

# Whispers

Spring 2016

[www.kidneysforlife.org](http://www.kidneysforlife.org)

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**...AND MUCH MORE**



**KIDNEYS  
FORLIFE**

## Thank yous...



### Harrison Family

Our thanks go out to Lauren, Wayne, Hayden & Keaton Harrison for all their fundraising efforts in 2015 which went towards the Manchester Children's Transplant Games Team. Their efforts included taking part in Rough Runner and a donation from Hayden's school, Urmston Infant School, which helped with their fundraising. The family raised over £1,500 which is fantastic and well done to all those concerned.

### The Dairy Queens

Holly Practico, Beth Ford & Charlotte Barber, our Dairy Queens, took part in a Skydive and other fundraising events in 2015 to raise monies for Kidneys for Life as their friend Joanne Bradley had received a kidney transplant from her Mum, Karen Part. The Dairy Queens are also part of the Cheshire County Federation of Young Farmers' Clubs who helped raise their total to over £5,600. – Well done Girls!



### Birtwistles

A donation of £3,100 was made by Birtwistle Catering Butchers of Irlam to Kidneys for Life following fundraising at the firm for which we at Kidneys for Life are really grateful.

### Christmas Cards

Thanks to everyone who purchased our Christmas cards last year. We raised over £8,000 so thank you all. Our cards will be available from September so look out for our leaflet in the Summer Edition of Whispers.





## Manchester to Dublin Cycle

A belated BIG Thank You to Tom and Fran Wright, Tom Tom, Jonathon Wright and last but not least David Wright.

Last year they cycled from Manchester to Dublin – along the North Wales coast, through the Wicklow Mountains National Park and past some of Ireland’s most famous landmarks.

Despite having to cycle 450 miles through some atrocious storms, they raised over £5,600 and said it was their best cycle ride to date.

## Renaissance Chapter 1219

A huge thank you to Renaissance Chapter 1219 who recently donated £250 to Kidneys for Life and which was presented by Michael Stanistreet, First Principal, and John Slater, Immediate Past Principal, to nursing staff on the Renal Transplant Unit at Manchester Royal Infirmary. The Chapter have been big supporters of Kidneys for Life over a number of years now and their support is greatly appreciated.



## Eliza Gornall

One of our young transplant patients, Eliza, and her family have been fundraising for Kidneys for Life organizing a variety of events, including a “Go Purple Day” at Newton Bluecoat School where Eliza attends. They have raised nearly £1,600 some of which was used to buy toys for the Children’s Renal Wards which were very well received just before Christmas.



# Thank yous...



## John Cook

John took part in the Abu Dhabi Yas Triathlon at the end of February in memory of his Dad who passed away last year due to kidney failure. Kidney failure resulted in him being kept alive by dialysis. John said "it gave my Dad and our family 5 more years of his life. I am now in my 60th year and will be finding the strength to compete thinking of my dad and how he was so brave and strong during those 5 years".

Well done to John for not only competing in a Triathlon but also for doing this in the heat of Abu Dhabi and raising over £1,500 in memory of your Dad.



## Kalo Events (MMU Student Events Team)

"Big, big congratulations to student Team Kalo from Manchester Metropolitan University for organizing their recent Masquerade Gala Dinner in aid of Kidneys for Life. There were tears, laughter, good food and an excellent band.

A BIG, BIG Thank You from Kidneys for Life for raising £ 2,000. "

## Ann Broughton

Many Thanks to Ann Broughton for raising over £4000 at the German Oompah Night in Grappenhall, Cheshire. Fabulous fun filled night of Singing Dancing and Drinking!



## **Birthday celebrations – 25 June 2016**

**This year Kidneys for Life celebrates it's 40th Anniversary and to mark the occasion we're holding a Birthday Celebration on Saturday, 25 June.**

Kindly supported by Andrew Cole and Manchester United, the Ball will be held at the Manchester United Football Club and promises to be the most amazing night.

Please join us to celebrate the Kidneys for Life journey over the past 40 years.

Tickets are £ 50 each and include Reception Drinks, 3-Course Dinner, Wine on the Table and Entertainment.

It's Black Tie for the gents and Party Dresses for the Ladies.

Let's get ready to Party!!!

