

NEWSLETTER

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Summer 2018

Manchester Royal Infirmary
Kidney Patients' Association
(MRIKPA)

Registered Charity Number

516871



Content

2	Content	33	Grafton St car park & Oxford Road
3	Committee members	33	Dates for your diary
4	Hello from your Editor	34	Quiz answers
5	Hello from your Chairman	35	Obituary Dr Madan Mohan Gupta
7	MRIKPA - AGM	37	Electronic Newsletters
17	Trends update	38	British Transplant Games
22	Home Dialysis	39	Membership application form
23	Afternoon tea	40	Donations & fundraising
25	Renal recipes	41	Gift Aid
27	The General Data Protection Regulation	42	Contact numbers
28	Quiz questions	43	Notes
29	Transplant patients and antibiotics	44	What we do
30	Travel Insurance		

Committee Members

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John Murphy	Committee Member		
Dr Arijit Sen	Committee Member	Arijitsen@hotmail.com	01706 345383
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Barbara Taylor	Committee Member	David.taylor5557@ntlworld	0161 486 9757

Hello from your Editor

Hello and welcome to the summer edition of the MRIKPA newsletter.

As I write this article it's another warm day in sunny Manchester, gone and hopefully forgotten are those cold snowy days of March.

This issue highlights our AGM which is to be held on Sunday 15th July at MRI. I do hope you can come as the association is there to support you the patient and your carer, so please support us, we welcome your thoughts and ideas.

Inside you will also find information about home dialysis, renal recipes and information about the transformation of renal dialysis at MRI, plus some pretty pictures of the new North Manchester dialysis unit.

I hope you enjoy reading the newsletter and wish you an enjoyable summer.

Take care & best wishes

Mike

mikejm.kewley@gmail.com

07530 452190

MRI Kidney Patients' Association



Hello from your Chairman

At the time of writing, we are in this May heat wave, pleasant for those that can get out and enjoy the sunshine but more uncomfortable for patients in hospital or on dialysis. Just as we hoped to be moving to state of the art facilities that ensure dialysis patients are comfortable no matter what is happening outside, there is a temporary delay on the North Manchester new facility while the lift issue is sorted. However from the open days ,it is clear that patients once settled can enjoy an excellent facility

We celebrated 50 years of transplants in March at an event put together by the amazing Kidneys for Life team. It was impressive to see the turnout of patients at the Principal Hotel to show their appreciate to the doctors both past and present and the MRI for this service that has changed so many lives. On a count upwards of transplant longevity, we got past 39 years before the last patient sat down to wild applause. The speed of change in the numbers of transplants done, taking 40 yrs to do 1000, then further 10 years to reach number 7000 is testament itself to the commitment of the transplant team and the breadth of age range is today staggering with fit 80 year olds donating and receiving.

In fact so much is happening in the world of Transplant to increase numbers, be it donor age, use of marginal kidneys, altruistic donation that we have asked the transplant team to come to our AGM and explain some of these in context of the MRI. Something any patient should be interested in and we would love to meet you. The meeting is on Sunday morning July 15th and is open to all and also gives you a chance to feedback into your association. More details on later pages.

Overall transplant numbers have gone up, but after many years of rising, live donation is falling . There has been an intensive study on why , and there appears to be no single reason. If you are lucky to have a cadaver, did you consider live donation? Some patients are embarrassed to ask relatives, some ask but relatives see it as too risky. Some just don't have relatives or lost touch. There seems a myriad of reasons why not to do live donation, how you reverse this trend on something so personal, seems difficult. In my book the donor has to work too hard to get through all the hoops and the one bright spot is Northern Ireland where all the tests are done on one day and they get far higher donation rates. A simple but apparently successful change that could be copied by all hospitals.

This rise in numbers has been very noticeable for anyone attending transplant clinic at the MRI, with waiting times rising, something that has become quite awkward to manage for anyone at work, let alone pressure on the staff with regularly over 70 patients attending. After much suggestion by the KPA, I am pleased that the first patients are being invited to a virtual clinic, where after 'a bloods only' clinic, stable patients can see their results on 'patient view' and have an agreed telephone call appointment to discuss. The benefits to all for this are clear and are a simple but very effective change to the service

On a personal note, after walking 1000 miles over last year, my dialysis challenge this year is to do the iconic London – Paris bike ride with the K4L team. Packing in over the 80 miles a day, I have elected to go on a tandem with a blind friend who is an enthusiastic ‘stoker’, while I am the pilot and poet at the front. It all looks a bit daunting at the moment, but I have been inspired by the dialysis patient who did the London Marathon so I will be looking for sponsorship of one of the 243 miles that have to be covered. Hopefully our next issue will have the requisite pictures of smiling faces under the Eiffel Tower.

Until then, Bonjour

Chairman Guy Hill
Helenandguy_hill@hotmail.com

Tel: 01565 654382



MRIKPA Annual General Meeting Sunday 15th July 2018

Main Board Room, Cobbett House, Manchester Royal Infirmary, Oxford Road, Manchester, M13 9WL

Dear Member

The MRIKPA Committee has pleasure in inviting you to attend the Annual General Meeting of the Association, to be held on Sunday 15 July 2018 at the Manchester Royal Infirmary. There will be a Chairman's report available at the meeting together with copies of the Committee's Annual Accounts for the 2017/18 and Reserves Policy. If you wish to attend, it is important for catering purposes for you to complete and return the form below. We look forward to seeing you at the meeting.

