Great Wall of China, cycled from London to Paris, cycled from Salzburg to Vienna, cycled around Cheshire, taken part in the Santa Dash, attended the Children's Transplant Games, she's run the London Marathon, taken part in a Skydive, been submerged in ice-cold water during Challenge the Wild and slid down a Zip Slide across the Manchester Ship Canal.

In 2021 Karen's cycling from Vietnam to Cambodia to raise more funds for Kidneys for Life but last month she challenged herself even more.

In September Karen ran 5 marathons in 5 days! Wonderwoman!! So what's my mission? Karen once told me she wasn't a great fundraiser for Kidneys for Life because she only raises small amounts. How wrong could she be? So far Karen's fundraising has totalled £ 19,803.66.

Would you please donate on her fundraising page <https://uk.virginmoneygiving.com/KarenAinsworth1> to show her just how fabulous she is?



**EMMA &
STUART'S
'I CAN BE
YOUR HERO'**

Stuart and I became a couple on 16th September 1995. 10 years later we married on 16/09/05 little did we know that day saying our vows in sickness in health and I'd even picked 'I can be your hero' by Enrique Iglesias what was to come in our future. He is diabetic we didn't fully understand the complications that could follow. We have 2 grown up children now 25 & 21. Around 2013 we found out Stuart's kidneys were failing and was

functioning at 35%. At this time we didn't know anything really about kidney failure and transplants even though he has had 2 brothers with kidney failure who have sadly passed away. Fast forward to 2017 and we knew that Stuart would need a transplant soon as his function had dropped to 20%. As his function had been dropping for a while we had discussed all the options about transplants and dialysis options. I spent a lot of time researching transplants and the procedure I would have to go through to be tested. As they wouldn't start the testing until he was at 15% it was a waiting game. I was ready to start testing and we just really wanted to know if I was a match for him or if we would go with the pooled option.

Stuart rang me 1 day in October 2017 after his Kidney hospital appointment his function had dropped and they wanted to get him ready for dialysis or a transplant. The day after I rang the living donor co-ordinator at Salford Royal and she sent me a form to complete and bring with me to my first appointment in November 2017. The day arrived and I was quite nervous as I hate blood tests! The co-ordinator put me at ease about the blood tests and it was nowhere

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near as bad as I thought – I was feeling very pleased with myself after that appointment! I had to wait for blood results to say if we was a blood match and a tissue match. To my surprise I got a call that night we was a blood match. That was 1 test passed - it's actually very nerve racking waiting for the results. Every okay is 1 step closer to being able to donate. My co-ordinator then booked me for an appointment with someone who would check I was fully aware of what I was doing and to check my mental health. That was early January and was a really nice meeting she was really nice and asked me what I knew about donation. I told her everything I'd been looking at including a book about living donations on amazon. This book was quite true to everything I did. I got home that day feeling really positive. We'd not been home long and Stuart had taken our dog for a walk when I got that the call to say we were a match! I was quite emotional then and Stuart was shocked we were a match.

So onwards to more tests. Days after that Stuart was admitted to hospital with vomiting and his function dropped to 9% he started to get better and was discharged the day before i had to go to hospital for a kidney function test.

I had to be there for 10am and was having hourly blood tests and a scan to determine my kidney function. Finally got out about 3pm as was so hungry you can't eat while on this test from the night before. I went straight to Marks and Spencers for a butty! Results came in at 120 so another test passed. I was then booked in for x-ray and CT scan for the end of January. From the letters I was worried we would be there all day but was only there 2.5 hours. Booked in then took to put a gown on then they put a cannula in to administer they dye for the scan. It was all run to perfection, no waiting. In for x ray then took for scans where they put the dye in. This is the one where you feel like you're peeing yourself! Also left a funny taste in my mouth. Then back to x-ray then told to go for a wee then back to x ray. There was no waiting; they took me straight in. I felt like it went so quick I don't know if Stuart felt the same. He was sitting in the waiting room with all my clothes! Through all this our coordinator had kept in touch. I was struggling with how to tell people as I was worried my family might try to put me off. I knew exactly what I was doing and did not want anyone to have a negative thing



to say to me. Our children knew about every test and were fully behind my decision. So I decided to only tell the people who needed to know at first work obviously as I would need time off for appointments and they have been fantastic about everything. I then had an appointment in February to meet a doctor to go over my results. So this was it I was either going to be told yes or no. I will admit I was very nervous before this appointment and it didn't help that it had snowed that night so I was late and stressed. Turns out they were all late. Well blood pressure was a bit high when I got there no surprise there. Seen the coordinator then went to see the doctor. It's one of the most nerve racking things I have ever been through. You really want to be able to donate you know in your head and heart you want to but it all comes down to results and the doctor.