**To reserve your place,  
please contact  
[carol.bonham@kidneysforlife.org](mailto:carol.bonham@kidneysforlife.org)  
or call 07714 864 833.**

**Book online via  
<https://kfl40th.eventbrite.co.uk>**



## Amanda's Story

**My mother, Leonie Scott, was a renal patient at Manchester Royal Infirmary and Macclesfield Dialysis Unit and sadly she passed away early in 2015 from Encapsulating Peritoneal Sclerosis (EPS). My Mum was my biggest inspiration and my biggest source of support. She understood exactly what I was going through with my own illness and held my hand throughout the multiple surgeries I have had for my Crohn's Disease.**

I am passionate about raising awareness about EPS and raising money for Kidneys for Life. I started to use exercise to help me to overcome fatigue and increase the movement in my digestive system so I could hopefully have a better quality of life and it really has helped me!

When I first got my stoma (which I promptly named Ludwig after Beethoven), I never dreamt that I would be physically fitter than I was before my operation! Post-surgery I had really problematic chronic fatigue and I had always been a person out enjoying life so to be driven to bed by fatigue was really frustrating, not to mention depressing. Eventually, I was referred to an endocrinologist who specialises in chronic fatigue and she diagnosed me with complex medical fatigue with the underlying issue being

my Crohn's Disease. She suggested that gentle exercise would help me to overcome my fatigue amongst lots of other techniques I could use to help me. So I started swimming and slowly but surely I started to feel better. Scientifically exercise releases endorphins which helps to fight against things like fatigue. However, whilst swimming, I came across a quote which was emblazoned on the wall:

'Champions aren't made in the gyms. Champions are made from something they have deep inside them – a desire, a dream, a vision. They have to have the skill, and the will. But the will must be stronger than the skill' (Muhammad Ali).

I began to desire a challenge with my stoma and so I took up running.

At first it was difficult. I had to focus on keeping myself hydrated and getting the balance of my lmodium right so that Ludwig stoma wasn't gushing output out as I was running. Yet, gradually, I built my distance up and 8 weeks after starting running I completed my first 10K which must have been the worse race to pick as the course was entirely hilly!! My poor thighs afterwards... However, it was a great achievement and I felt mentally and physically better, not to mention more confident about what I could achieve athletically with my stoma. From there, I

began training for my half marathon. I have since gained a medal across 5K, 10K, half marathon and marathon distance.

I have the honour of being picked to be one of the faces of the Great Manchester Run 2016 and my advert is currently on the television.

I run to raise money to help others like my Mum, in the hope that one day the outlook for EPS patients will be improved. Running also helps me with my disease; it helps with managing my disease and pain but mostly it gives me a desire to overcome the obstacles placed in my path that having Crohn's Disease presents me. I find that exercise helps to give me a positive frame of mind. Having a stoma was no obstacle to completing the races and at times it was easier to run with a stoma than without – I wasn't worried about toilets along the way! Now, I am training for triathlons!

My Mum taught me to never give up and to always work towards achieving my dreams. I hope that she will be looking down on me with pride and to borrow a quote from A.A. Milne, I really have learnt that:

'I am braver than I believe, stronger than I seem and smarter than I think' since she passed away.

Amanda Scott



*After the Great Manchester Run 2015!  
Running in memory of my Mum,  
Leonie Scott.*





## Manchester Run 2016 – 22 May 2016

**Be inspired by Amanda and join the Kidneys for Life Manchester Run Team on Sunday the 22 May.**

The Manchester Run is a fantastic event with a great atmosphere and incredible cheering support all along the route.

Kidneys for Life will provide a running vest or T-shirt, fundraising support and on-the-day hospitality including a lovely leg massage for those tired legs!

All you have to do is get registered at [www.greatrun.org](http://www.greatrun.org), get those legs training and raise as much as you can to fund vital research within Manchester Royal, Salford Royal and Manchester Royal Children's hospitals.

Please let us know when you've been successful and we'll add you to the team.

**Make sure you're part of this truly fabulous event. Register NOW!**



## Manchester Junior & mini runs – 21 May 2016

**The Manchester Junior & Mini Runs take place on Saturday the 21 May at the Etihad Stadium, Sportcity.**

The 1.5k Mini Runs are for children aged between 3 and 8 years and the 2.3k Junior Runs for children between 9 and 15 years of age.

The course includes a cheering point at the halfway mark and there'll also be a band along the way for an extra boost to get you over the finishing line.

Enjoy a great day out and raise vital funds for Kidneys for Life.

