



**KIDNEYS
FORLIFE**

Fundraising for the MRI Renal Units

Whispers

Spring 2010

www.kidneysforlife.org

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**Kidneys for Life
fundraising for MINT**

Charity number 505256

Marathon Man

He's never running a marathon after two kidney transplants?

Legal expert, husband and father of two, Des Gardner is 42 and just a tiny bit crazy. Over the years he has had two kidney transplants, the first in 1991 when he was a student, the second one in 2004. Both operations allowed him to recommence his normal life, marrying Ali and fathering two lovely daughters – Grace (now 10) and Hope (now 8).

After each set-back Des bounced back and confirmed his faith in the medical teams at Manchester Royal Infirmary as well as the need to look after his transplanted organ.

As he acknowledges, **"It's given me a career and I am financially independent. It also gives you a normal life... That is the most precious thing in the world."**

For him, keeping as fit as possible was and is the only way forward. So he began to run, and run, and run. To strengthen his will-power, he decided to train for the 2010 London Marathon.

Des is running the London Marathon on 25th April to raise funds for Kidneys for Life.

Although Des is the first to admit that he was never a natural born athlete, he tells all those who visit his webpage, www.virginmoneygiving.com that his two transplants have given him 18 years of unbelievable health. Because of this, his reasons for running the marathon are clearly explained.

"I am running the London Marathon to show how transplants change lives and to say thank you to all my family, friends, work colleagues and the many amazing professionals at Manchester Royal Infirmary who have supported me over the years."

This year sponsored by Virgin Money, The London Marathon is a great British sporting event, bringing together elite athletes, serious sport enthusiasts and a huge mass of fun-runners, rubbing shoulders with politicians at one corner and perhaps a pantomime horse at the next. Most importantly the event is a Guinness Record Breaker when it comes to fundraising. Since the first race in 1981, 746,635 runners have passed the finish line and raised more than £400 million for charities and good causes, making it the largest annual fundraising event on the planet.



No doubt you're familiar with the gruelling 26 mile course, twisting around London's famous landmarks, so, please think of Des on Sunday, 25th April and hope for easy going weather. Perhaps you'd like to sponsor him. Visit his website for details or please get in touch for details on how to send in sponsorship.

Awards for Research

North West NHS Innovation Awards 2009

Professor Paul Brenchley, Dr Sandip Mitra and Professor Rein Ulijn have won the award in the category of Medical Devices, Equipment, Diagnostics or Therapeutics for the 'Renephra' project. 'Renephra' is the innovative concept of transdermal fluid and toxin removal – a novel treatment to address the medical need for better treatments for patients with kidney failure. The technology has two component parts: a wearable

transdermal hollow micro-needle array to access the fluid/toxin reservoir below the skin (in the interstitial space); and a designer hydrogel cassette that specifically captures fluid and toxins present in the interstitial fluid. The technologies are combined into a device that is wearable and allows for slow, continuous fluid and toxin removal without the need to be physically attached to a dialysis machine.



Northwest Biomedical Awards: Bionow

Professor Paul Brenchley, Dr Sandip Mitra and Professor Rein Ulijn have also won the award on Emerging Technology Project of the Year,

organised by Bionow (the NorthWest Regional Development Agency's (NWDA) Biomedical Cluster Support Group) for the 'Renephra' Project



Nephrologist Consultant wins Research Fellowship in Canada

Dr Declan de Freitas studied for his medical degree at the Royal College of Surgeons in Ireland and completed his medical training in Dublin, during which time he developed an interest in Renal Medicine and Transplantation.

In 2004, he came to Manchester and joined the MRI renal team where he continued his training to consultant level, which he finally completed this year. During his time at MRI, he enrolled in the University of Manchester PhD programme and carried out research, including a clinical trial to see if a drug called erythropoietin would help transplanted kidneys work better.

Declan won a prestigious position in Edmonton in Canada where he is undertaking a research fellowship under the supervision of Prof. Phil Halloran, one of the godfathers of transplantation. He is continuing his research into kidney injury with a view to improving the information gained from kidney biopsies.

Assuming he survives the weather in Canada (-52°C this Winter), he will take up his post as a Consultant Nephrologist at the MRI and Tameside in early 2011.



Accounts

Here is a summary of the charitable accounts for Kidneys for Life fundraising for MINT.

