



**KIDNEYS
FORLIFE**

Fundraising for the MRI Renal Units

Autumn 2010 Whispers

www.kidneysforlife.org

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How are we getting involved in research and development?

**£6,500 Raised at 2010
Great Manchester Run!**



More information and photos from this great day.

...AND MUCH MORE

**Kidneys for Life
fundraising for MINT**

Charity number 505256

British Transplant Games

Nine children of all ages from the Royal Manchester Children's Hospital, supported by their families and staff, took part in the British Transplant Games in Bath on 19-22 August 2010.



They competed in a variety of events including swimming, table tennis, badminton, obstacle race and track & field events such as long jump, ball throw and 25m, 50m, 100m and 200m dash. The team finished 6th out of 17 children's teams. Well done to everyone who took part including their supporters both family and staff.

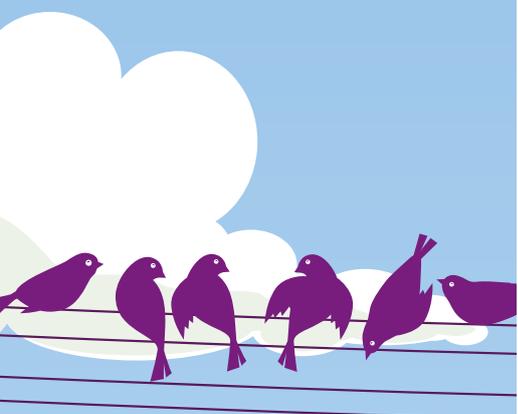
To enable them to take part in the Transplant Games the children and families contributed towards the costs and raised monies throughout the year and Kidneys for Life also gave a grant to the team.

This is what Denise Roberts, Manchester Children's Team Manager of the Paediatric Renal Transplant CNS said to Kidneys for Life:

"Many, many thanks for supporting the Manchester Children's Transplant team at this year's British transplant games in Bath. We had a fantastic time and managed to win 6 Gold medals, 10 silver medals and 6 bronze medals including silver medals in the team events, the swim and track relays. Not bad for a team of nine!"

For us though, it's not about winning medals, it's about taking part and celebrating life. It also gives children and families the opportunity to network and make friends and meet people who have had similar experiences to them. That support is invaluable, as children with renal failure often feel isolated and marginalised out in the community and for many, the transplant games give them a sense of achievement and pride."

Kidneys for Life Social Media



Kidneys for Life have now entered the social media age although only tentatively, you can now find us on Facebook and we also have a Twitter account: <http://twitter.com/kidneysforlife>

Please help us to increase our Facebook and Twitter traffic, and raise our profile, by posting information on our wall.

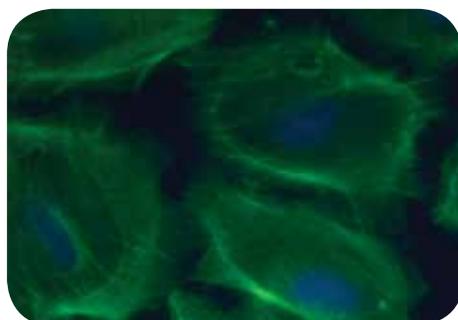
Research Updates



Rachel Lennon

Rachel Lennon is a Paediatric Nephrologist working at the Royal Manchester Children's hospital. With fellowship funding from the Wellcome Trust, she is investigating causes of proteinuria, where kidneys leak excess protein into the urine. Rachel's research is based jointly at the Manchester Institute of Nephrology and Transplantation (MINT) and the Wellcome Trust Centre for Cell-Matrix Research at the University of Manchester. She is studying human kidney cells with the aim of understanding how they interact with their local environment.

Using powerful new proteomics technology, Rachel is analysing cell and matrix interactions and these studies will help to build up a picture of the important proteins needed to maintain health. By understanding how cells work at the basic level, it will be possible to consider new methods of treatment for patients with kidney disease.



