

IN THIS ISSUE

Millie-Mae fundraising



Millie-Mae and her team have been raising funds for Kidneys for Life for the whole of 2013...

New Recipe



Spicy beef recipe inside...

...AND MUCH MORE



Kidneys for Life fundraising for MINT

Manchester Institute of Nephrology & Transplantation

Charity number 505256

With thanks to...



Dr Tom Jones – 80th Birthday

We would like to offer our congratulations to Dr Tom Jones of his recent 80th Birthday, in particular we really liked his invitation:

*I'm coming up for eighty
please join me in some fun
it would be great to see you
but presents, I'd like none
I've got a drawer of hankies
and socks that fill a bin.
If you want to buy me something
then please listen in
just give a little money
to help my favourite cause
Kidneys for Life is the one for me.
Please give and save my drawers*

Tom family and friends donated a total £1,106.25 so thanks to you all and I do hope you enjoyed the party.



Magnet Inn Band Night

Our thanks to Dave Marchant and everyone involved in making the Band Night such a success. The event was held at the Magnet Free House on the A6 in Stockport, 150 tickets were sold and took place upstairs in the function room. The Staff at the Magnet were a tremendous support for the event, we would also like to thank the performers on the night who spent a considerable amount of time practicing to ensure everyone had a great night out.

Although monies are still coming in it looks to have **raised over £1,000 for Kidneys for Life.**



Golf Club

We have been very fortunate in our association with a number of Golf Clubs in 2013, we were chosen by Elaine Mansell, Lady Captain at Davyhulme Golf Club, Sandra McAllister, Lady Captain of Congleton Golf Club, Mark Johnson, Golf Professional at Styal Golf Club and Keith Clegg of Glossop Golf Club – **between them all they raised over £9,250** – well done to everyone concerned.

Mark Twain Pub, Whitworth, Rochdale

Big thank you for the support of Doris and the team at the Mark Twain for all of their work in **raising over £2,200 for Kidneys for Life** in their support of the Manchester Children's Transplant Games Team.



Sarah May & Dave Wright

Our thanks once again to Sarah & Dave for organising the Black Tie & Tiara Ball at The Lowry Hotel in November last year **raising over £7,200 for Kidneys for Life and Transplant Sport UK.**

Teresa Jones

Teresa organised a charity evening of music at Unsworth South Social Club to raise funds for Kidneys for Life as a friend, Luke Hooper, recently received a kidney transplant.

Thanks for everyone who came along on the night for an evening of music and fun and **raising £369.**

Can you help me?

I joined the Kidneys for Life team last November and since then I've been amazed at the level and amount of research that is happening at MRI.

World leaders in their field working right here; researchers, consultants, doctors, nursing staff and patients collaborating together, making sure you receive the most cutting-edge treatments and the best patient care.

I've met lots of kidney patients, adults and children, over the past few years. One of my dear friends passed away after having two transplants. She was the most joyful and full of life person I've ever met yet she painted a self-portrait, her body in a cage, trapped by the kidney disease. It still makes me cry.

I come from a business background and I'd like to add my skills to the mix. I'm hoping to work with businesses, large and small, throughout the North West; to find ways of working together for our mutual benefit. I can help with staff motivation and PR, provide opportunities to practise business skills and even try to get those invoices paid earlier.



So, how can you help me?

If you're employed in a business can you tell me whether you have a Charity of the Year, do you have a Charity Champion or who's the right person for me to contact? I'm only asking you to donate a few minutes of your time.

Or if you own or run a business, please get in touch. I'm only asking you to donate 30 minutes of your time for an initial chat.

If we can all work together then, one day, a kidney will be for life. **Please get in touch NOW!**

Carol Bonham
07714 864833
carol.bonham@kidneysforlife.org

Phosphate Additives

It is important to be aware of the 'hidden' sources of phosphate in your food, in the form of phosphate additives.

What are phosphate additives?