Register NOW at [www.greatrun.org/manchester-run/junior-and-mini-great-manchester-run](http://www.greatrun.org/manchester-run/junior-and-mini-great-manchester-run)



## Tandem Skydive – 23 April

There are still places available for the Tandem Skydive on 23 April at Cockerham Airfield near Lancaster. We are asking for a registration fee of £50 and a minimum sponsorship of £345.

If you are interested please see our website [www.kidneysforlife.org](http://www.kidneysforlife.org) under News & Events or contact Irene Chambers on [fundraiser@kidneysforlife.org](mailto:fundraiser@kidneysforlife.org) or 0161 276 6671

## 4 countries cycle challenge – 31 August

Cycling the 270 miles from Dover to Amsterdam over 4 days you'll take the ferry from Dover to Dunkirk, cycle past the battlefields of WW2 into Belgium and on to Bruges, before winding your way along the waterways of Holland, past tulips and windmills, into the city of Amsterdam where you will celebrate the end of your 270 mile challenge!

More info: <http://support.kidneysforlife.org/event/4Countriescycle2016>

Contact: Sarah May E: [sarah.may@kidneysforlife.org](mailto:sarah.may@kidneysforlife.org) or M: 07743 688794

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## Royal Liverpool to Manchester Royal cycle ride – 18 September

### This is a brand new bespoke Kidneys for Life event for 2016!

Cycling 50 miles from one transplant hospital to another through the beautiful Cheshire countryside in support of Kidneys of Life. You can cycle at your own pace, enjoy a water stop in Thelwall and refreshments at the finish whilst raising awareness of the need for organ donors and vital funds for life-saving research.

- Registration fee: £15
- Minimum Sponsorship: £50
- One-way bike transport: £10

For more details please contact:  
[carol.bonham@kidneysoflife.org](mailto:carol.bonham@kidneysoflife.org)  
or call 07714 864 833.



## Kidneys on Ice!

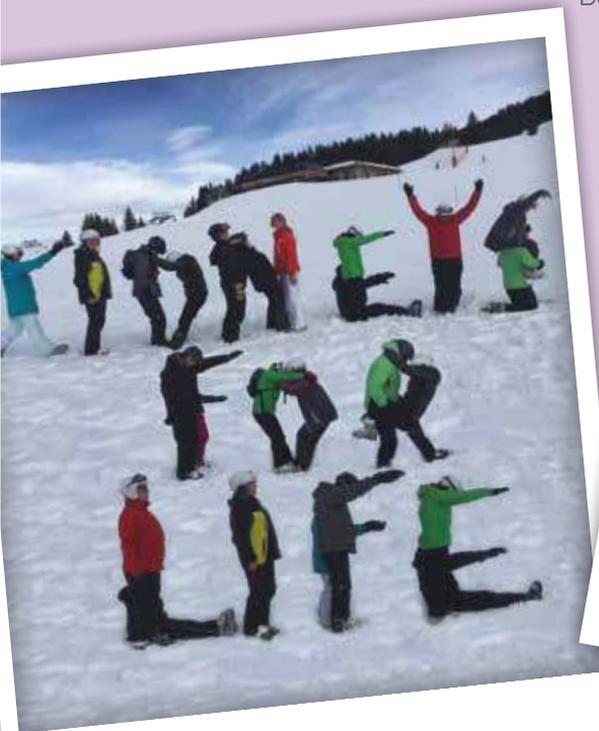
**In January a group of 12 skiers, including Kidney Donors and Recipients went to Courchevel in the French Alps to raise awareness of KFL and kidney donation in general.**

They skied in Kidneys for Life T-shirts and encouraged lots of locals and tourists to join in the fun of promoting awareness.

One highlight was meeting Eddie “The Eagle” Edwards who was on a film shoot in the area and he gladly donned a Kidneys for Life shirt for a much appreciated photo opportunity.

**In total £2,400 was raised by the group.**

Many thanks to Nick and Heather Mullen for their wonderful and generous hospitality, Martin and Louise Bartlett, John and Roz Hind, Martin and Mags Kersey, Jeff and Sarah May, Richard Topham, Bernadette Downes and Leigh Wintle.



# Kidneys for life China trek - October 2016

## What's on your bucket list?

If it's the Great Wall of China, Tiananmen Square, the Summer Palace and the Forbidden City then register now for the Kidneys for Life China Trek 2016.