Muir Morton

Muir Morton is training to be a nephrologist in adult renal medicine. Muir is leading a research project on Epstein-Barr virus infection in adult renal transplant patients along with Dr Michael Picton, Beatrice Coupes and Professor Paul Klapper.

This study is investigating infections that can occur after transplantation. It is focusing on Epstein-Barr virus (EBV) infection (known for causing glandular fever). 482 people with kidney transplants under Manchester Royal have now joined the study which is fantastic and we aim to involve a total of 500. Recruitment is due to stop within the next two weeks. The next step is to process all the initial samples and surveys of symptoms. This will enable us to then calculate what proportions of transplant patients currently have signs of EBV infection. The purpose of the study is to better understand the natural history of EBV infection after transplantation with a view to developing guidelines to allow better care and management for any individual affected.

The research team would like to thank all participants who have joined the study so far and we will aim to keep all involved informed of our progress.

Photo on Left:
Cultured Kidney Cell

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...

Wythenshawe Dialysis "Step Down Room"



Money has been raised which has contributed to relocating and decorating a "step down room" for patient's training for Home Haemodialysis. The room now has a radio, DVD player, pictures and subdued lighting and provides an environment more in keeping with the home situation. We would like to thank Councillor Shirley Sockett, former mayor of Bollington, who contributed monies she had raised during her year as mayor, Declan Hartnett raised money through sponsorship for the Wilmslow half marathon and Graham Hopwood also supported this development. These donations have also provided DVD players for patients and a colour printer for producing patient information in the training unit.

Stamford House

A fundraising event was held at Stamford House in support of Dan Bailey, one of their gym instructors, who is suffering from kidney disease. The event raised £1,300 in total and we would like to pass on our thanks to everyone concerned.

Glossop Golf Club Raise £1,050



Again we would like to thank John O'Grady and Keith Clegg for organising another Golf Day on behalf of Kidneys for Life at Glossop Golf Club in July this year. The event raised £1,050 and we would like to thank all of the teams who participated on the day but particularly John and Keith for organising such a fantastic event.

The Stanley Arms

Our thanks once again goes to Steve & Sandra Williams of The Stanley Arms in Aughton, Ormskirk for their fundraising efforts at the pub and raising £1,045.

Gill & Hazel Bate

A fundraising event was organised by Gill & Hazel and held at Woodhey Court in Sale to raise funds for Kidneys for Life and we would like to pass on our thanks to everyone involved.

Renaissance Lodge

Our thanks once again for the support of Renaissance Lodge (Masons) at the Manchester Charity Giving Evening.

John Wilson Goes Coast to Coast



John, whose brother has received a kidney transplant here at the MRI, decided that he would cycle from Lands End to John O'Groats in August of this year and raise funds for Kidneys for Life. John completed the cycle ride and at the same time raised over £2,200 in the process. Well done to John who took 10 days to complete the distance of 921 miles and all this just a few days before his 50th Birthday. You can read about his venture in his blog at <http://uk.virginmoneygiving.com/JohnWilson>

S&I Sealy Ltd



Kidneys for Life were nominated as Charity of the Year for S&I Sealy last year and they raised a total of £650 from a number of events including their "Dress Down Days" for which we would like to extend our thanks.

Charity Christmas Cards

A) Glittering Tree

Size:203x148mm
Finished in gold foil and contains insert.
£4.95 for 10

B) Silver Trees

Size:203x148mm
Finished in silver foil and contains insert.
£4.95 for 10

C) Village

Size:160x160mm
Embossed and finished in gold foil on textured board. Contains insert.
£4.25 for 10

D) Santa's Little Helper

Size:140x140mm
Contemporary Christmas design.
£3.75 for 10

E) Robin on a Lamp Post

Size:95x195mm
Finished in silver foil.
£4.00 for 10

F) Snowman

Size:146x104mm
Designed by Hattie Dufton from Manchester High School for Girls.
£4.00 for 10