The doctor was happy for me to go ahead as long as my 24 hour blood pressure check was okay. This was booked for 27th March. It was slightly uncomfortable and was going off every half hour during the day and every hour at night. It actually only woke me once. So we then just had to wait for the doctor to check the results and forward everything on to Manchester Royal. He finally said yes everything was fine and everything was sent off to the surgeon. We got our appointment for April at Manchester Royal We were both quite nervous that day we didn't know what to expect. It was a very straightforward appointment. We met our surgeon Mr Tavakoli and he went through the operation with us both and all the things that could go wrong. Nothing I hadn't heard before. To our surprise he checked his calendar and said I can do the operation on the 29th May! So that

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was it all go from there. We had our pre op which was a quick appointment to go through our admission and we both had another ECG. A couple of days later they had to move the op back by 1 day.

We were busy up till then getting the house tidy and ready for when we were both recovering. The 29th finally arrived and we had to ring the ward at 2pm to check our beds were ready. They weren't and were told to wait for a call. That finally came at 6pm so that was it we was going. I was nervous. I was still worried in case it couldn't go ahead for some reason. Admitted had blood tests and met nurses etc. Operation morning arrived and they got me up nice and early! Got into my hospital gown, saw a surgeon and an anaesthetist to go over everything again. They said I would be going down at about 8.30am. So I decided to go and see Stuart before I went. He looked more nervous than me! Only managed to see him for a couple of minutes and they came to take me down. I had a really nice porter and a lady who stayed with me from taking me from the ward till I was put asleep. Next thing I know there waking me up in recovery. I wasn't sore, just very thirsty. Not sure how long I was there just that I was back on the ward at 3pm

was very groggy but they'd removed my kidney successfully and Stuart was still in theatre. A few hours later Mr Tavakoli came to see me to say all had gone well with Stuart and he would be back on the ward by 8pm. I don't really remember much else about that day. Think I just slept. So Thursday morning arrived and Stuart texted me to see how I was. It was the first contact we'd had since the op. He was sore but doing okay. The nurses said I could go and see him that day. They removed my catheter that morning and I was able to try to get up. That first time was really hard and that was when I really felt sore. It was sore to move and walking was at a snail's pace. I tried to see Stuart that afternoon but he was having a scan so I went back to bed. I wasn't very well that night and didn't manage to go back to see Stuart. Friday arrived and I was determined to see Stuart that day. I had stopped feeling sick so made the walk that afternoon for such a short walk it took me ages. I could see a difference in him straight away even though he was still on his drips and drains. Think it was then that it really sank in that it had gone ahead and was so far working. I was feeling a lot better by Friday night and even though it was sore I managed

to get about a bit more with the help of a towel secured over the cut with my dressing gown strap! That helped a lot. Stuart creatinine was dropping and function was up. Saturday morning I was told I could go home! It was really nice to get home even though I spent the next 4 days in bed most of the time. I kept in touch with Stuart all the time mainly him checking I was resting and not doing anything! I have 2 adult children at home that helped me through the first few weeks they cleaned and did shopping for us. We did have a scare when they was concerned about Stuart's creatinine and it really frightened me to think that the kidney could reject but they said to him that as I'm only small this was to be expected and the surgeon had to do a bit of work on my kidney before it was placed in Stuart. So panic over.

He was discharged exactly 1 week after the op and had to go back to the clinic twice a week. I won't lie, the next few weeks were very hard for me. I was on painkillers for 5 weeks. What was amazing was that Stuart was doing so much better than me. I was always tired and walking anywhere took me ages. To help with the pain I was using a hot water bottle as well. After 7 weeks

we both returned back to work. Stuart was on once a week at the clinic. My creatinine was 90 and kidney function 61 so I am very happy.

I don't have any regrets at all about my decision to donate and would do it again if I could!