Phosphate additives are chemicals that are added to a wide variety of processed foods during manufacturing. These foods include processed meat, ham, bacon, reformed chicken, sausages, processed cheeses, some fizzy beverages including cola drinks and instant puddings and sauces.

Although phosphate additives are usually present in small quantities, they can significantly contribute to your daily phosphate intake. This is because our bodies absorb the phosphate from food additives much more effectively than the phosphate that occurs naturally in foods such as milk, eggs, and cheese.

How do I know which foods contain phosphate additives?

To help you identify 'hidden' phosphate, it is important that you check the food label. The ingredients list on the food packaging will name the food additives, either by chemical name or by E number. Look for words that include 'phosphate' or 'phosphoric'.

Commonly used phosphate additives:

E number	Phosphate Additive
E338	Phosphoric acid
E339	Sodium phosphates
E340	Potassium phosphates
E341	Calcium phosphates
E343	Magnesium phosphates
E450	Diphosphates
E451	Triphosphates
E452	Polyphosphates
E541	Sodium aluminium phosphates

How can I reduce my intake of phosphate additives?

Read the food labels to compare products and, wherever possible, choose those without phosphate additives. **Try to avoid processed foods.** Choose fresh, unprocessed foods which are lower in phosphate.

Upside down Lemon Cheesecake Recipe

250g of Quark (or very low fat cream cheese)
75g lemon curd
50g ginger biscuits
You will need four small ramekin dishes or something similar.



This recipe is simple to prepare, does not have a long list of ingredients and makes a fresh and tasty every day pudding. It does have a high sugar content so if you are Diabetic - just a small portion!

Method

- Mix together the lemon curd and Quark.
- Divide equally between your four dishes.
- Break the biscuits into small pieces – fine breadcrumb consistency.
- Sprinkle these evenly on the top of your mixture.
- Place in refrigerator for at least 2-3hours. And overnight if possible.

Serve with

Serve with some stewed apple, tinned fruit or a small portion of summer berries.

Spicy Beef Recipe

560g Sirloin/rump steak
4 small tomatoes, peeled, de-seeded and sliced
4 Spring onions, thinly sliced
1-2 Garlic cloves, crushed
4 Celery sticks
2-3 tsp Mild chilli powder
2tbsp Paprika
1 Beef stock cube
300ml Water
2 tbsp Clear honey
2 tbsp Red wine vinegar
2 tbsp Sunflower oil
1 tbsp Worcestershire sauce



Method

- Cut the steak into 1cm strips. Add the paprika and chilli powder, evenly coating the beef. Leave to marinate for one hour.
- Cut the celery into 5cm lengths and then into strips about 5mm thick.
- Make up the stock by adding the stock cube to the water and adding the Worcestershire sauce, honey and red wine vinegar.
- Heat the oil and fry the spring onions, celery and garlic for a minute before adding the steak. Continue to fry on a high heat for 3-4 minutes.

- Add the sauce and cook until the meat is well coated and sizzling hot.
- Add the tomatoes and heat through. Serve immediately.

Serve with

Rice or noodles.

Enjoy!

Three Transplants and still going strong

Alan Silcock turned 60 in Oct last year, a milestone for anyone but Alan a miraculous one. Way back in 1968 Alan and his Dad, Jim, underwent what was pioneering surgery, Jim became a live kidney donor to Alan who was 14 years old at the time and suffering from chronic renal failure.

The surgery was carried out by Prof Roy Calne at Addenbrookes Hospital and it was last chance saloon for Alan and his Dad; the op was a great success and both were soon back home on the farm in Lancashire.

Alan lived life like a normal teenager and met me, Ann, when he was 20 and we married two years later in 1976 and have gone on to have three children, Marion, Andrew & Matthew.

In the summer of 1987 Alan's transplant began to fail, it was devastating for everyone, he was admitted to MRI and haemodialysis kept him going which was not easy when you are a farmer but you keep doing what you can. Jan 1989 brought the middle of the night phone call – 'we have a kidney for you' so off we

went and again the op went well and after a few hiccoughs the kidney settled down.

