



**KIDNEYS  
FORLIFE**

Fundraising for the MRI Renal Units

# Spring 2009 Whispers

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

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**...AND MUCH MORE**

**Kidneys for Life  
fundraising for MINT**

## Viva Espania!

**Back in September 2008 sixteen people including seven dialysis patients, partners and staff from Tameside Dialysis Unit went on a holiday to Majorca in Spain.**

Staff members Dave Clarke, Joyce Swallow & Rowena Balneo helped organise the trip including arranging dialysis for the patients during their stay. The trip was partly funded by Kidneys for Life with the aim of enabling dialysis patients to take a trip abroad with others in the same situation which will hopefully lead them to taking holidays with family and friends in the future. In fact Kathleen and her husband have had a timeshare in Malta which they haven't used since Kathleen went on dialysis and as soon as they got back made arrangements to go in November and had a fantastic time. Everyone had a great time and found that getting together with others in the same situation really helped and in fact a number of them are already planning next years holiday!



### Pictured Above

Some of the Tameside dialysis patients, partners and staff who holidayed in Majorca in 2008, this trip was part funded by Kidneys for Life.



### New Fundraiser for Kidneys for Life

Welcome to this new edition of Whispers. I am the new Fundraiser for Kidneys for Life having been appointed last year following the departure of Caroline Siddall back in December 2006. I have previously worked for charities raising funds for young people both at Fairbridge and Bolton Lads & Girls Club. I now hope that I can make a difference for those affected by kidney disease by raising funds to further the research and help provide patient amenities.

**Irene Chambers, Fundraising Manager**

### Get in touch!

If you have any feedback or contributions please email [irene@kidneysforlife.org](mailto:irene@kidneysforlife.org)

# A Donor's Perspective of the Paired Waiting List

**My mum was diagnosed with gradual kidney failure a few years ago now, and at the beginning of 2007 she began her dialysis treatment and was placed onto the Kidney Donor Waiting List.**

My first thought was to put myself forward to be a direct donor for her, I felt that I was lucky to be at a stage of my life, with no dependants and a company that was very supportive, where I could offer to do this. Unfortunately we quickly found out that I was not the right blood group to be able to do a direct donation, Mum is blood group O so only someone from that group too would be suitable. It was at this stage that the Live Donor Transplant Nurses at the hospital told me about the paired exchange scheme. It was something I was immediately keen to sign up for, to me it is as simple as me giving a kidney direct to my mum, well at least the end result is the same thing, and a bonus is that another person benefits too.

I had to go through a few small (and painless) tests at the hospital and I was pleased to be given the all clear and have us entered onto the register. The staff at the MRI have been really kind throughout the whole time I have

been in contact with them and they are always there to answer any questions I have, they give you all the information you need and ensure that you are making the decision independently and understand the whole process.

So now we are on the list, it's just a case of sitting back and waiting really, the cross checks are run nationally every 3 months, and we hope that we will be one of the lucky pair that finds a match soon. For now though I'm just pleased that mum is on both registers, the solo one and the paired one, and this really does give her the best opportunity to get a donor as soon as possible. Me personally, well I'm just happy to have the chance to do my bit to support her at this time. I'd encourage anyone who is interested to contact their hospital. The way I see it is, the more people on the register, the better everyone's chances are!

**Helen Godley**



**Pictured Left to Right**

Helen, her mum Evelyn and her sister Alice taken just before they ran the Great Manchester 10K run last summer. Between them and their friend Kate Hawkins, they managed to raise a total of over £1,500 for Kidneys for Life.



## New Website Launched

**Visit [www.kidneysforlife.org](http://www.kidneysforlife.org) today and you will see we've undergone a complete revamp.**

Take the time to have a look, we would welcome any suggestions for information you would like to see on the website.

Email: [fundraiser@kidneysforlife.org](mailto:fundraiser@kidneysforlife.org)



## A House of Cards!

**Following a kidney transplant a few years ago I'm always keen to help out raising funds for Kidneys for Life. So when Irene asked for some help in selling charity Christmas cards at Wilmslow library I said yes.**

I had this vision of sitting in the corner of Wilmslow library at a small desk with a few boxes of Christmas cards, a collection box and a nice flask of tea and a box of biscuits. The day being spent talking to the few customers who purchased the cards and leaving about 4pm. I met Irene outside the library accompanied by her mum and followed her into the library up some stairs to the first floor and into a huge room overflowing with Christmas cards. I thought to myself, this is not what I expected.