EVENTS DIARY



24th April 2021 TANDEM SKYDIVE

Always an amazing event with our daring fundraisers.

Already signed up to this event is the lovely Marjorie who is taking part to celebrate her 80th birthday! There are still spaces so if you're tempted then do get in touch.

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: £400

<https://kidneysforlife.org/event/tandem-skydive-2021/>



Sunday 23rd May 2021 SPRING CYCLE

Why not join us for our very Spring Cycle! This 25 mile route is perfect for cyclists of all abilities.

Chapeau Events are fully supporting this awesome event and will be adhering to any social distancing measures in place at the time of the event...

Come join us and have some fun and raise much needed funds for Kidneys for Life.

REGISTRATIONS MUST BE COMPLETED – THERE WILL BE NO OPTION TO BOOK ON THE DAY!

The event is open to those over the age of 16 – those who are under the age of 18 must cycle with a parent/guardian.

KFL Socially Distanced Spring Cycle!

<https://kidneysforlife.nutickets.com/Santacycle2020>



2021



12th September 2021 **GREAT NORTH RUN 2021**

As a result of the global events in 2020, the 40th Anniversary Great North Run will now take place on 12th September 2021. It's always an amazing event and there is no doubt that the 2021 places will be snapped up very quickly!

We have only got 10 places available so if you are interested in running for KFL then please get in touch as soon possible.

Registration for the Great North Run is £75 and we ask that our runners aim to raise £225 per person.

<https://kidneysforlife.nutickets.com/54963591>

3rd October 2021 **VIRGIN LONDON MARATHON**

The Virgin London Marathon is back for 2021 and, for the first time ever, it will be an Autumn Marathon. Whether this is your first marathon or your 21st why not apply for a Kidneys for Life place?

Excitingly there are two ways to run the marathon this year. You can run the actual iconic marathon or you can apply for one of our Virtual Marathon places. It's known as a lifetime challenge and one of the most famous marathons in the world. If you have been lucky enough to get your own place in the ballot and would like to run for Kidneys for Life please get in touch and we can send out a running vest to you.

We only have a limited number of spaces so if you're tempted please do get in touch for more info –

penny.mcknight@kidneysforlife.org

EVENTS DIARY



26th September 2021 MANCHESTER 10K, HALF MARATHON AND JUNIOR & MINI RUNS

The Manchester Runs didn't take place in 2020 so it's going to be so special to take part in 2021! The Manchester 10k Run is the largest 10k in the UK and will take place on the same day as the Half Marathon which 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. You can also enjoy Kidneys for Life hospitality before and after you take part.

It costs just £45 for the Half Marathon and £39 for the 10k to register your own place.

More information can be found online at

www.greatrun/great-manchester-run. Just get in touch when you have registered and we will send you a T-shirt or Running Vest and a sponsorship pack.

10th – 20th October 2021 VIETNAM TO CAMBODIA CYCLE CHALLENGE

The event is now taking place in October 2021 and we would love to see our group grow! We have a closed Facebook group where we discuss and share training tips and this comment is one I thought was really relevant to share – especially if you are considering taking part but worried about the challenge itself:

'Most of the people who go on KFL cycle rides haven't been on a bike since they were kids but they take part and love the adventure. Anyone who has been on a past event will say it's not about how fit you are, it's more about sharing the achievement of completing the challenge and meeting wonderful people along the way.'

There is plenty of fundraising and training time so if you would like more info please get in touch.

Explore royal palaces, dazzling green paddy fields and temples on this enchanting cycle challenge across two beautiful countries. Take in the wealth of experience each has to offer – from the bustling Vietnamese city of Ho Chi Minh to the serene Cambodian temple of Angkor Wat – all whilst raising vital funds for Kidneys for Life.

Registration Fee: £399
Minimum Sponsorship: £3,800

<https://kidneysforlife.org/event/v2c/>

BBC NORTH WEST TONIGHT

Many of you may have spotted Lisa Blair, whose son Rory had a transplant back in 2018, on BBC North West Tonight. Lisa was interviewed by Roger Johnson and spoke about life during lockdown with her children and the anxiety that they faced as a family as lockdown restrictions eased. Lisa suggested that wearing an armband that highlighted a person is social distancing may be a good option as it would be easily visible and safe for all ages to wear.