About 6 years later things started to slow down, the kidney wasn't functioning well, it kept plodding along until 2001 when dialysis was suggested by Dr Gill Hirst, she kept us both positive through challenging times. This time CAPD was used, a much more user friendly method, life on the farm carried on.

Our daughter Marion married Carl and made us grandparents in 1999 and again in 2001, Georgia then Chloe, very welcome distractions. Our eldest son Andrew was working with us on the farm, which was a great help, youngest son Matthew also helped when he could. Dad Jim kept an eye on us as well.

Having had two transplants, you think you have had your share, but not so, another early morning phone call on in Dec 2003 saw us setting off to MRI for a third transplant. A full day of tests and Alan went to theatre at 6pm, by 9.30pm he was ringing home to let us know he was OK. Thing didn't go well to start with, a couple of visits back to theatre and then Alan was fit, which was scary. A week later things really started to settle down and around day 10 he came home.



We now have two more grandchildren, Jamie and Cassie and our daughter-in-law, Lisa.

Sadly Jim passed away in 2009 at the age of 83, his wife Ada had been looking after him during a short illness. His generous gift of life to Alan all those years ago brings us to where we are now.

After a family party at home, we celebrated Alan's 60th with a surprise party at the local village hall. Around 120 people helped us keep it a surprise; that takes some doing. Rather than presents we suggested donations to "Kidneys for Life" and "Multiple Sclerosis Society", our daughter Marion was diagnosed with

MS last year. **Thanks to everyone who donated, we raised £750 for Kidneys for Life and £500 for MS** and had a really good night with our family and friends.

Without MRI and all their support, things would have been very different. Colin Short – always positive, Sheila Russell – always helpful, Sue Perrin and Anne Palmer for making dull clinic visits fun and all the many doctors and nurses we have seen over the years and continue to see.

A very big THANK YOU.
Ann & Alan Silcock

Millie-Mae Fundraising 2013



We told you about Millie-Mae in the last edition of Whispers when she took part in the British Transplant Games in Sheffield last year. What we didn't mention is that Millie-Mae and her team of helpers had been raising funds for Kidneys for Life for the whole of 2013.

Millie-Mae and her team:

Amee Burgess
Mark Greenwood
Lee Alcock
Allison Sherrington
Beverley Knight
Sharon MacDonald

The team organised supermarket bag packs twice a month, auctions and fundraising nights.

Millie-Mae's classmates at Bridgewater Primary, Little Hulton, also raised £4,668.08 of the grand total of £17,235.08 which is such a tremendous amount considering that their initial target was £10,000.

Amee said: *"Millie-Mae doesn't really realise the value of what we've raised but she knows it's a lot and that we're all really proud of her."*

Kidneys for Life are also proud of Millie-Mae and her team for all their fundraising and we would like to pass on our thanks to everyone concerned for such a tremendous effort and ask you all to please support them again this year if you can, even if it's only sparing a few hours on one of the bag packing sessions – **details of which are on our Facebook page.**

They will spend 2014 raising cash for Kidneys For Life and The Swallows Head and Neck Cancer Support, in memory of a close friend of Allison's.

British Transplant Games 2014

The Games are to be held in Bolton in 2014 on 7th to 10th August and you can find more details on the website www.britishtransplantgames.co.uk

We are looking for new members for the Manchester Adult Team and if you are interested in taking part in activities such as golf, table tennis, crown green bowls, archery, badminton, cycling, darts,

fishing, squash, swimming and track & field events please get in touch:

Manchester Adult Team
Zoë Dixon MBE
07780 858558
zoe_dixon@tiscali.co.uk

Great Manchester & Great North Run 2014



If you want to take part in the Great Manchester Run 2014 on Sunday, 18 May you can either register for your own place via www.greatrun.org and if you would like to raise funds for Kidneys for Life just let us know once you have a place and we can sort out a T-Shirt or Running Vest and a sponsorship pack.