Join Titus Augustine & Neil Parrott (Transplant Surgeons), Melanie Phillips & Sarah May (Donor Recipients), Denise Roberts (Specialist Children's Nurse), Karen Ainsworth (Kidney Donor) and a number of supporters.

**There are just a few places left so please don't miss out.**

**For more details contact: carol.bonham kidneysforlife.org or call: 07714864833**

## In memory of Sheila Gandy

Our mum and wife Sheila Gandy, took poorly in May last year, she was initially hospitalised due to breathing problems which later was diagnosed as renal failure. She needed to have dialysis, which was to provide quality to her life, although it would not prolong it. At this point she discussed her wishes and she wanted us to raise money towards Kidneys for Life.

Her daughter, Tracey, does lots of fundraising for charities so she asked Tracey to organise a fundraiser in her honour which was an 8 hour Spinathon on 4 Oct 2015. During her time of illness Sheila put all her efforts into attending her daughter's wedding as she was giving her away. Medical Staff and

Sheila worked hard to achieve this. It was a fantastic day as she got to spend her day with family and friends.

Sheila deteriorated quickly after the wedding and six days later Sheila sadly died at home, the place where she wanted to be. The Spinathon was done in memory of Sheila Gandy. We had 18 bikes continually going for the eight hours with lots of people coming and going. Harvey Livett, who Tracey sponsors, came and did the event.

**Sheila's wish was to raise £5,000 from the Spinathon and we raised £4,600. Today the figure is £6,334.00 all for Kidneys for Life.**Tracey Bold

## Bob's Story

**In 2002 I went for a job interview. I got the job then had to undergo a medical where the nurse found protein and blood in my urine. After tests this proved to be CKD.**

I was dumbstruck because I thought I was ok. My world was turned upside down. My first thought was how can I cope with this and what do I do next. My family was very supportive and the hospital was fantastic.

I've come to terms with my CKD and I am now a home dialysis patient, using the machine every other day for 5 hours at a time.

My wife, Jackie, encouraged me to join a rock and roll dance group and at first I was very reluctant but OMG what a life changer it turned out to be!

We go out Friday and Saturday most weeks, and even though I can't dance to every dance the social aspect is brilliant.

So I wanted to let other patients know that even though mine and my family's lives have changed, you can still lead a full, active life within reason and know your limitations.

Last year not only did Jackie and her sister take part in the Blackpool 10km Run to raise funds for Kidneys for Life but they also managed to get some of the Rock and Roll clubs involved too. So a big Thank You to the Sale club: Its only Rock and Roll, Denton club: Jive time Rock and Roll, Halifax's: Halifax Rock and Roll and the Flixton club: Crepes and Drapes. Not forgetting the DJs Franky and Dereck for their fantastic music.

Jackie and Bob Devlin



## Scott Crighton

**“On the 7 January this year Scott Crighton from Coppull, Chorley, took part in the Siberian Ice Marathon braving temperatures of -25 degrees with a wind chill of -33 degrees.**

Scott took part in the Siberian Ice Marathon, one of the World's coldest runs to raise vital funds for Kidneys for Life - a charity extremely close to our families' hearts. Scott not only competed in the Siberian Ice Marathon he was also the first International Runner to run across the finish line and the only runner to also play the Bagpipes and run in his traditional Scottish clothing - THE KILT!!!

As well as this race, Scott will also be taking part in the Manchester Marathon on 10th April, the full UK Ironman on the 17th July and the Berlin Marathon on 25th September. Scott will be training pretty much everyday, racking up lots of miles Swimming, Cycling and Running.

Although Scott took part in the extremely cold Siberian Ice Marathon and has the tiring Manchester Marathon, the enervating Ironman and the draining Berlin Marathon to name a few, this is nothing compared to what people have to go through when they have serious Kidney conditions.

Scott is hoping to raise as much money as he possibly can for Kidneys for Life and so far has raised just over £1.5k”

Vikki Crighton

**On behalf of all at Kidneys for Life I would like to thank Scott, firstly, for taking part in the Siberian Marathon – not something I would do lightly and then going on to a number of other challenging events – we will report on his progress in the next edition  
– Irene Chambers**



## David Van Dellen

**You might have seen David (Consultant Surgeon) on North West Tonight recently where he was interviewed live about the incredible number of transplants that took place at the MRI last year – 317 in total with 5,800 since the Transplant Units inception in 1968.**

It is an incredible feat for which all the staff over the years should be proud of. David also highlighted the sacrifice that living donors make as without them the Unit would have been unable to perform these life changing transplants for those on the waiting list.