We took Lisa's suggestion on board and now have our own branded Velcro armbands for sale. These will fit over coats or jumpers so will be suitable for use in all weathers. We are selling them at cost price - £5.

Lisa wore her Kidneys for Life t-shirt for the TV interview and even whilst the interview was being broadcast orders for the t-shirt were coming through on our website - I think we may have found our new brand ambassador!

When you shop with Kidneys for Life, you're not only donating but by wearing our merchandise you're increasing awareness of kidney disease. So take a look - we've got brand new hoodies in stock, snoods which are perfect in the cold weather and we even have cycle jerseys made from bottle tops (yes, really made from bottle tops, you have read it correctly!).

Shop: <https://kidneysforlife.org/shop/>



**IF YOU ARE
INTERESTED IN ANY
OF THESE EVENTS**

**please get in touch or
visit our website
www.kidneysforlife.org/events**

penny.mcknight@kidneysforlife.org
Mobile: 07523 105 598

victoria.thomson@kidneysforlife.org
Mobile: 07507 001829

‘SIMPLY THE BEST’ FUNDRAISING DINNER - DATE TBC

At the time of going to print, we are yet to announce a new date for the ‘Simply the Best’ fundraising dinner. We are very grateful to be working closely with the Ishtiaq Family who are such fantastic supporters of Kidneys for Life.

We will post details of the new date over the coming weeks.

Live music for the evening will be provided by Seven Eyes (if you haven’t heard their work then take some time out to listen to them) and an amazing 6 course fusion menu will be a treat for the taste buds.

If you would like any further information on this event please contact Victoria (Victoria.thomson@kidneysforlife.org)

KFL SUPPORT FROM NEWLY FORMED ULTIMATE WARRIORS CRICKET TEAM!

We set up our social Sunday Cricket Team after Covid had reduced our season to the best part of six weeks. In this new condensed world of cricket, our squad was formed and selected using Zoom and WhatsApp but fortunately we were able to use our wrestling inspired team name to attract the best part of 15 fixtures including midweek T20s and 40 over games on the weekend. Finally, after a couple of close initial games where we ended up on the wrong side of the result, we realised we needed to go all in with our own personalised team kit and when it came to a sponsor’s logo I realised that Kidneys For Life would be the perfect partner for our new team.

Having lost my father to complications arising from Kidney failure in 2016 I understand the importance of the tremendous work the charity is doing and how it impacts the daily lives of so many families. My father, Saeed Kirmani (1944-2016) was a tremendous cricket fanatic and I hope that the on field growth of the Ultimate Warriors can bring much needed awareness and contributions to the wonderful work the charity is doing and then we will never ever truly feel like we have ever lost a game of cricket!

Thank you to Basit for supporting Kidneys for Life and we look forward to hearing of the team’s progress in 2021!

KIDNEYS FOR LIFE SELECTED AS ROYTON ROAD RUNNERS CHARITY OF THE YEAR!

In 2019 when we heard from Stewart & Karen Jones that they were nominating KFL to be the charity of the year we were so honoured and then absolutely over the moon to hear that we had been selected, by vote, as their charity!

Back in January 2020 I met up with Karen and Stewart and we discussed plans for the year – so many exciting events had been planned, it was going to be a great partnership. Then the lockdown happened.

But, this didn't stop the club supporting us. Karen had been training for her first marathon and in her words: 'Running has never come easily to me and I always said I would never run a marathon! That is however until this year when my Stewart's kidney started to fail for a 2nd time. We've been down this road before and we know how hard and bumpy that road can be. My wonderful father in law donated the first time and we've had 12 fantastic years making memories with our girls but we always knew that wasn't forever. It was still hard to hear the Doctor tell us that my husband's kidney was failing again and he urgently needed a transplant.' As it stands the Manchester Marathon is now due to take place in October 2021 and Karen has already smashed her £500 target!

Then there have been numerous RRR Quizzes – held on Zoom of course where those taking part are asked to make a donation to KFL!

The Dawn till Dusk challenge – what a day! The idea came from Carl O'Callaghan who wanted

to run an event to get all the runners together safely. So on the 21st of June from 5am until 8pm runners were set off every hour in groups of 4. The target was 4.5 miles however most did more! With a quiz on the Friday night, the weekend raised £350 – amazing!