We do have a number of charity places for both the Great Manchester & Great North Runs but they are limited so first come first served. if you would like one of these places all we ask is that you pledge to raise a minimum of **£120** (Manchester) or **£250** (North) (which

includes the registration fee) and we will provide a T-Shirt or Running Vest and a sponsorship pack.

We are also looking for our young supporters to join us again at the Junior & Mini Runs which are being held on Saturday, 17 May at Heaton Park.

If you are interested in taking part in any of the runs please do get in touch with Irene Chambers either on **0161 276 6671** or email: fundraiser@kidneysforlife.org



Gala dinner in Wonderland

Students from Manchester Metropolitan University, Phoenix Events organised a Gala Dinner with a Wonderland theme as part of their degree course in Events & Management and at the same time raising awareness of organ donation and funds for Kidneys for Life.

The Phoenix Events team comprised of Liam Devonport, Annie Bhatti, Anzelika Kaskure and Roxana Mocanu, you can see from the photos from the night what a splendid event it was and our thanks go to the students for organising such a brilliant event. We would also like to thank the following for their support of the event:

- No Eyed Theatre – for providing all the costumes and giant mushroom!
www.noeyedtheatre.com
- Stage Squad - provided all the actors and actresses who wore the costumes and performed.
www.stagesquad.co.uk
- I do...photography - provided Alice in Wonderland photos for raffle prizes.
I-do.photography@hotmail.com
- Stef Parkinson - provided Alice in Wonderland photos for raffle prizes.
stefparkinsonphotography@outlook.com
- Lucy Mae & The Tom Cats - Live band on the night. lucymae@ffaudio.com
- Ryan Larkin - Magician and mentalist for the evening.
www.facebook.com/mentalistryan
- Designer Flowers - Provided the bouquet of flowers as a raffle prize.
www.flowers-uk.co.uk
- Duncan Laing - DJ for free on the night.
spunkylaing@msn.com
- David Silis - Photographer.
www.facebook.com/daviderchi
- Andrea Staton - Venue dresser for the event at a very small cost. astaton@btinternet.com



Activities on the wards

Kidneys for Life has been helping to organise a number of activities on the Renal Wards at the MRI including a Pamper Day which took place on the Female Transplant Ward, Quiz Nights on the Transplant Ward and our ongoing Paper Artwork on Ward 36.

On the Pamper Day trained beautician A'Dell Harper gave facials and manicures to our patients with the help of Amy, Victoria & Irene. Cupcakes especially baked for the occasion, non-alcoholic Bucks Fizz and a selection of magazines completed the spa experience. Ladies could browse a table full of beauty products kindly donated by L'Oreal, Debenhams and Costco as well as staff, family and friends. Every patient received a pamper bag full of goodies on the day.

Patient Dorothy Wallace said: "When I woke up today I wasn't expecting anything like this at all! It's really cheered me up. My favourite part has been my new French manicure done by Amy.

Our Quiz Nights have gone down a treat and at the last one in February the "Female" ward took the trophy – let's see

what happens next time.

Artist Nicky Colclough is also on Ward 36 helping patients to make artwork out of paper products and we will be looking to put up an exhibition of the work at the end of the Project in April.

We have been working with the Healing Environments Project at the hospital to bring activities to the Renal Wards and Dialysis Centres and these are just a start with more to come. We welcome suggestions of any activities you feel would be beneficial for patients – just get in touch!

Fistula band campaign

By Lorraine Pooley



Lorraine Pooley

Dear fellow patients,

I begin this feature with 'My Story' and then move onto how Polycystic Kidney Disease (PKD) changed my life and created a passion for me to contribute back to the MRI for the wonderful care I've received over the years.

Here I also wanted to talk a little about my reason for pursuing a Fistula Awareness Campaign, because I see this as an important issue and ensuring staff as well as patients are ensuring the best care is being provided/ received to their 'life-lines' for the treatment of renal disease.