David is taking part in the London Marathon this year for Kidneys for Life and the funds raised from this run will go directly to support patients and work related to



Encapsulating Peritoneal Sclerosis - Manchester is an international referral centre for patients affected by this life threatening condition. It is an effect of long term peritoneal dialysis and, without treatment, is almost universally fatal. (Please see Amanda's article whose Mum, Leonie, suffered from EPS). Manchester provides expertise in treatment for patients both nationally and internationally, and is at the forefront of support for patients with the disease and research into improved outcomes.

## Remembering

Ann Bradford

David Bray

Sheila Gandy

Jean Herrmann

Irene Lyon-Hayes

Ernest Spencer

William Wharton

Brenda Williams

# World transplant games 2015 – Argentina

**23 – 30 August 2015**  
**'POWERED BY THE GIFT  
OF LIFE'**

The 20th bi-annual World Transplant Games took place on the coast of Argentina in a town called Mar Del Plata, which was a six hour coach journey south of Buenos Aires. The World Games are our Transplant Olympics and the biggest international celebration of the gift of life that there is. It is a unique opportunity to share in giving thanks to all donor families and living donors, to demonstrate the healthy and active lifestyle that can be achieved after transplantation and to raise the profile of organ and bone marrow/ stem cell donation. The logo for the Games said it all, 'Powered by the Gift of Life.'

Over 800 athletes from 44 countries across the globe competed in age categories across 13 different sports, including cycling, swimming, track and field, racquets, golf, volleyball and even the South American sport of Tejo. We compete for medals but the whole experience is a celebration and is about fun, friendship, great camaraderie between teams and living life to the full! This was my seventh World Games and it was great to catch up with friends from all over the world, meet new ones and soak up the wonderful atmosphere that is the World Transplant Games.

The Great Britain team consisted of 107 Transplant athletes, including 12 juniors and we topped the medal table with 122 Gold, 76 Silver and 48 Bronze medals! Argentina finished second overall and South Africa third. There were 6 athletes competing from the Manchester Adults Team and 1 Junior, all producing amazing performances in their events to bring home medals:-

Ayesha Brookes (Junior) – 3 Gold; 3 Silver  
Sam Clarke – 2 Gold  
James Colbeck – 1 Gold; 2 Silver; 2 Bronze  
Zoe Dixon – 2 Gold; 1 Silver; 1 Bronze  
Juliet Lewis – 4 Bronze  
Neil McLeod – 1 Gold  
Paul Reynolds – 1 Silver

I'm looking forward to next year's British Games to be held in Liverpool and then in 2017 the next World Games will be in Malaga, Spain, and I will certainly be aiming to take part!

On behalf of all the Manchester Team members who competed I would like to thank Kidneys for Life for their generous sponsorship which helped us all to successfully represent our country, raise awareness of transplantation and above all celebrate the gift of life, thank you.

## British transplant games

**28th – 31st July 2016**  
**Liverpool BE A PART OF IT!**

Once again I would like to introduce myself, my name is Zoë Dixon and I am your Manchester Adults Transplant Games Team Manager.

The team includes kidney transplant recipients and bone marrow/stem cell transplant recipients from Lancashire and South Cumbria, Manchester, Greater Manchester and North Cheshire and welcomes new members of any age or sporting ability, it might even inspire you to take up something new! It is a unique opportunity to share in giving thanks to all donor families and living donors, demonstrate the healthy and active lifestyle that can be achieved after transplantation, raise awareness of organ donation and to celebrate the gift of life!

If you would like to take part in the British Transplant Games 28th – 31st July 2016 in Liverpool then please do get in touch with me. Registration will open in February and the closing date for entries will be by the end of May 2016.

Over the four days athletes compete in a range of sports from Archery to Volleyball and many in-between including Cycling, Lawn Bowls,

Swimming, Athletics, Darts, Snooker, Golf and various Racquet sports. There are also social events for Supporters and Living Donors to take part in such as Five-a-Side Football, Soft Cricket, Golf and the Donor Run. The weekend is rounded off with a fantastic celebratory gala dinner.

It's the taking part that counts and the whole experience is a celebration and is about fun, friendship, great camaraderie between teams and living life to the full! We very much welcome new team members so if you are interested in taking part please do get in touch.