Imagine my surprise when I entered the room to see 16 tables arranged in a U shape and on top of these tables there were between 40 - 60 boxes of Christmas cards. In the middle of the room were tables on which were placed all varieties of toys and games. In two of the corners of the room a till was located to take the money for the cards. I was a little concerned thinking to myself what have I let myself in for.

Later I found out that 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. For 2008 the Wilmslow library shop opened from October until early December while the rest opened from November until December. Because the organisation is run by volunteers it is able to give 100% of the money made to the various charities.

About 40 charities were represented at Wilmslow and they provided customers with a large range of Christmas cards to choose from. Also on sale were calendars, wrapping paper, toys and gifts. Five of us ran the shop; Irene, Lucy, Caroline Siddall, another helper and me. We started a 9am and finished at 5pm, with a short break for lunch. It was harder than my normal day job!

A steady stream of people throughout the day bought the Christmas cards, toys and gifts. We also took orders for cards to be printed, handed out pre-ordered cards, checked in the other charity volunteers bringing cards to placed in their boxes and helped people with their card selections. By the end of the day we took in excess of £2,500 which is excellent news for the different charities.

Although not what I expected I really enjoyed the day and I've volunteered to help in 2009 but there's always room for more volunteers. But if you just want to buy good quality Christmas cards for good causes you now know where to go.

**Mike Kewley**  
**Kidney Transplant Patient**

**If anyone would like to help with the Christmas Card sales both helping out in the library or stocking up the cards on a regular basis whilst the Christmas Card shop is open please get in touch.**

**See back page for contact details**

### **Design a card in Celebration of the gift of a Donated Organ**

Kidneys for Life are running an exclusive card design competition where we want you to design either a card front or a verse/poem which celebrates the gift of this precious offering. Your card entries may be for either a person who has received a donated organ or who has received an organ who would like to say thank you to the donor family. Quite a challenge but we know you can do it!

The competition is open to all ages and has been split into three categories: Up to 12 years of age; 13-19 years and 20 years & above. The maximum card size is A5. The deadline for entries is Friday, 29 May 2009.

**The Prize** – all the winning designs will be photographed and then printed and will be sold on behalf of Kidneys for Life to raise funds for the MRI Renal Units.

Please send your entries to: Irene Chambers, Fundraising Manager, Kidneys for Life fundraising for MINT, Renal Unit, MRI, Oxford Road, Manchester M13 9WL

Please note that due to the cost of postage & packaging we will be unable to return any cards entered into the competition.

## New Equipment for MRI

Kidneys for Life were able to purchase two new pieces of equipment in the last year.

**Zochonis Charitable Trust** donated £50k to enable Kidneys for Life to purchase a OCT (Optical Coherence Tomography) machine – OCT uses a narrow beam of light (from a low energy laser or light emitting diode) to interrogate tissue structure in real time in a non invasive way. It is being used in research to look at peritoneal membrane function which is extremely important for those renal patients on peritoneal dialysis.



**Blackburn Lions Club** donated £10k to purchase a replacement FPLC – (Fast Liquid Protein Chromatography) It enables separation and purification of components from complex extracts of cells and tissues based on their molecular characteristics. It replaces the original FPLC equipment donated by Blackburn Lions in 1988.



## Tracey's Story



**Pictured Above**

Tracey and her husband on their wedding day in 2007.

**I was diagnosed with diabetes at the age of 11 and from then on my life was never to be the same again...**

After 17 years and a multitude of complications leading from my condition I was placed on the transplant list in 2004 for a combined kidney and pancreas transplant.

In August 2004 I received my life changing organ transplant. From that day my life has been completely changed. I am living the life I choose not the medical condition that was chosen for me.

In 2004 I met my partner and in 2007 we became husband and wife. A day I never thought possible only a few years earlier.

My sincere thanks to everyone for this life changing opportunity and the precious gift of life I have been given.

**Tracey, Kidney and Pancreas Transplant Patient**

## 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 past year...**



1



2



3



4



4

### 1) The Stanley Arms

Steve Williams suffered from diabetes for a number of years and in 1997 after his kidneys had failed he went on CAPD dialysis and was put on the waiting list for a kidney transplant. In 2000 he received a kidney transplant which was life changing. Steve and his wife Sandra run The Stanley Arms in Aughton near Ormskirk and have for a number of years now helped raise funds for Kidneys for Life. In 2008 however, they surpassed themselves and raised a tremendous £5,000 through a variety of ways including collection tins, raffles, sponsored runs, Santa dash, charity quiz, staff donating their tips and support from local businesses.