My story living with polycystic kidney disease (PKD) - Who am I?

My name is Lorraine Pooley; I am 52 and have Polycystic Kidney Disease (PKD). I am presently an outpatient at the Manchester Royal Infirmary (MRI) and have had three surgical procedures here in the past 2-5 years. Throughout my renal journey spanning over 25+ years, I have had a rewarding and interesting life – I am always positively driven.

When my Father passed away at the age of 36 from PKD, I (nor anyone else) could predict the impact it would have – at times I felt unprepared about my future. I was 11 years old (and the eldest of 6); my siblings and I were all screened soon after our Father passed away and other than me, (who was diagnosed as having

an obstruction in the left kidney), my siblings and I had no other signs of PKD. We suffered more heartbreak when two of my dad's brothers and his sister died as a result of the same condition.

I rarely thought about my PKD growing up; life was busy with five siblings, work and getting married. It was not until my daughter Nicola started suffering water infections and doctors asked if there was a history of kidney problems in the family, when things took a different direction. From this consultation, my siblings and I were screened again. Four out of six of us had inherited PKD and our kidneys were showing cysts.

We regularly attended appointments and I particularly began to feel changes with my stomach, which felt a little when I was in my late 30s. As I got in my 40s, I started to put a little bit more weight on and the cysts were getting bigger. Secondary, I also developed a cyst on my liver. I ached a lot and experienced a lot of discomfort and back pain. I had trouble sleeping, plus with ongoing fluid retention I was also becoming rotund and looked pregnant – I felt breathless with the fluid building pressure and the extra weight I was carrying.

In 2008, my kidney function dropped suddenly; the fluid built up more and I was struggling with day to day life. I continued with regular hospital appointments in 2010 and it was then

that doctors informed they would need to remove one or both of my kidneys. This was to ease the discomfort that caused fluid retention and the cysts making my kidneys and liver enlarged. It was during this period that my youngest sister, Melissa Wilding, offered to donate her kidney to me, once my double nephrectomy had taken place....amazing!

The journey

The first step took place in October 2011 when I was admitted to MRI to potentially have both my kidneys to be removed and to also make room for my new kidney (kidney transplant). However, the amount of fluid in my body meant doctors decided to remove just one kidney. There were complications too and I also started dialysis at the same time, so recovery was slow and the transplant did not take place as originally planned - some initial disappointing news, since it meant I had to be put on a HD treatment regime.

I had to go to Royal Preston Hospital for HD three times a week following discharge from the MRI, spending four hours there each time. It was tough at first, as they worked to get my HD treatment prescription right, but I tried to make the most of the difficult time on dialysis and certainly coped in a positive manner and adapted to what was, in effect, saving my life and preparing me for my kidney transplant. Throughout my sixteen months on dialysis, I got stronger;

the health care staff at the MRI began the 'Work Up' again for me and my sister for my kidney transplant.

Then we got the date for the transplant 14/2/13 - Valentines Day!

We had regular stringent checks, which took a couple of months and finally my kidney transplant went ahead. The transplant was carried out by Titus Augustine at the MRI on the 14/2/13; me and my sister recovered well and for ME, it gave me my life back. From the first moment I came round, I felt this breath in me, warm, hungry for life, feeling amazing and of course I was happy and proud of my sister. My sister was home in 5 days and is still doing great. I did have a double hernia operation in July 2013.

I am now on the road to recovery and will continue to have routine appointments, (especially since I still have one polycystic kidney and a polycystic liver and lasting effects from the hernia I developed too during my time on HD). Following all this, throughout my positive renal journey, I became more aware of everything that was happening to me and others and certain aspects of this I was unhappy about.

I recalled being told my vascular surgeon told me in 2011 to treat my fistula access like gold, so I decided to make a decision to take it upon myself and make a fistulae awareness campaign my focus. I also

promised fellow patients I would do something about ensuring there was more awareness highlighting issues and concerns of access care. This was my pledge to make a difference for fellow patients in the future.