C



A



H



B



D



E



F
Design by
competition
winner
Hattie Dufton



G



J



I



K



L

Whispers

G) Snowmen

Size: 165x83mm
Finished in silver foil.
£3.50 for 10

H) Christmas Robins

Size: 174x87mm
Finished in gold foil on textured board.
£4.00 for 10

I) Rudolph & Friends

Size: 150x150mm
Finished in a high gloss with red foil.
£4.25 for 10

J) Snowdrops

Size: 150x150mm
Delightful Christmas image.
£3.50 for 10

K) Three Kings

Size: 122x170mm
Embossed and finished in gold foil.
£4.00 for 10

L) Xmas Wreath

Size: 125x125mm
Features a high gloss varnish finish.
£2.75 for 10

Thank you to all those of you who purchased our Christmas Cards last year either online, through the Fundraising Office or at the various Charity Card outlets in Wilmslow, Sale, Hale & Knutsford. We raised over £4,000 from our sales last year and all profits went directly to Kidneys for Life. If you could help this year by purchasing our cards it would be very much appreciated.

One of the cards this year is the winning design (Snowmen) from Hattie Dufton of Manchester High School for Girls, if you would like to see your design in next years selection please see our Christmas Card Design for 2011 article on page 9.

The cards are again available to collect from the Fundraising Office at the MRI and the satellite dialysis units by arrangement. If you would like them delivering to you within the hospital contact Irene Chambers by phone 0161 276 6671 or email fundraiser@kidneysforlife.org to arrange.

Cards can be purchased from:
Wilmslow Library (30 Oct – 11 Dec),
Hale Library (15 Nov – 6 Dec),
Sale Waterside (16 Nov – 4 Dec),
Altrincham Library (6 Nov – 4 Dec) or
Knutsford (15 Nov – 6 Dec).

Or online at:
www.christmas-cards.org.uk/kidneys

If you would like to purchase your cards by post please complete the order form below and return it to: Kidneys for Life, Renal Unit, Manchester Royal Infirmary, Oxford Road, Manchester M13 9WL. Please make cheques payable to "Kidneys for Life" and don't forget to add on postage and packaging. Allow 14 days for delivery.

All cards are in packs of 10. Greeting inside all cards reads: "With Best Wishes for Christmas and the New Year."

Last orders for Christmas delivery must be received by Friday, 3 December.

Order form

Code	Description	Cost	Quantity	Total
A	Glittering Trees	£4.95		
B	Silver Trees	£4.95		
C	Village	£4.25		
D	Santa's Little Helper	£3.75		
E	Robin on a Lamp Post	£4.00		
F	Snowman (by Hattie Dufton)	£4.00		
G	Snowmen	£3.50		
H	Christmas Robins	£3.75		
I	Rudolph & Friends	£4.25		
J	Snowdrops	£3.50		
K	Three Kings	£4.00		
L	Xmas Wreath	£2.75		
TOTAL				
P&P (If applicable)				
Donation* - Thank You!				
Grand Total				

Post and packaging

For orders up to £15 - **£3.00**
For orders between £15.01 and £45 - **£4.00**
For orders over £45 - **£5.00**

* Donations will go towards Kidneys for Life
Registered Charity No: 505256

Personal details

Complete your name and address and just tick the boxes below its that simple:

Name

Address

Postcode

Email

Tel

How would you like your cards to be delivered?

- I will collect my cards from the Fundraising Office near Ward 10
- Please deliver them to me at Ward..... (P&P free)
- Please post them to my home address (P&P applies, see below)

giftaid it

Use giftaid to make your donation worth more. For every pound you give to us, we can get an extra 28p from the Inland Revenue.

Complete your name and address above and just tick the box and sign below - it's that simple.

- I want all donations made for the last six years and all future donations to be gift aided until I notify you otherwise. To qualify for giftaid what you pay in income tax or capital gains tax must at least equal the amount we will claim in the tax year.