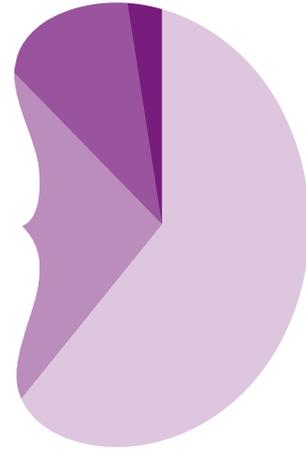
A full copy of the accounts can be found on the charity commission website www.charitycommission.gov.uk and searching on our charity number 505256.

Income Total £78,011



- Voluntary Income **£52,481**
- Investment Income **£25,530**

Expenditure Total £117,984



- Charitable Activities **£73,446**
- Cost of Generating Voluntary Income **£27,214**
- Governance Costs **£14,578**
- Depreciation **£2,746**

Fancy joining us for the Great Manchester Run 2010?

We have a number of charity places for the Great Manchester Run 2010 which is due to take place on Sunday, 16 May this year. All we ask is for you to raise a minimum of £75 in sponsorship which includes the registration fee. We will provide a T-Shirt or Running Vest and a sponsorship pack. Places are limited so first come first served.

All entries must be confirmed by the 9th April 2010 so please get in touch with Irene Chambers soon.
Tel: 0161 276 6671 Email: fundraiser@kidneysforlife.org



Playing Around!



Kidneys for Life made a grant to enable the purchase of play equipment including sensory play items to the Children's Renal Section at the end of last year.

In addition an American Pool table was also provided for the Teenage Zone which we are sure will be used extensively by the patients there.



Kidneys for Life Online



After a number of technical difficulties with our website, we are pleased to announce that it is now up and running so please visit us at:
www.kidneysforlife.org

Leaving a Legacy

Over the years, gifts from legacies, amongst other things, have been instrumental in enabling the Manchester Institute of Nephrology & Transplantation (MINT) to conduct its vital research into kidney disease and transplantation.

Whilst you may not be in a position to support our fundraising activities at the moment, by remembering Kidneys for Life in your will you can be assured that our vital work and research will continue for many years to come. Every gift, regardless of the size can make a significant difference to the lives of people living with kidney disease.

No one really likes to think about making a will, but making a will can bring peace of mind knowing that your loved ones have been provided for and your wishes will be carried out.

There are a number of ways your will can be drawn up, one such way is to visit www.totallyfreewills.co.uk where your will is provided online by a reputable solicitor, completely free of charge (providing you have no complex issues to handle). Discounts are available for more complex wills.

For further information on how your will can support our precious work please contact Irene Chambers on:
0161 276 6671
fundraiser@kidneysforlife.org



With Thanks To...

Whilst we recognise the help of all patients and volunteers who have supported Kidneys for Life in the past, we have highlighted just a few from the last six months...

The Dorsey Family



Clifton Cricket Club was the venue for a fundraising evening organised by Bill, Michelle & Liam Dorsey, which raised over £2,000. The event was fronted by super group "Loose", the family and Kidneys for Life would like to thank all members, family & friends, with a special thanks to Kevin Spencer of MBN events for the donation of auction prizes, without which they would not have been able to raise such a fantastic amount.

Lee Spencer

His wife Krista may have called him a silly, mad old fool for taking part but Lee with a 15kgs pack on his back took part in the Paras' 10 in September 2009 which is a 10 mile gruelling endurance race used in paratrooper selection. Lee completed the course in a fantastic 1hr 38mins and raised over £200 for Kidneys for Life. Lee is also a friend & relative of Rose Spencer who also deserves a Thank You.

Maria Giacoumi



Maria Giacoumi organised a fantastic Charity Evening Event on 17 October 2009. The audience were entertained by Singers, Spanish Flamenco Artists, Comedians, Classical Singers. Musicians and much more including a raffle and silent auction. A fantastic evening was had by all and the event raised over £2,350. We would also like to express our thanks to Greater Manchester Probation Trust who supported the event.

Read All About It!



We would like to say a big thank you on behalf of the Renal Dialysis patients to all those involved in enabling them to receive free newspapers whilst they are on dialysis at the MRI. Our thanks goes to Trinity Mirror, Ceva Logistics, Smiths News and Linda Rakauskas here at WHSmith at the MRI.