Lorraine Pooley's Fistula awareness band campaign

My vascular surgeon was amazing and informed that I need to 'treat this arm like GOLD' (i.e. no pressing, no pushing, heavy lifting before or post fistula operation). More importantly, he informed 'do not to let any staff, medics inside or outside the hospital to ever use your fistula arm for needling or taking your Blood Pressure'. I adhered strictly following this particular communication. The fistula became my 'life-line' and special to me.

However, the words of protection of my fistula worried me in during my day to day life moving forward with regards to household chores, (e.g. washing, lifting, vacuuming, shopping, driving and general mobility etc.). Above all, for me what was perhaps most tormenting was the psychological effect of this lifeline had, having to repeatedly tell some medics and nursing staff that I had a fistula and to 'please do not use BP Monitor or Needles in that arm'.

What happened to cause more anxiety was I met a few fellow patients during

my time on HD who felt the same and actually almost had their Fistulas 'blown' by nurses using a BP monitor on fistulae arms. I was lucky as I voiced my concern, but others I spoke too during and since my research I learned 1) were vulnerable, 2) elderly, 3) unconscious, 4) been admitted to other than renal and 5) have had near misses. One fellow patient I came across had her fistula damaged in surgery and was unrepairable and affected her general renal care and psychologically played havoc!!

I began my campaign to promote the use of a FISTULA AWARENESS BAND. My campaign began in October 2011.....my passion from 3 years ago, but it gained more momentum in 2013.

To promote my campaign, I approached a series of social media (Facebook groups) including the Renal Patient Support Group (RPSG) to help promote my awareness campaign. I coordinated this project with the chief in research for the RPSG, Shahid Muhammad who was very invigorated by my project. Over a period of one month, the campaign posted on the RPSG group 'wall' received 110 comments relating to various areas where care of fistulae access can be/ should be improved and where fellow patients using the group also highlighted psychological issues. Posting on several additional renal-related Facebook groups, my campaign received 180 comments in total in just one month!

The message I wanted to highlight and prompt was clear. I want my fellow patients in the RENAL ARENA, who have a Fistula or going to have one in the future - that it is important to protect your access and wear one of these bands (now available from the MRI) so that 1) it makes you feel safe, 2) less vulnerable, 3) less scared and 4) in control. However, I also want to inform that fellow patients please still ensure that you get more understanding about your fistula access, empower yourselves with how to look after your kidney disease and fistula access and help inform others around you - to make sure that on any hospital ward (not just renal) that the staff become more aware.

There were numerous times I felt anxious and vulnerable every time I went into hospital for surgical procedures, worried about theatre, scared to go to sleep and at times was worried about my access being damaged. I don't want that for my fellow patients and neither do healthcare staff. Because my campaign has highlighted so many issues and concerns; Shahid has contacted a fellow colleague at an academic institution to use the comments as a teaching tool for undergraduate nursing students. I also hope to present the findings of my campaign at a prospective conference in November 2014.

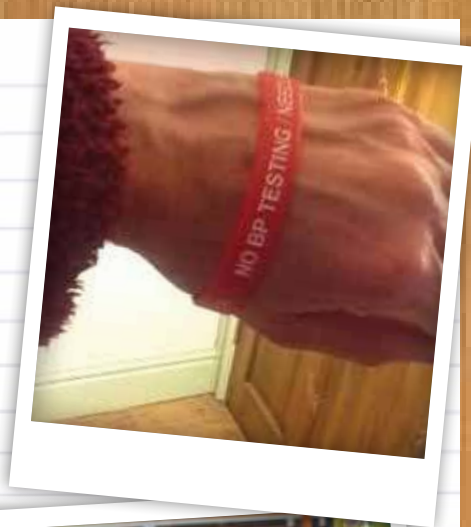
Page 18/19 Whispers

Moving forward, I have now had the 1st Anniversary Party of my transplant on the 14/2/14 and now grateful the Fistula Awareness Bands in place here at the MRI. The £450 I raised from my party for Kidneys for Life is going towards a project I'm working on around the Fistula Campaign in collaboration with the MRI to make you, my fellow patients, feel more confident about the care you receive. I hope to share this with you soon.