Signature

Date

History of Renal Research and Development at the MRI

Professor Paul Brenchley

In the early eighties, I was working as a clinical Immunologist in Saint Marys Hospital and just getting interested in renal research. Netar Mallick and I had our first joint research project on IgA nephropathy with a young doctor, John Feehally doing his M.D. (Didn't he do well; having finished his training here in Manchester, he went on to become a Consultant Nephrologist and Professor in Leicester and developed an original programme of research in IgA nephropathy which has given us a new insight into the composition and function of IgA antibodies in this disease. John has been President of the UK Renal Association and is President Elect for the International Society of Nephrology).

Netar and I and later, Ram and I supervised many other junior doctors during their research training in Manchester and we have kept the same focus and emphasis on the importance of clinical research on patients with renal disease, on dialysis or post transplantation. Patient focused research like this wasn't always easy to get funded years ago as the major funders of research gave much greater preference to animal models of disease as they were thought to be more "academic" and had less variability in response to specific interventions.

One major shift in emphasis has been the importance of working on the real problem i.e. the human disease not the

rat version. This has been driven over the last 5 years by the Dept of Health insisting that NHS resources be focused on improving outcomes for patients and this attitude has affected how the other major funders in particular Medical Research Council, Wellcome Trust and National Medical Charities spend their money on research. Now, clinical translational research to show an impact on patient care in a short time frame of 3-5 years is seen as the gold standard and this premise is at the heart of the National Institute of Health Biomedical Research Centres established in London, Oxford, Cambridge and Manchester.

The topics and methods used in research have changed over the last few decades. In the 70's and 80's there was a lot of immunology and biochemistry research on antibodies, complement and animal models of disease. In the 90's, renal cell culture of mesangial cells, the role of the extracellular matrix and cytokines and growth factors came to the forefront of research. Molecular biology became a powerful tool to investigate gene expression in disease. Since the Human Genome Project reported the complete human genome sequence in 2000, and the HapMap project reported in 2003, the genetic variation between individuals, genetics and the interaction of gene and environment has developed a powerful new approach of genetic epidemiology to look for associations of

genes with complications and outcomes of treatments.

In terms of renal replacement therapies, haemodialysis machines and membranes have got better; smaller more efficient machines, pure water supplies with biocompatible dialysis membranes. CAPD (continuous ambulatory peritoneal dialysis) which just got going around 25 years ago, has improved with better solutions (Ram Gokal's research on glucose polymers here in Manchester was of world wide importance and led to the development of Icodextran) and greater clinical knowledge about controlling peritonitis. Automated PD is now very common.

Transplantation outcomes have improved over the last two decades with better tissue matching and there is now a much better choice of immunosuppressive drugs for doctors to use to control acute rejection.

In terms of drugs to help alleviate some of the medical problems that occur when kidneys stop working, EPO (Erythropoietin) has made a big impact on renal anaemia. There are also better drugs to control phosphate levels, high blood pressure and lipid levels which all make a contribution to making life better for the patient with kidney disease or on dialysis.

So what of the future? Is it possible to predict how research will alter life for the better for renal patients?

Certainly new knowledge of the disease mechanisms related to kidney disease is accumulating at a faster rate than ever. The powerful methodologies of genomics (studying gene expression), proteomics (studying proteins) and metabolomics (studying the metabolites or breakdown production of the body's biochemical pathways) coupled with sophisticated bioinformatic software and computer modelling will produce novel ideas and new candidate targets for drug discovery and treatment. So for the area of kidney disease leading to renal failure, I think we will understand the mechanisms of membranous nephropathy and IgA nephropathy which could lead to specific immune interventions to induce disease remission. I think there will be new drug treatments to reduce or prevent proteinuria which coupled with knowledge of the genes that promote disease progression and therefore who is most at risk of this, it should be possible to stop a lot of patients ever getting to renal failure.

For patients on dialysis, I can see that AV (arteriovenous) fistulas will last longer and that haemodialysis will become even more efficient at removing metabolic toxins. For peritoneal dialysis,

we should be able to prolong the life of the peritoneal membrane and stop the fibrotic process that shortens its usefulness in some patients.

For kidney transplants, we know the problem now is not enough organs are available for transplantation. If the obesity epidemic really takes off in the developed world causing more diabetes and therefore more kidney disease, this problem will only get worse.