The Royton Road Runners are a determined group! Wanting to keep the fantastic spirit alive they logged onto the clubs Strava and in 2 months and 5 days have run and walked over 17000 miles!

It's not all been running and quizzes at RRR though. Jarod Gritt set up his Lockdown Workouts and encouraged those taking part to make a donation to KFL – he raised £130. Thank you Jarod.

In the middle of December 2020 Royton Runners club treasurer, Jenny O'Callaghan announced the amazing news that the final total of all the years fundraising was £2778! As 2020 was such a difficult year to fundraise we are so very grateful to all the members of The Royton Road Runners for all their hard work.

The way that you have adapted your plans to enable you to continue to support us during this time has been inspirational – and whilst we have not been able to meet the members of RRR to say thank you in person we would like everyone at the club to know just how grateful we are for your support. You are all fantastic!

WHISPERS



me. So, I had to call my parents and say they should probably come back home – this is something that my sister still likes to remind me about!

The year prior to my transplant I married my husband, Peter, and he has supported me throughout the years. Dr Ackrill and his wife both came along to our wedding reception! 3 years after my transplant we had our daughter, Katy.

I really can't believe how lucky I am to have had 25 years from this transplant. I have always kept myself active – I go on regular long walk and bike rides. I am vegetarian and eat healthy foods and think positive thoughts. I keep myself busy and live life to the full.

I am so grateful to the donor who has given me my life.

To celebrate my kidney anniversary I set up a fundraising page for Kidneys for Life and am so pleased to have raised £583.50.

ANGELA NICHOLLS – 25TH KIDNEY ANNIVERSARY!

I started with kidney problems at around the age of 10 with a trip to the Doctors. I was sent to Booth Hall Hospital where I was told I had reflux due to many water infections and my kidneys were too badly scarred. I was referred to Dr Ackrill at Withington Hospital. When I was 18 I was told that I would need a kidney transplant. I started on Haemodialysis in August 1994 and then the special call came on July 5th 1995. My parents were in Glasgow for my younger sisters' graduation when the call came through to me that there was a kidney that might be a good match for



KFL EVERY LITTLE HELPS

Every Kidneys for Life event was cancelled in 2020 and the cupboard is bare.

So we're launching our "Every Little Helps" campaign.

Collection Tins and Home Money Boxes are still bringing in a small, but steady, valued income that we need to fund vital research to improve the lives of every kidney patient.

Karen Part has a collection tin in her shop, Archers in Altrincham, and to date that tin has raised £1,294.93 from varying amounts ranging from £29.94 to £129.07.

Transplant patient Claire Glynn has a collection box at home and puts her small change in which has added up to £288.83 to date.

Another transplant patient, David Hussey, takes his collection tin into badminton clubs where he used to play as well as asking his

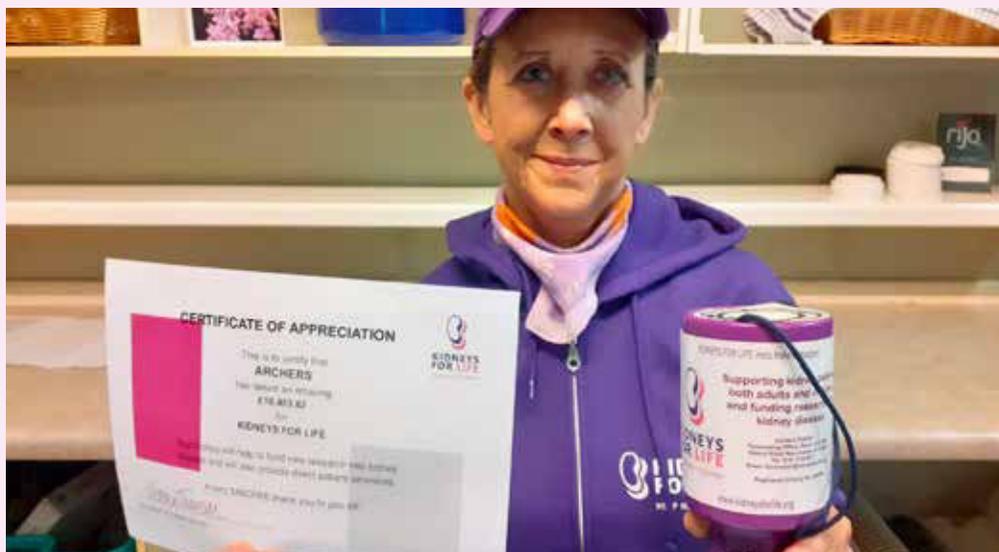
family to donate. David's raised £698.97.