If anyone wishes to contact me for inspiration, support, patient to patient advice on Chronic Kidney Disease (CKD), PKD or HD, feel free to email me at: awishforakidney@gmail.com. I am happy to talk to you or meet up.

Be strong, be positive, be happy and I hope this helps you on your renal journey.

Thank you Lorraine Pooley



Fistula Packs

On the suggestion of Lorraine Pooley (featured in this edition) the Vascular Access Nurse Team has developed a Fistula Pack for all our patients with either a Fistula or Tesio Graft, which contains Emergency Bleed Contact Cards, wristband advising of fistula, sign for over the bed when an inpatient and a dressing pack, which includes swabs and clamp.

The packs are in the process of being finalised ready for distribution.

Fistula wristbands

A wristband for renal patients with a fistula are now available free to all MRI patients and those at their outlying dialysis satellite units including Tameside, North Manchester, Prestwich, Macclesfield, Stockport and Wythenshawe.

These are silicone wristbands that you can wear to highlight to healthcare workers they must avoid using your 'Fistula' arm for blood pressure testing or needles (taking blood or putting a cannula in). They are available in a number of sizes to suit most wrists.

These should be available in most areas that treat patients with kidney failure at MRI and outlying dialysis satellite units.

If there are none available at the time please ask them to contact the Renal Dialysis Access Nurse based at the MRI. Alternatively you can email your name, hospital number, left or right arm and size (wrist measurement in centimetres) together with your address to fundraiser@kidneysforlife.org and we will arrange to send one out in the post.

Kidneys for Life has supported the production of these wristbands.



Dates for your diary

Maria Ogunyemi (nee Jiacomui), kidney transplant patient, invites you all to a fun Charity Evening – Saturday 10th May 2014 at Willow Bank Hotel, Fallowfield, Manchester

5 piece live band, other live acts, stalls, raffle, hot food included, late bar till 1 with hotel rooms available at reduced cost (Tel: 0161 224 0461 quote charity event)

Smart / casual dress code.

Cost per ticket including meal – £20!

For further information and to get tickets, please contact Maria at maria_ogunyemi@btinternet.com or visit our website under future events.



Barcelona to Nice Cycle Ride, departing the 28 Jun returning the 4 Jul 2014

The Barcelona to Nice Cycle Ride connects two of Europe's most beautiful cities. The adventure begins on the Catalonian coast where participants will pedal their way from Spain's much-loved Barcelona onwards to France through ever-changing landscape.

The vibrant city culture of Barcelona will soon give way to the charm of rural French towns and villages as you cross the border and follow the sweeping coast lines of Southern France.

Cyclists will never stray far from the coast and will be rewarded with frequent breath-taking views before arriving at their final destination in the heart of the French Riviera, Nice.

Registration fee: £149
Minimum sponsorship: £1250

For more information please contact Carol Bonham on 07714816877 or e-mail: carol.bonham@kidneysforlife.org

For details on these events please see our website www.kidneysforlife.org/ and if you would like to receive updates of our events by email please contact Carol Bonham.

Remembering

John Alcock

Keith Bates

Kenneth Burke

Mark Edwards

Sheila Heraghty Smith

Anne Russell

Herbert Stephenson

We would also like to acknowledge the two kind legacies from Christopher John Makowski and Mr W J Sumner which were received by us recently.

Thank you

Our Christmas Card sales in 2013 raised over

£6,200

Thanks to everyone who helped by purchasing our cards which will be on sale again in Autumn.



Don't forget to "like" our Facebook page to find out what is happening at Kidneys for Life.