The challenge in this area is two fold:

- **To make all kidney transplants last a lot longer say on average another 5-10 years which will stop a lot of patients coming back onto the transplant waiting list**
- **To develop an artificial kidney from stem cells or embryonic tissue that is at least as good as dialysis today.**

I think all of these are achievable over the next 25 years. What is clear is that in Manchester we have a good team of doctors, nurses and scientists dedicated to finding the answers to these problems. We have an excellent Hospital and University with research facilities and staff comparable to anywhere in the world. But that's not enough to get the breakthroughs in research that we all

want to happen. Patients are an essential part of moving the research forward.

Without patients being interested in taking part in research either by giving blood samples or taking part in clinical trials of new treatments, it is impossible to improve treatments or make new discoveries. Fortunately, in Manchester we have active and interested patients keen to help us get the answers to the problems of kidney disease. Let's hope that together, we can solve these problems over the next 25 years.



Professor Paul Brenchley

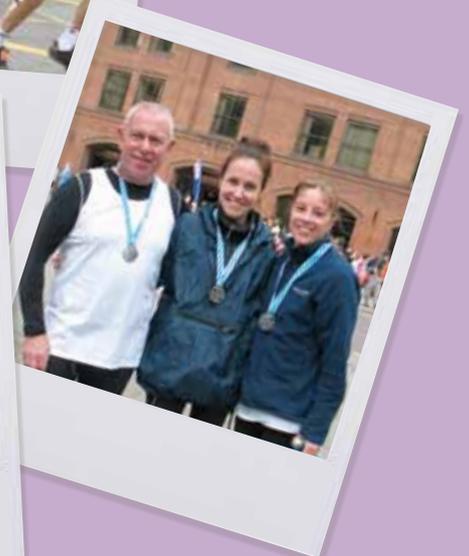
Director of Renal Research Laboratories

MINT - Manchester Institute of Nephrology & Transplantation.

Great Manchester Run 2010

Kidneys for Life had 45 runners in this year's Great Manchester Run which took place on Sunday, 16 May and although the weather was not the best everyone enjoyed the day and completed the run. Our group of runners raised a fantastic £6,500 so our thanks goes to everyone who took part.

If you are interested in taking part in the Great Manchester Run next year which will take place on Sunday, 15 May please do get in touch with Irene Chambers either on 0161 276 6671 or email: fundraiser@kidneysforlife.org