Tim Sands



Tim Sands has raised over £830 by competing in three events in 2009 on behalf of Kidneys for Life, the Manchester 10k, Cheshire Triathlon in May and the Tatton Park Triathlon in September. Donations were also received from Sand Hairdressing in Altrincham from events held there. Rose Spencer who is a friend & relative of Tim's is a dialysis patient waiting for a kidney transplant and as he says is an inspiration and constant source of support. Tim and Billy Brench (Head of Colouring at Sands) will be participating in the Manchester Run again this year.

Chris Dunne

Chris also took part in the Tatton Park Triathlon in September 2009 and raised over £525 for Kidneys for Life.

Boots Rochdale

We would like to thank Boots Rochdale for their help and support which enabled each of our Renal Patients to receive a small gift at Christmas.

Once again, thanks to everyone who has helped support Kidneys for Life.

Calamity Joanne!

If loosing an eye, crippling a foot and having my stomach sliced open several times wasn't enough to ruin my looks, I reckon fate was making damned sure it would bring me down, when my hair fell out. Well HA! It didn't work.

After almost 30 years of diabetes I lost most of my sight, and in fact had to start wearing a false eye to look my usual, gorgeous self. I felt very lucky that modern prosthetics looked so natural. Over the years I also lost a lot of feeling in my lower legs and feet, again through diabetes. This meant that when I broke my ankle several years ago, I didn't know, and it remained undetected until the bones could no longer fuse properly. This left me with my beloved 'turnip' foot and a noticeable limp. Still I carried on making the very best of a bad job, and I did it rather well.

A couple of years later the diabetes became uncontrollable, which is life threatening and blooming' inconvenient. So, a pancreas transplant was suggested, and I was happy to go on the waiting list for a suitable organ... for two years. I finally got one, but rejected it, had it removed and received another one a few months later. For 12 months I thanked a Galaxy of lucky stars while my body accepted and thrived on this wonderful organ. Positively fizzing with life I began to feel really well, making me realise how sick I'd been for years. In fact I even managed to set up my own copy-writing business. Nothing was going to stop me now, so what if my stomach resembled a road map of Great Britain, I could still look good even though it took a bit longer, like any 40 year old.

Just a few months ago my hair began to fall out, faster than my Guide Dog's as he made ready for his winter coat.

This can be a side effect of some immune suppressing drugs and can also happen after major surgery, so it's hardly surprising when some of us transplant patients begin to loose our hair. I'd get up on a morning to find a carpet of hair on my pillow and after washing my locks I would almost block the shower!

To say I was devastated would fall well short of the mark. Although my hair was never my crowning glory, it had always been there as an essential accessory. As Samson needed his for his strength, I needed my hair for the faith I had in myself. The more it fell out the less I went out. When I finally saw the bathroom light reflect brightly off where once my parting had been, I felt like closing down, giving up and wrapping myself in a permanent duvet. Woe was definitely me.

I've never asked 'Why me?', but when an enlightened friend suggested A WIG, I stamped my foot and wailed, "Why my hair?"

I couldn't take the wig option seriously. Don't get me wrong, as an ex-extension addict I loved wearing them, but for fancy dress purposes only. In fact, I had a Rula Lenska, a Daryll Hannah and a Something That Looked Like The Dog's, but anyone could tell, with every nylon strand, that they were wigs. On the other hand, I'd just started a new business and had to tout my talents around the local business community. Networking they call it and I couldn't do



it as a bald bombshell. Worst still, I was invited to a Harvest Ball, along with my husband. 'I've got no hair' just wouldn't excuse our absence as we simply had to go. I tentatively unwrapped my knock 'em dead, velvet red frock and slipped it on. I looked in the mirror and laughed, possibly hysterically.

I felt my familiar stubborn streak take command of the situation. I wasn't going to miss out on life, especially as it had just started again. A few disallowed words later, I literally swore that I would go to the ball, even if it meant I bought a wig. Later that day, I found a hairdresser and wig supplier I liked the sound of and made an appointment with them that very week.

On the day, I went along with someone I trusted, with a discerning eye, my mother of course. At that stage I didn't have the highest of expectations. How wrong I was. We entered the salon and nobody stared at me as we were lead to a private room. Like a giant Clairol colour chart, one wall was covered with mounted wig samples, all seemingly long gorgeous tresses, in various glossy colours. Even my mother gasped and I had to sit on my hands so I wouldn't touch. Once the assistant arrived, she told me that I could try any wig I wanted to, which was a bit of a mistake. For two hours I swapped a conker coloured 'Rosalind' for a flame red 'Carmella', or a honey gold 'Guinevere' for a chocolate satin 'Angelica'. I had the time of my life!