Research Grants awards 2013

Transcal Study

While the reasons for patients with renal failure having problems with their blood calcium levels are well understood, these problems sometimes persist after having a transplant, and there is little research to explore this. Problems with calcium metabolism can make patients feel unwell, increase their risk of strokes and heart attacks, and can damage their transplant by causing kidney stones.

In this study, the researchers will analyse blood and urine tests, looking at levels of various markers related to how the body handles calcium, in order to see which of them may be implicated.

It is hoped that this will lead to further work to improve the identification and treatment of calcium disorders in patients who have received a renal transplant.

Development of EPS Surgical Service Website and Creation of Support Package for EPS Patients and family

Encapsulating peritoneal sclerosis (EPS) is a rare but devastating complication of peritoneal dialysis, a commonly used technique to replace kidney function. Patients can become extremely ill and it is recognised that surgery can be a successful and life-saving treatment if

patients are diagnosed and referred before they become very weak and sick. In the UK, Manchester and Cambridge have been chosen as national referral centres for the surgical treatment of established cases. Since the start of this initiative, over 90 patients have been referred to Manchester including European and international referrals.

The unit has developed a world-wide profile as a centre of excellence. We have noted that we are still getting patients who require emergency surgical intervention which carries a much higher risk of death and complications. This indicates that there is still a need to increase awareness and greater publicity about the surgical treatment both locally and internationally. We feel that the development of a website containing all the information about the surgical treatment and process of referring to our centre would be beneficial for both patients and doctors treating the condition. This might lead to earlier referral to our centre and subsequently much improved outcomes.

There is also a need to develop patient information packages in conjunction with patients who have already experienced the service so that the whole process can be described in detail to help to prepare patients for their difficult journey through this process.

Kidneys for Life awarded 8 research grants at the end of last year totalling £95,342. A summary of just three of these grants are set out below to show you what we are using our donations to fund by way of research.

Understanding the immune pathology of SLE membranous nephritis

Systemic lupus erythematosus or lupus is a disease that causes persistent inflammation in several different organs in the body. SLE affects about 500 in 1 Million people in the UK and millions of people worldwide. Lupus nephritis or kidney disease in lupus is a serious manifestation of lupus that can range in severity from mild blood and protein leak in the urine to persistent inflammation with worsening kidney function or even kidney failure. Kidney biopsy findings help to predict severity of the disease and the way disease will progress. Treatment strategies are also directed by kidney biopsy findings. There are 5 different classes of lupus nephritis based on these biopsy findings ranging from Class 1 to Class 5. Class 5 lupus nephritis also called membranous lupus nephritis is similar to the way membranous nephropathy (MN) presents in patients. The latter condition is found in patients that do not have lupus.

It is known that lupus is an autoimmune disease which means that the immune system produces antibodies against self, attacking different organs in the body.

A high antibody level shows that disease is severe and decreasing antibody levels will be seen when treatment is given. In this study we hope to find other, more specific antibodies in the blood of patients with Class 5 lupus nephritis.

Previous research has shown that besides this autoimmune process, there are genetic and epigenetic (meaning environmental factors causing heritable change without affecting genetic sequence) mechanisms causing lupus. This will result in identifying which patients with lupus will get lupus nephritis, picking up disease early and developing drug therapy to reduce or stop antibodies causing inflammation. This will therefore improve lives of lupus patients affected worldwide.



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

Name

Address

..... Postcode

Signature Date

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

I want to giftaid my donation*

* I confirm I have paid or will pay an amount of Income Tax and/or Capital Gains Tax for each tax year (6 April to 5 April) that is at least equal to the amount of tax that all the charities or Community Amateur Sports Clubs (CASCs) that I donate to will reclaim on my gifts for that tax year. I understand that other taxes such as VAT and Council Tax do not qualify. I understand the charity will reclaim 28p of tax on every £1 that I gave up to 5 April 2008 and will reclaim 25p of tax on every £1 that I give on or after 6 April 2008.