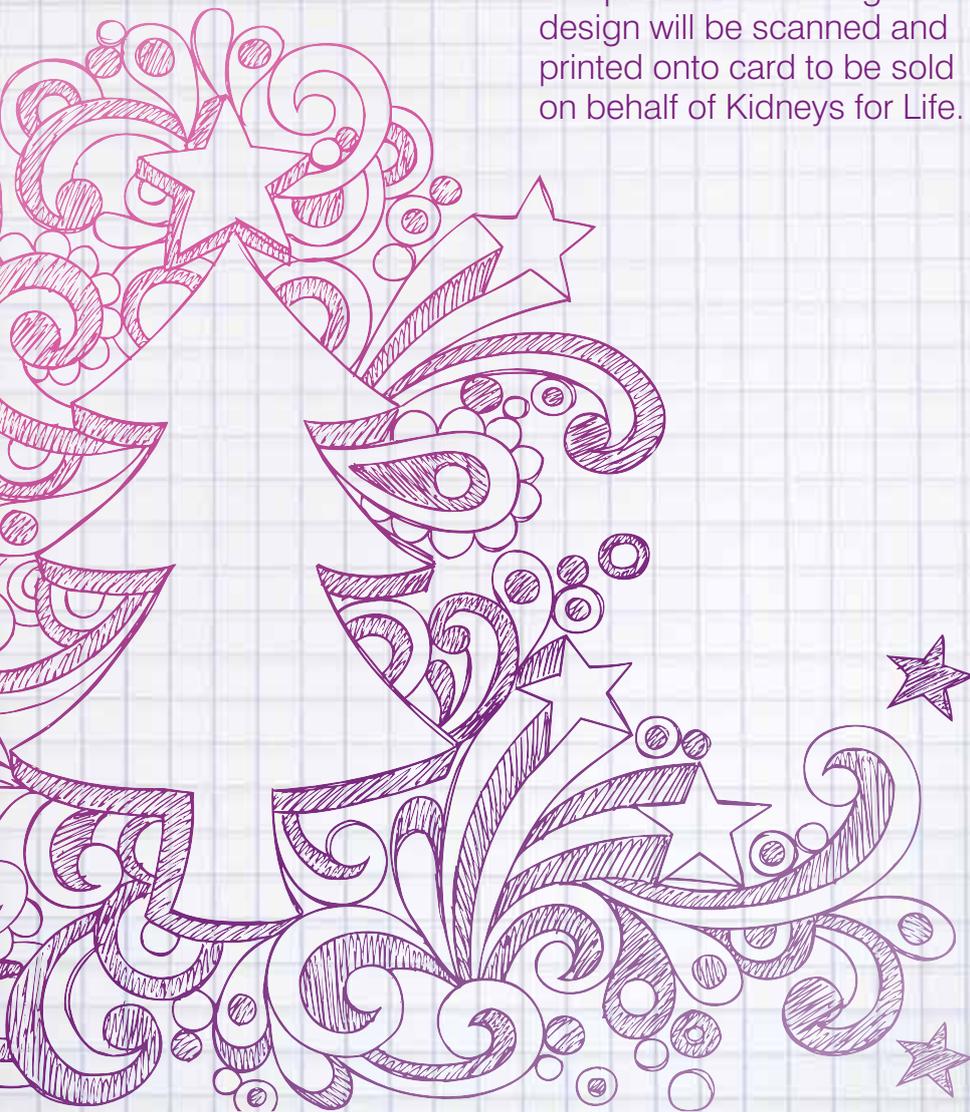
Get Creative for Christmas!

Following on from our successful design from Hattie Dufton we are holding a Design a Card for Christmas 2011.

Kidneys for Life are running an exclusive card design competition where we want you to design a Christmas Card which will be sold on behalf of Kidneys for Life in 2011.

The competition is open to everyone. The maximum card size is A5. Deadline for entries is 28 February 2011.

The prize – the winning design will be scanned and printed onto card to be sold on behalf of Kidneys for Life.



Running Man...

Des Gardner completed the London Marathon on Sunday, 25 April in a very respectable 4 hours 48 minutes which was only three minutes outside the time he had been training for.



In total Des, his family and friends raised a tremendous £5,050 – well done to everyone who supported Des in this endeavour and please accept the thanks of everyone here at Kidneys for Life for such a tremendous effort it was really appreciated.

The sponsorship monies raised by Des are to be put towards the specialised piece of medical equipment which enabled the living donor kidney transplant from Helen to Evelyn Godley (see page 10) who have incompatible blood groups.

ABO Incompatible Treatment Ends in a Successful Transplant

On Friday 23 April 2010, Evelyn Godley's wait for a kidney transplant finally came to an end. But surprisingly the organ came from a donor who had previously been told they were not a suitable match!

Evelyn's daughter Helen, 32, had put herself forward to be a donor several years before when she found out that her mum needed a transplant. But after initial tests revealed that they were an incompatible blood group match (Evelyn is Group O and Helen Group A), they both believed that a direct transplant was never going to be possible.

Keen to explore all options available they registered on the paired donor list and were initially excited when a match was made on their second run. Unfortunately this match was not to proceed, so they went back to normal life, waiting and hoping.

However things were about to change, and whilst in Australia, for a friends wedding, in January this year, Helen received a call from her sister Alice to say that the MRI had been in touch. **"I was thrilled when my sister told me that the hospital had been in touch and were proposing a new option for us. I couldn't wait to get home to find out more about what was involved."**

Three weeks later Evelyn and Helen were sat at the hospital with two other couples whilst the whole procedure was explained to them. Alice says: **"We'd heard about ABO Incompatible treatments before, but had heard that they could be quite aggressive and uncomfortable to go through."**

The staff at the MRI explained that things had now moved on. The new treatment shouldn't cause any real discomfort to the recipient and the treatment period was short.