When I finally calmed down, I was advised to go for something as close

Christmas Card Competition Winners!

as possible to my own colour and style. I dutifully looked at the mousey brown shoulder length bobs. I departed having ordered a very long, deep chestnut gold 'Chrystelle', as close as possible to the hair I've always dreamt of. If I was going to have a wig then I was really going to have a wig and this Rapunzel was more than ready to let her 'mono fibres' down.

I've never looked back. The ball was as good as a ball can be, even better because I swanned around in my frock and locks, looking like I was born to it. I've even discovered that dark chestnut gold doesn't really show up oxtail soup. Chrystelle has only blown off once and that was in a Scottish gale in November. I've even stopped boasting about my wig, when people compliment me on my hair. Now that's progress. I am now hooked, especially as the time it takes for me to get ready has quartered and there are no bad hair days.

So YES I do say 'HA!' at a fate that thinks it can knock me down. My transplant is still working beautifully and although my eye's still false and my leg still limps, I look bloody good, considering.

Joanne Roberts
Pancreas Transplant Patient



Winner - Hattie Dufton

The card competition featured in the last edition of Whispers was won by Hattie Dufton of Manchester High School for Girls and the Runner Up was Julie Coomer. Well done to all our entrants.

Hattie's design will be reproduced and sold on behalf of Kidneys for Life along with our other Christmas cards later this year. Please look out for this design and others either online at www.christmas-cards.org.uk/kidneys, through the Fundraising Office at the MRI or at the Charity Card Shops in Wilmslow, Sale, Hale and Knutsford from late October.



Runner Up -
Julie Coomer

What does the Transplantation Laboratory do for you?

There are two main biological barriers to successful organ transplantation and there is an agreed, evidence based national system to allocate donated kidneys so that immediate rejection due to these factors is avoided. Both the national kidney transplant list and the allocation process are managed by the Organ Donation and Transplantation Directorate of NHS Blood and Transplant (ODT/NHSBT).

Firstly, as is the case for blood transfusion, the donor must be ABO blood group compatible with the recipient. Donor kidneys are usually offered to blood group identical recipients but under certain circumstances they can be offered to a compatible patient.

Secondly, it is essential to be sure that the recipient does not have antibodies directed against the donor's HLA antigens (tissue type). HLA tissue types are proteins on the surface of the cells which make up our organs and we inherit them from our parents. They can be considered as the 'barcode' which identifies our organs as belonging to ourselves and there are many, many different HLA types. In transplantation the HLA type on the donor organ is recognised as different by the recipient's immune system and this can result in the transplant being rejected. If antibodies against the donor's HLA antigens were present at the time of transplant they would cause immediate rejection.

Someone may produce antibodies to HLA antigens if their immune cells have been exposed to another person's HLA type that is different from their own. That can happen during pregnancy because the baby will inherit some of dad's HLA type, following blood transfusion and transplantation.

In the Transplantation Laboratory we determine a patient's HLA type from the DNA extracted from their blood sample. Samples are usually tested in batches and we have recently had an exciting development in this area. We have acquired a new robotic instrument, the first in Europe, to process these tests. The results of this routine HLA typing are usually reported within two weeks. When necessary, samples can also be HLA typed individually and that takes approximately four hours.

Another important test that we do is to test the serum (the fluid part) from the blood samples that are sent to us each month for antibodies. As the antibodies can appear and disappear over time it is important that we receive and test regular samples while a patient is on the transplant list and also after transplantation. There are two types of HLA antibody test; firstly we find out whether the patient has any antibodies and then, if they do, using a more complex test we find out which HLA types they are directed against. In addition, if a female patient has had children, there is a possibility that she produced antibodies around the time of pregnancy but they have since dropped to a very low level. They would not cause immediate rejection but might increase in level if the donor had a tissue type they recognised, causing rejection in the weeks after the transplant operation.

Whenever possible, we HLA type the father of the children or the children themselves so that we know which tissue types the patient's immune system was exposed to during pregnancy. Those are recorded as unacceptable in a donor for that patient in order to avoid the risk of rejection.