Heather Green puts her collection tins in a butcher's shop and her Mum and Dad's Garage and since the end of 2018 has raised £283.38 in the tins.

In July 2015 Khushi Khurshid brought in her first collecting containing £35.78. She now places 4 tins in various local shops and collects them regularly when she thinks they might be full and she's raised £1,317.54 for Kidneys for Life.

These are just a few of the people who put out collection tins but to everyone who supports Kidneys for Life by doing this – A MASSIVE THANK YOU!

If you know someone who would let you put a collection tin in their shop or business or you would like a home money box for your small change please get in touch. Every Little Helps!



A NEW TRANSPLANT ALERT APP

In 2018 the Trust ran an initiative called Wouldn't It Be Good If (WIBGI) in which Trust staff were encouraged to submit ideas which would improve things for their patients. The Transplant Alert App (TAA) was one of the winning entries and it will soon be available to all patients who are waiting for a transplant.

The smartphone App has been developed by Desap, a Manchester-based App development company, and it is compatible with iOS and Android operating systems. All patients on the waiting list will be encouraged to sign up and download the App. The App will allow the Transplant Team to send patients messages relating to their transplant. If an organ becomes available, a special "organ alert" message can be sent. These alerts override the "do not disturb" settings on a mobile phone and provide a very loud audible alert. Special permission was obtained to allow this facility to be used in these exceptional circumstances and it means that patients won't miss out on the opportunity of a transplant when their time comes.

The App can also be used to send patients occasional non-urgent messages. These can either be directed to all patients who have signed up, or just an individual patient if we need to send them a personal message. The messaging facility can also work in the other direction, and it means that patients can

let the Transplant Team know when they're going to be on holiday, if they're unwell, or if they have any other concerns they'd like to discuss. Sometimes, patients might be contacted to confirm that their contact details are still correct and as up-to-date as possible.

The Transplant Team was involved in the entire process including the development of the specification, feedback on initial designs, logo designs and the selection of suitable alert sounds. The Trust Information Governance team provided advice on all aspects of data confidentiality and helped with the process of undertaking Data Privacy Impact Assessments. The development of this App took approximately 12 months from the funding being made available to completion. The project was managed by the Trust Innovation Team who also assisted with the preparation of Privacy Statements and End User Licence Agreements. In the longer term the hope is to incorporate user feedback into a second version and encourage other transplant centres in the UK and abroad to adopt the system.

If you would like to register for the Transplant Alert App please email:

victoria.thomson@kidneysforlife.org

TRIBUTE FROM PROFESSOR PHIL KALRA TO PROFESSOR DONAL O'DONOGHUE OBE WHO DIED PEACEFULLY AT THE CRITICAL CARE UNIT OF STEPPING HILL HOSPITAL, IN STOCKPORT, ON 3RD JANUARY 2021, AFTER BATTLING COVID-19.

“Donal was a wonderful man who became a legend in our specialty. So many lovely pieces have been written about Donal’s magnificent national and international achievements underpinned by his unfaltering work ethic and charismatic personality. Here I would like to add my own personal reflection on the person who was my great friend and colleague for almost 30 years.

Donal had many unique talents, one of the most captivating being that most people who spent any time in his company would soon feel that they had a friend for life. He played a large part in the establishment of my own career and I am sure that there are many others who would say the same. In Greater Manchester it was Donal’s leadership that spearheaded re-configuration of our services, giving patients with kidney failure better treatment options, leading us out of the dark ages during which 50% of local dialysis patients received peritoneal dialysis as haemodialysis resource was so scarce. And Salford appeared on the UK renal map. It is in large part thanks to Donal’s vision and efforts in the Renal National Service Framework and then as National Clinical Director of Kidney Care that we have all seen major expansion of our renal services; I now work in a vibrant renal centre with 20 consultant colleagues, a far cry from our trio of the mid 1990s.