British Transplant Games website:  
[www.britishtransplantgames.co.uk](http://www.britishtransplantgames.co.uk)

Transplant Sport website:  
[www.transplantsport.org.uk](http://www.transplantsport.org.uk)

Contact Details: Zoë Dixon MBE  
Tel: 07780858558  
e-mail: [zoe\\_dixon@tiscali.co.uk](mailto:zoe_dixon@tiscali.co.uk)



## Phosphate binders & timings from the Renal Dietitians

Phosphate is a mineral that people with kidney disease may have heard of. Our bodies absorb phosphate from different food and drinks, including dairy products, meat and fish, additives found in food preservatives and brown fizzy drinks. For people without kidney disease, their kidneys filter the phosphate and it is passed out in urine. However people with kidney disease need to be more careful with phosphate, as their kidneys cannot filter the phosphate as well and it is absorbed in to the blood.

Your kidneys help control the levels of phosphate and calcium in your blood. Phosphate and calcium work together to keep your bones, teeth, heart and blood vessels healthy. These levels prove more difficult to control when the kidneys are no longer working properly. An imbalance can lead to weakening of the bones and a build up of calcium in blood vessels.

Binder	When to take tablet	How to take tablet
Calcichew	Before meal	Chew or suck
Calcium 500	Before meal	Swallow
Fosrenol Tablets	With or immediately after meal (within 15 mins)	Chew very well
Fosrenol Powder	Immediately after meal (within 15 mins)	Mix with a small quantity of soft food (e.g. apple sauce)
Osvaren	Before meal	Swallow (can break into 2)
Phosex	During meal	Swallow
Renvela	During meal	Swallow
Renvela Powder	With meals	The powder should be dispersed in 60ml of water prior to administration. The suspension should be taken within 30 minutes of preparation
Renagel	During meal	Swallow
Velphoro	During meal	Chew

## Dates for your diary

Often when kidney function reaches a 'pre-dialysis' stage, or when dialysis is required it may be necessary for you and the Dietitian to review your diet and to try and reduce your phosphate intake. You may also need to take a phosphate binder. As the name suggests, these work by binding phosphate in the gut before it is absorbed by the body and into the blood. There are lots of different binders available however the table below lists the most widely available and advises how and when to take them.



### Saturday, 23 April

Elmas Mediterranean Restaurant "Gourmet Tasting Evening" in Lymm at 7.30pm - Three Course Fine Dining experience with Entertainment and dancing. Tickets £35 being organised by Carol Treasure. For tickets please contact Carol at [drcaratreasure@gmail.com](mailto:drcaratreasure@gmail.com)

### Friday, 13 May

Mike Donovan is organising an event at The Garden in Hale at 7.30pm - Sparkling Drinks Reception followed by a Gourmet Tasting Menu plus Entertainment. Tickets £39.50. For tickets please contact Mike Donovan at [miked@networkm.co.uk](mailto:miked@networkm.co.uk)

### Saturday, 14 May

Des Johnson, Ryan Crawford, Jonty Morris and Michele Scappaticci are organising a Starlight Ball at Crewe Hall at 7pm - Sparkling Drinks Reception followed by 3 Course Meal plus entertainment and dancing with the Legendary Johnny Spangles and his Dancing Girls. For tickets please contact Sarah at [sarah.may@kidneysforlife.org](mailto:sarah.may@kidneysforlife.org) or Des at [des@nlh.biz](mailto:des@nlh.biz)

### Saturday, 10 December

It's never too soon to think of Christmas! The Kidneys for Life Christmas Party, hosted by Neil Parrott, will be at Oaklands Masonic Hall, Hyde. Tickets: £ 30 including 3-course meal and dancing. Details available soon.

## Make a Donation and Help Make a Difference...

**Kidneys for Life raises money to enable research into kidney disease, transplantation and dialysis and the Research Teams at the MRI, Royal Manchester Children's Hospital and Salford Royal Hospital have a proud history of being at the forefront of many acclaimed scientific discoveries and internationally celebrated success. The research work undertaken by the teams offers real hope for patients both now 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 giftaid to make your donation worth more (see below).**

Name .....

Address .....

..... Postcode .....

Email ..... Telephone .....

Signature ..... Date .....

I enclose a cheque made payable to Kidneys for Life for £ .....

I want to giftaid my donation\*

\* I am a UK taxpayer and understand that if I pay less Income Tax and/or 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 any difference.