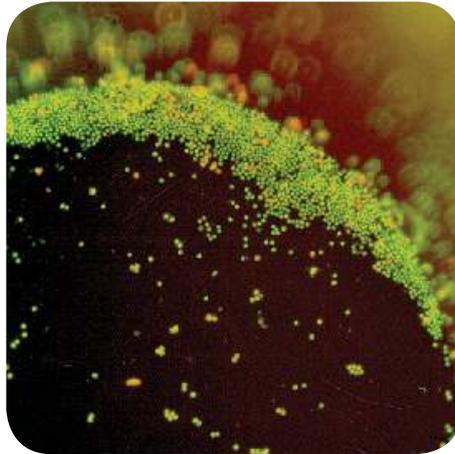
When we have been notified by the transplant surgeons that a patient is to go on the transplant list, we make sure that we have received all the necessary information, that we have completed the HLA typing and that the antibody testing is up to date. We then register the patient on the national kidney transplant list using an electronic link to the national database. They are also registered on the local information management system as being on the list. It is essential that the patient's blood group, HLA type and details of any antibodies are recorded because these are crucial for finding a matched donor. Scientists in the laboratory are responsible for keeping the HLA information up to date on the national database. They also make other changes requested by the doctors caring for the patient such as temporarily suspending them if they become unavailable or unfit for transplant.



Dead Cells -
Crossmatch Positive

There are nearly 800 patients registered for a kidney alone transplant in Manchester and we register over 200 new patients each year.

All UK transplant centres collaborate in the national kidney allocation scheme that is managed by ODT/NHSBT. When organs are donated from someone who has died, the donor is HLA typed in the nearest laboratory and the result reported to ODT. Using a complex computer algorithm, they identify suitable recipients taking account of ABO blood group, antibody status and HLA mismatching (HLA mismatching does not prevent successful transplantation but it is well established that HLA mismatched transplants are more likely to fail in the long term than those that are matched). In addition, there is a complex system for prioritising patients that places considerable emphasis on how long they have been waiting. Patients with rare tissue types are also prioritised if there is a suitably matched donor for them.



Living Cells -
Crossmatch Negative

Once the kidneys have been allocated in this way, they are transported to the recipient's transplant unit. The next step is for a pre-transplant crossmatch test to be carried out to confirm that the patient has no antibodies directed against the donor's HLA type. The Transplantation Laboratory is responsible for crossmatching all the patients who will receive their kidney transplant in Manchester. Scientists are available 24/7 to provide this service and there is always a consultant clinical scientist on-call to provide advice.

In the cytotoxic crossmatch test patient serum samples are tested against white blood cells from the donor. If the cells are killed that indicates that the patient has antibodies directed against the donor and there is a high risk that the transplant would be rejected. That is termed a positive crossmatch and the transplant would not proceed. If the donor cells are not killed then the crossmatch is reported as negative and the transplant can proceed. If patients are known to have a higher risk of rejection because they have had a previous transplant or they have high levels of HLA antibodies then they also require an additional more sensitive flow cytometry crossmatch test that uses fluorescence markers to detect antibody binding to donor white blood cells. As before, no antibody binding is reported as a negative crossmatch and the transplant can proceed. Crossmatch testing takes between five and six hours.



HLA Typing using DNA -
Setting up the Test

The Transplantation Laboratory also tests patients after their transplant in order to detect any antibodies directed against donor HLA types. This helps the doctors diagnose rejection and decide which treatment would be best.

The Transplantation Laboratory has approximately 30 scientific staff of whom 3 are consultants. We are actively involved in training and currently have 6 trainee clinical scientists. In addition to the support we provide for kidney transplantation we also support other organ transplant and bone marrow transplant programmes in Manchester. There are a number of research projects relating to transplantation and we are actively involved in audit. Our team of administrative staff are crucial to the smooth running of the department.

Susan Martin and Judith Worthington
Transplantation Laboratory
Manchester Royal Infirmary

Renal Remembrance Service

A Remembrance Service will be held at Salford Cathedral in July 2010 to remember those renal patients who have passed away in 2009.

If you would like to attend or require further information please contact Noel Hurley on 0161 276 4652



Another House of Cards

You may recall that last year I volunteered to help Irene to sell charity Christmas cards at Wilmslow library well guess what, I did it again.

The sale of the cards is run annually by an organisation called the Combined Charities Christmas Shops run by local volunteers.

Set up 37 years ago by Sheila Hallas it has gone on to raise £3.25 million for more than 120 charities and opens temporary shops in Wilmslow, Macclesfield, Altrincham, Hale, Knutsford and Sale libraries.