Myself, I hold treasured memories of time with Donal, with our families, social time during conferences and other shared passions. I am particularly grateful that, although we shared an office, my nose was never rubbed in the success of his beloved Red Devils at the expense of my team in white that had languished in the lower leagues for much of the last two decades. Together we even

persuaded Sir Alex to sign an autograph to ‘My friends across the Pennines’!

We have lost a stellar figure of modern nephrology. But we have also been tragically deprived of a modest, loveable and inspirational person who brought light and warmth into many of our lives. Donal O’Donoghue’s memory will be cherished by me, by our colleagues in Salford, and by countless others who were touched by a unique gentleman during a remarkable life.

Rest in peace my dear friend.”

We extend our very sincere condolences to the O’Donoghue family. More tributes to Professor O’Donoghue can be found by visiting Tributes to Professor Donal O’Donoghue - Research & Innovation (www.ncaresearch.org.uk/news/tributes-to-professor-donal-odonoghue/) and you are also able to post your own tributes on this page.



REMEMBERING

'John Gannon - Manchester DJ Legend'

John Gannon spent decades spinning discs at some of Manchester's best-loved venues including The Cypress Tavern, Jillys Rockworld, The Ritz, Tiger Lounge, FAB Cafe and Satan's Hollow.

He died after a long battle with kidney failure, aged 55 on Sunday 5th July 2020.

Friends say John, who was born in Longsight, before moving with his parents and two brothers to Hulme was responsible for shaping and defining the alternative and rock scene in the city.

John's partner Dawn Lonergan, with whom he lived with in Didsbury, said 'I was with him for 18 years in total. He was a lovely, gentle, intelligent soul who made friends the world over. He will be sadly missed by us all.'

A fundraising page was set up in John's memory and this can be viewed at <https://visufund.com/in-loving-memory-of-john-gannon>



Geoff Burgess

Sadly, kidney transplant patient Geoff Burgess passed away in August. For the past 25 years Geoff was very much involved in the Manchester Kidney Patient Association – Chair and Vice-Chair being just two of his offices. He also volunteered to talk to pre-dialysis patients at MRI and was always guaranteed to raise a smile from his very worried listeners.

He was a strong and delightful man, never short of a story - particularly from his police days – and he always enjoyed telling them.

A very practical person he maintained a very positive attitude throughout his years as a kidney patient.

He'll be very sadly missed not only by his wife, Hilary and his children and grandchildren but also by his kidney family.



REMEMBERING...

Brian Leech

Kau Shu Kei

Lee Baker

Louis Jones

Tony Travis

Ken Clarke

Joan Owen

Geoff Burgess

John Matthew Bacon

David Baybutt

Nancy Bennett

Francis Bliss

Michael Brocklehurst

Anthony Doyle

David Edmondson

Stephen Ellis

Dale Fullen

John Gannon

Claire Halfpenny

Christine Holliday

Kevin Monks

Bob Moores

Audrey Lilian

Muggeridge

Ronald Pamphilon

Joan Rigby

William Rowland

Roger Shaw

Paul Slater

Betty Speakman

DIGITAL TRANSFORMATION AND KIDNEY TRANSPLANTATION

Kidneys for Life is excited to fund research exploring how technology can be used to support kidney transplantation. The project, led by Mr Videha Sharma, aims to better understand the management of patient data and information along the transplant patient pathway. Currently there is a lot of variation in practice across the UK with no standard referral process and largely paper-based administration. Information is stored across multiple IT systems, which do not talk to each other or share information across NHS trusts, primary and social care. This means that doctors, nurses and coordinators spend a lot of time on administrative work, manually pulling information from different sources and summarising it themselves to make clinical decisions and deliver care. This is highly inefficient and takes away time spent with patients addressing questions and concerns.

The way technology is implemented in the NHS at present often increases the workload of doctors and nurses. There is significant duplication of work and systems are not designed with clinicians in mind. By undertaking this research, the team hopes to develop an electronic shared care record that meets the needs and requirements of the transplant team and allows data and information to be shared seamlessly across the North West Transplant Network. No project like this has been done before in the UK and it is the hope of the team to develop a solution that may be replicated in other parts of the country.

BENEFITS

This project is designed to directly benefit patients by streamlining pathways, improving access to data and releasing clinical time to deliver direct care. The potential for digital health interventions to support complex clinical pathways is tremendous – however this has not been explored in transplantation before. We hope to set an example in our regional transplant network, which may subsequently benefit other regions and the wider NHS.