A couple of weeks later the Godley family were given the good news that they had been chosen as the most suitable candidates to undertake the treatment. Helen explained: **"From then on it moved pretty rapidly, both myself and Mum underwent additional tests, including extra blood samples to use during the treatment. We saw the independent assessor and met the surgeon. Everything for me proceeded just as it would if we were involved in a normal transplant."**

The ABO Incompatible treatment is normally done over a period of two weeks, where the recipient visits the MRI every other day for treatment, this lasts approximately 4 hours. However, in Evelyn's case, the treatment period was condensed into one week, this was due to the surgical date which had now been decided upon. She visited the hospital everyday for a week and moved her usual dialysis treatment from Macclesfield hospital to the MRI to cut down travelling time. Alice remembers that week: **"It was a busy week for Mum, quite tiring with long days spent at the MRI. But throughout it we were all feeling optimistic and happy that she was getting this opportunity."**

It was only on the morning of the operation itself that the family found out that Evelyn's levels had come down

enough to allow the op to proceed. Helen said: **"It was such a relief, we knew all the way though the build-up that at anytime the doctors might discover that the treatment wasn't working for Mum, or other obstacles may come up. Now we were ready to just get on and do it!"**

The transplant went ahead exactly the same as any other live donor transplant. First Helen was taken into surgery and once the kidney had been successfully removed, Evelyn followed her down. **"Alice stayed at the hospital with us all day, she was there early to give me moral support before the operation, and was by my bedside when I woke up to tell me how Mum was getting on. With all the running around she did that day, I think she actually had the toughest job out of all three of us!"**

The operation was successful and the following day both Evelyn and Helen were already beginning to recover. Helen was discharged four days later and even managed to get to her friends wedding one week after the operation!

Evelyn stayed in hospital for a few extra days whilst staff monitored her levels, but nobody could believe how quickly she was improving.

After leaving hospital Evelyn went to stay with her elder daughter Alice for a few days. Alice says: **"It is important for both donor and recipient to have someone they can stay with for a few days after the operation for support, both emotional and practical. We decided it would be a bit cramped**

Pictured from left to right: Alice Spreckley, Helen Godley and Evelyn Godley. One of the main advantages of the transplant has been it has open the possibilities of travel again. Something Evelyn loves to do. Evelyn, Alice and Helen are planning a holiday in Germany for later this year to celebrate!

here with both staying with us, so Helen went to a friends house whilst Mum came to us."

Helen agrees: **"I couldn't have been a donor for my mum without the support I have had from so many people. My work were fantastic allowing me to have the time off and friends and family have rallied round us both to help us through."**

Five months on and everything is looking good for the Godleys. Helen returned to work after a month off and Evelyn is relishing her new found freedom and time. **"Although my full recovery has been a gradual process, it has truly changed my life. The staff at the hospital have been so supportive and helpful. We couldn't have hoped for a better outcome."**



Raising Money for ABO Incompatible Treatment

In order to provide the best treatment for patients with end-stage kidney disease, there is a real need to increase the number of living donor kidney transplants carried out.

To bring this about we need to deal with the obstacles which hinder living donor transplantation; these includes crossing barriers such as ABO blood group incompatibility, which historically was seen as a major negative indicator for transplantation.

Helen and Evelyn are one of the first living donor transplants at the MRI with incompatible blood groups. This new treatment involved passing the patients blood through a "Plasma Machine" where a special column removes only the blood group antibodies as a course of treatment prior to the transplant and for a short period following the transplant.

The MRI would like to purchase this specialised piece of equipment and Des Gardner has agreed that his sponsorship monies be used towards this and we have also received a donation from friends and family in memory of Dora Machin. We are waiting on the results of an application for the rest of the funding which we hope to hear about soon.



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.