### 2) John O'Grady and His Team

John and his team of fundraisers donated 21 DVD players & headphones for use by patients on the Kidney Transplant Ward (Ward 10) at the MRI. Some of whom are on ward for a long period of time and do not have access to television during their stay. The fundraisers included his granddaughter Lucy Smith who raised £650 all by herself and Winsford Pigeon Association.

John is also a member of Glossop Golf Club and the Club held a Golf Day on behalf of Kidneys for Life and raised £1,445 which has gone to pay for an Ophthalmoscope and two special recovery chairs for transplant patients.

### 3) Boots Help with Christmas 2008

Boots at Rochdale helped bring some festive spirit to Christmas 2008 for all the renal patients at the MRI Renal Unit and it's satellite units including Tameside, Wythenshawe, Macclesfield and Prestwich. We would like to thank Amanda Crowe & Janet Neal and everyone at Boots for their help in organising these presents and the discounts given which enabled everyone to have a lovely gift from Kidneys for Life. Boots Rochdale also helped raise £500 from a raffle held at a recent fashion show!

### 4) Michael Cockayne

Michael's help and advice at the launch of Kidneys for Life was invaluable. Not only in raising funds with activities such as the Manchester City Veterans Football Match but also in raising awareness of kidney failure in dialysis by allowing us to use his story as the basis of the Kidneys for Life show garden at the RHS Tatton Garden Show. Unfortunately Michael passed away at the end of last year and he will be sadly missed.

### John Carsberg

John is a renal patient who took part in this year's Great North Run on behalf of Kidneys for Life and raised over £300!

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

# Research Update



**Professor Paul Brenchley, Trustee of Kidneys for Life and Head of Renal Research gives us an update on the current and future research at MINT (Manchester Institute of Nephrology & Transplantation).**

## Current Research

### Stopping progression to kidney failure

- **Membranous Nephropathy (MN)**  
This is the commonest cause of nephrotic syndrome in adults with a third of patients eventually losing their kidney function, a third suffering impaired kidney function and a third getting better. This study is trying to identify the target antigens in the kidney glomerulus (filter) that are attacked by antibodies circulating in the bloodstream.
- **Systemic Vasculitis**  
This is an inflammatory disease of the small blood vessels in the kidney and often other organs such as the lung or skin can be involved. It mainly affects adults and if not quickly brought under control it can lead to rapid loss of kidney function. This study is trying to identify the components of the inflammatory mechanism and identify genetic markers that predict the patients response to treatment and outcome.
- **Understanding how heart disease and kidney disease are linked.**  
Patients who have a progressive kidney disease are at risk of developing heart disease as well and this combination of clinical problems can be difficult to treat effectively. We have started a study to look at patients as soon as they are diagnosed by their GP in primary care to follow them over several years in order to see

what biomarkers can predict who has the best and worst outcomes. This project is linked with a cardiovascular imaging study to determine the earliest changes that occur in the structure of the heart in patients with kidney disease.

### Understanding and preventing peritoneal membrane damage and scarring

- **New imaging methods for detecting membrane scarring**  
About 40% of patients on dialysis use peritoneal dialysis. As with haemodialysis, there are advantages and disadvantages of this form of treatment. A common problem for patients who have been on PD for years is that the membrane slowly loses its function due to thickening and scarring. We are developing new imaging methods that can be used frequently to try to detect the rate of scarring of the membrane before it loses its function. If we can pick up this problem early, we can start to try new therapies to control the problem
- **Looking for the cause of “sterile peritonitis”**  
Although peritonitis is much better controlled now than when PD first become available, any episode can damage the membrane. However about one in five episodes on average has no identifiable infection diagnosed. We are investigating the cause of this so called “sterile peritonitis”.
- **UK - EPS network**  
While scarring of the peritoneal membrane is quite common in PD patients who have used the technique for a long time, a rare complication can occur called Encapsulating Peritoneal Sclerosis (EPS) which is difficult to treat other than by surgery. With other major Renal Units in UK such as Sheffield, Stoke, Cardiff and London, we have set up a network to monitor all patients on PD. So far over 25 units have joined the scheme which is managed from Manchester and funded by the Kenyon Gilson Fund. Recently, Manchester and Cambridge have been funded by the NHS to treat all cases of EPS occurring in UK through the NSCAG Centre for EPS Surgery led by Titus Augustine, one of MINT’s transplant surgeons.
- **Looking for Biomarkers that are linked with the development of EPS**  
The Global Fluid Study based in Cardiff and run by Prof N Topley since 2002 has collected peritoneal fluid on over 600 patients on peritoneal dialysis in the UK. A small number of these patients have developed EPS since then. This project is attempting to identify components in the spent PD fluid that are linked with the appearance of EPS at a later stage. It is a multi-centre UK study involving Renal Centres in Cardiff, Stoke, Sheffield and Manchester to analyse the composition of PD fluid using state of the art techniques.