Videha, who leads the project commented:

“The impact transplantation has on the lives of patients with kidney failure is immense, and it is a privilege to care for these patients. My hope for this project is that by understanding the needs and requirements of the multi-disciplinary transplant team as well as how patients experience the service we will be able to identify how technology may best support the practice. We have excellent support from our participating hospitals and I am excited to demonstrate how regional interoperability is essential to support clinical pathways across multiple NHS organisations.”

RESEARCHERS INVOLVED

Mr Videha Sharma, Prof Titus Augustine, Dr Sabine van der Veer, Prof John Ainsworth.

We welcome the contributions of patients and if you have any questions or comments please get in touch with Videha via email: videha.sharma@postgrad.manchester.ac.uk

RENAL REMEMBRANCE SERVICE

Each year Kidneys for Life work with Sarah Brewerton, Chaplain at MRI, to host a Renal Remembrance Service. It's always such a special and obviously highly emotional event. This year the service had been planned to take place in July (and then in November) at The Lowry but due to ongoing restrictions the decision to make this an online event has been made. We have worked closely with Sarah and the organising committee to put this special online service together and will be sharing details shortly with our bereaved supporters.

If you would like further information on this please contact Victoria on 0161 276 6671.

We have also set up a Remembering page where you can light a virtual candle by making a donation to Kidneys for Life. If you would like to remember a loved one but would prefer not to make a donation please do get in touch so that we can arrange this for you.

<https://visufund.com/light-a-candle-on-our-lake-of-remembrance>



TANDEM SKYDIVE 11TH OCTOBER 2020

Another fantastic skydiving event! There were 8 brave participants, most of whom were from CLC Group, and were jumping in memory of Anthony Gregory. Anthony's son Mark (who works for CLC) and Anthony's grandchildren Anna & Brad were just some of our brave jumpers today.

The group raised £3408.45 which is truly amazing. A really sincere thanks to Lee Smith & Mark Gregory for organising the group and supporting KFL.

We were also delighted that Renal Children's Nurse, Amy-Lea also took part and also loved the experience!

Our next day is booked for April 24th so if you're tempted to take part please get in touch for more info!

CORPORATE SUPPORT

CARDINKY

When Danny Cameron became a Dad his son, Fred, needed dialysis treatment.

From then on Danny, Mum Tamsin and their families have supported Kidneys for Life from Day 1.

Luckily, Danny was a match and Fred's transplant was a success!

Since then Danny, an illustrator, designed some greetings cards especially for Kidneys for Life. His modern designs are cheekily illustrated and aim to raise a smile - and we all need a smile!



The more cards you buy – the more Danny donates – that's easier than running a marathon!

Danny continues to support Kidneys for Life by donating a percentage of his card business, Cardinky and has recently agreed to be on the judging panel of our Kidneys for Life water bottle competition, please visit our website www.kidneysforlife.org for more details.



CATAX

It was the most beautiful, sunny day for the Catax Golf Day in aid of Kidneys for Life.

This year the event was held at Mere Golf & Country Club near Knutsford - a stunning setting for a golf day - overlooking the mere.

Everything was well organized to be within government guidelines with temperature checks on arrival, lots of sanitizer stands around the building and tables of four well-spaced out in the main function room for bacon butties at 8.30 am.

But when you were outside the tranquil atmosphere of Mere almost made you think that COVID was a distant nightmare.

After a warm-up the golfers set off at 10 for their Shotgun start.



Four hours later it was a relaxed, chatty drink at the bar before the presentations and buffet and then on to the fundraising.....

HC Promotions had brought along a variety of sporting memorabilia, current and past, that could be auctioned or sold whilst DollarsandArt owner, Jim Wheat, displayed some of his amazing artworks.

One, in particular, a portrait of Donald Trump – complete with a dollar note signed by the man himself - received lots of attention and even more comments. Jim always knows how to attract an audience!

The day raised over £ 1,800 so a MASSIVE Thank You to the golfers and Catax.



WE VALUE YOUR SUPPORT

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

Victoria Thomson - 07507 001 829
victoria.thomson@kidneysforlife.org

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 Victoria Thomson, Kidneys for Life, Renal Transplant Labs, 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.