Charities sell their cards at the different locations run by volunteers which mean that 100% of the money made goes direct to the various charities. Kidneys for Life are one of those charities.

I helped out all day at Wilmslow on Tuesday 24th November working alongside Irene, Nick another kidney transplant patient, Lucy and another helper. Once again I was staggered by the number of charities whose cards are available to the public to buy and the variety of gifts including calendars, toys and jewellery. All at very competitive prices and some a great deal cheaper than large stores. We were busy all day with a steady stream of people buying their cards and presents. Not much time for tea, biscuits and mince pies (yes I know high in potassium but it was near to Christmas) but the pleasant company and the thought that I was doing something worthwhile made the day speed by. And this was not the end.

On Saturday 28 November I, along with Margaret my wife helped Irene and her husband out for half a day at Hale library. Although not as big as Wilmslow there was still a very good variety of cards and gifts for sale to the general public. Irene very kindly supplied the coffee from Costa Coffee and once again we had a steady stream of people through the doors until we closed at 4 o'clock in the afternoon.

This time I knew what to expect so I wasn't daunted by the size of the operation and operating the tills! Its hard work standing on your feet all day and I've certainly got a great deal of admiration for people working in shops everyday, week after week.

Overall Kidneys for Life made £3,450 from the sale of the cards at the libraries, an incredible amount of money considering its just about selling cards.

And for me the best thing about helping is that I feel I'm giving something back especially when I have been so lucky to receive a kidney transplant which has allowed me to live a normal life.

**Mike Kewley
Kidney Transplant Patient**

Current Research

Below are just two of the research projects which we are working on at the moment.

Dr Leonard Ebah

Leonard's research uses various methods to extract tissue fluid (the fluid surrounding cells). This fluid will be analysed for toxins that are retained in kidney disease, in comparison to blood.

This will tell us if toxins are evenly distributed in body fluids or if tissue fluid contains larger quantities of certain toxins, hence their poor removal by current methods of dialysis. Initial analyses for small toxins like urea show similar levels, but this may not necessarily be the case for more complex ones.

The study will continue for at least another year.

Dr Muir Morton

Muir's work involves looking at the prevalence of Epstein Barr Virus (EBV or glandular fever) in the transplant population. After transplantation, new EBV infections and reactivation of previous infection can occur. In many, this infection will cause no clinical symptoms or illness. In a small number of people, EBV infection can persist and may go on to cause a condition called Post Transplant Lymphoproliferative Disorder (PTLD) which is serious and potentially life threatening. As part of the project, Muir will be using blood taken from volunteers to validate an EBV home testing kit for more efficient diagnosis and treatment

Rachel Lennon – Wellcome Fellowship



Dr Rachel Lennon is a Paediatric Nephrologist at the Royal Manchester Children's Hospital.

Her research is based on understanding basic mechanisms of proteinuria (excessive protein in the urine) and Nephrotic Syndrome. In December 2009, Rachel was awarded a prestigious four year fellowship from the Wellcome Trust and this will enable her to continue this important research.



Get in Touch...

If you would like further information on any of the articles in this edition of Whispers or you would like help with fundraising ideas do please contact Irene Chambers.

Irene Chambers
Fundraising Manager

Tel: 0161 276 6671

Email: fundraiser@kidneysforlife.org

Kidneys for Life fundraising for MINT,
The Renal Unit,
Manchester Royal Infirmary,
Oxford Road,
Manchester M13 9WL

Donations

When making donations to Kidneys for Life or collecting sponsorship for events such as runs, walks etc please don't forget to:

giftaid it

Using Gift Aid means that for every pound you give, the charity you are supporting will receive an extra 28 pence from the Inland Revenue, helping your donation go further.

This means that £10 can be turned into £12.80 just so long as donations are made through Gift Aid. Imagine what a difference that could make, and it doesn't cost you a thing.

Donate online at:
www.kidneysforlife.org



Make a Donation and Help Make a Difference...

MINT has a proud history of being at the forefront of many acclaimed scientific discoveries and internationally celebrated successes. The research work undertaken by the team working in MINT 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 fundraising for MINT, The Renal Unit, Manchester Royal Infirmary, Oxford Road, Manchester M13 9WL

Don't forget to giftaid to make your donation worth more (see above).

Name

Address

..... Postcode

Signature Date

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

I want to giftaid my donation*

* To qualify for Gift Aid what you pay in income tax or capital gains tax must at least equal the amount we will claim in the tax year.