## **Making transplanted kidneys work as well as possible**

When kidneys are donated for transplantation, it can take on average 18 hours before they are engrafted into the recipient. During this time they are kept cold but they still suffer damage due to lack of nutrients and oxygen (known as ischaemia). In addition, when the blood flows through the transplanted organ for the first time (known as reperfusion) it can set off another inflammatory mechanism which damages the kidney so that it may take up to 2 weeks before it works properly. Reducing this ischaemia-reperfusion damage to transplanted kidneys is the focus of a major study involving both a clinical trial of an existing drug that may have benefit for this new use as well as laboratory studies on the kidney cells that get damaged.

## **Future Research**

- Understanding mechanisms of proteinuria & nephrotic syndrome in children
- Evaluating a genetic test for predicting kidney outcome in SLE nephritis
- Developing new dialysis methods
- Identification and removal of new uremic toxins
- Developing new tests for and improving treatment of early vascular calcification
- Studying why fistulas fail early and improving the life of fistulas
- Optimising immunosuppression to prevent virus induced cancer post transplantation
- Optimising palliative care for patients who chose not to dialyse

## **Are YOU up for a Challenge?**



**Do you fancy abseiling or a zip slide at Baitings Dam in Leeds on Sunday, 28 June? We are looking for people to join us in raising funds for Kidneys for Life by taking part in either the abseil or zip slide or both!**

Baitings Dam provides a 60m abseil and 200m zip slide from the Dam to the valley below.

**If you would like to take part in this event please contact Irene Chambers for further information.**

## **Celebration Event**

**Manchester Royal Infirmary are celebrating 40 years of kidney transplantation and over 4,000 transplants and are holding a Celebration Lunch to mark this milestone.**

The lunch is to be held at Hulme Hall on Friday 20th February 2009 from 12 noon to 2.30pm, where you can meet old and new staff as you learn about the early years and share the experiences of patients and professionals alike.

Gain an insight into what the future promises for kidney and pancreas transplant patients and find out what role the MRI will play.

Spaces are limited, for further information email [fundraiser@kidneysforlife.org](mailto:fundraiser@kidneysforlife.org) or call **07779 133326**





# How Can You Help?

**MINT has a proud history of being at the forefront of many acclaimed scientific discoveries and internationally celebrated successes and is one of the leading centres in Europe for the care of renal disease.**

The MRI surgeons were the first to perform a non heart beating pancreas transplant in the UK. The research work undertaken by the team working in MINT offers real hope for patients both now and in the future.

**You can support us in one or more of the following ways...**

- I would like to help place counter top collection cans in shops and pubs on behalf of Kidneys for Life.
- I will organise an event to raise funds for Kidneys for Life. Fundraising can be fun and there are many ways to raise money such as:
  - Sponsored events
  - Holding a themed party such as a 60's or 70's night
  - A fundraising event in your local pub or club
  - A concert or dance
  - Golf event at your golf club.
- Many employers support charities, particularly those that help their employees or local people.
  - Some companies appoint a "charity of the year"
  - Some companies match any funds that their staff raise with an equal amount.

Would you or your family or friends consider nominating Kidneys for Life to your employers as a local charity worthy of support.
- I am interested in helping to set up/ or becoming a member of a local fundraising committee and would like further information.
- I would like to be part of the Kidneys for Life fundraising team of volunteers. Please send me further information of how I can help.
- I would like to make a donation in support of the work carried out by Kidneys for Life fundraising for MINT.



**Please indicate how you would like to support MINT and return to:**

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

**Use giftaid to make your donation worth more (see opposite).**

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

Name .....

Address .....

..... Postcode .....

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

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

I want all donations made since 6th April and all future donations to be gift aided until I notify you otherwise. 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.

# 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**  
Fundraising Manager

**Tel:** 0161 276 6671

**Email:**  
fundraiser@kidneysforlife.org

**Web:** www.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 a 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**