I/we will be attending the MRIKPA AGM on Sunday 15 July 2018	
Name/Names:	
Address:	
Telephone number:	Number of people attending:
How many people will require CAPD facilities?	

If you wish to nominate someone to stand as an officer on the next (2017/2018) MRIKPA Committee you may do so by completing the form below. Print the names of the Nominee, Proposer and Secunder under the appropriate headings before Nominee signs the final column to indicate their agreement to be nominated. Please read the notes before completing the form.

Committee Membership Nomination Form 2018/2019			
NOMINEE	PROPOSER	SECONDER	NOMINEE TO SIGN
Chair:			
Vice Chair:			
Other:			
Treasurer:			

MRIKPA Annual General Meeting Sunday 15 July 2018

Guidance Notes for completing the MRIKPA Committee Membership nominations form on the next page.

The elected members of the Committee are the trustees of the Association and, as such, are bound by charity law. The Charity Commission requires those standing for election to the Committee to demonstrate an understanding of the general role and responsibilities of charity trustees, knowledge of the objects of the charity to which they seek election, and to be able to indicate what they can offer to the charity, to assist it in achieving its objects.

The Committee comprises three officers, (Chairman, Vice Chairman and Treasurer), and a maximum of ten other elected members. In addition to the elected members, the constitution allows other people to be co-opted onto the Committee, to provide particular skills, knowledge or expertise.

Each member of the Committee has at least one specific function, e.g., Newsletter Editor or Fundraiser. These responsibilities enable all members to play a full role in the Committee and to share its workload.

The Committee normally meets once a month, (apart from January and August), on the first Wednesday evening in the month. Meetings are held in the Main Board Room at Manchester Royal Infirmary, beginning at 7.30 p.m. and usually lasting no more than two hours. Officers' and Sub Committee meetings are held as required.

Only current members of MRIKPA can stand for election to the Committee, or act as proposer or seconder for nominees.

The proposer and seconder for any nomination must be two different people and may not be the person nominated. They should seek the agreement of the person being nominated prior to nomination, and the nominee must sign the form indicating a willingness to be nominated.

Unsigned nominations will not be accepted. Individuals may be nominated for more than one post on the Committee, subject to the rules shown above.

In the event of more than one valid nomination being received for any of the officers posts and/or more than ten valid nominations being received for the other Committee posts, ballot papers will be given to MRIKPA members present at the AGM, to determine those nominees to be elected.

COMPLETED NOMINATION FORMS MUST BE RETURNED TO:

Margaret Bennett, MRIKPA Secretary, 4 Norden Avenue, Withington, Manchester M20 1ET by 29 June 2018

2nd AGM for the MRIKPA
Committee Membership Nomination Form

Print below the names of nominee, proposer and seconder under appropriate headings before nominee signs the final column to indicate her/his agreement to be nominated.

2018/2019

Nominee	Proposer	Secunder	Proposer to sign
Chairman	Guy Hill		
Vice Chairman	Geoff Burgess		
Treasurer	Janet Richardson		
Other Committee members	John Murphy		
	A Sen		
	M Caddick		
Newsletter editor	M Kewley		
	W Iqbal		
	B Taylor		
Secretary	M Bennett		

Constitution of the Manchester Royal Infirmary Kidney Patients' Association.

1. Title:

The name of the organisation shall be the Manchester Royal Infirmary Kidney Patients' Association (MRIKPA), hereinafter referred to as the Association.

2. Objects:

The objects of the Association shall be to promote, the welfare of persons receiving treatment at MRI, for disease or illness affecting the kidneys, irrespective of where they are referred from; (hereinafter called the kidney patients), and to provide support and advice to them, their relatives and others concerned with their welfare. The Association also supports other kidney patient groups throughout the North West.

3. Powers:

In furtherance of the objects of the Association, but not otherwise, the association shall power to:

- Provide opportunities for kidney patients, their relatives and others concerned with their welfare, to share ideas of mutual benefit.
- Provide support and practical assistance for kidney patients, their relatives and others concerned with their welfare, according to need.
- Promote a wider knowledge and understanding of the needs and problems of kidney patients, their relatives and others concerned with their welfare, to the public and the appropriate authorities.
- Raise funds for the achievement of the objects.
- Campaign on behalf of kidney patients for improvements in treatment.
- Promote well-being of kidney patients, their relatives and others concerned with their welfare by signposting to the provision of a trained counselling service, (as provided through the Trust).
- Do all such other lawful things as are necessary for the achievement of the objects of the Association.

4. Membership:

Membership is open to anyone willing to support the objects of the Association. An individual's membership of the association may only be terminated for good and sufficient reason and the individual concerned will have the right to be heard by the Committee accompanied by a friend, if necessary, before a final decision is made. All members shall pay such subscriptions at such times and in such a manner as the Annual General Meeting shall, from time to time, determine. Members shall be given at least fourteen days' notice, in writing, of the annual general Meeting of the Association.

notes.

Any resolutions for consideration at the AGM must be notified, in writing, to the Secretary no less than one calendar month prior to the AGM. Any such resolutions considered at the AGM shall be carried by a simple majority of those present at the meeting, with the chairman of the meeting having a second, or casting vote, in the event of an equality of votes.

Notice of a Special General Meeting shall be sent, at least fourteen days before the date of any such meeting, to the addresses of all members as appearing in the records of the Association. Resolutions shall be carried at a SGM by a simple majority of those present at the meeting, with the chairman of the meeting having a second, or casting vote, in the event of an equality of v

5. Committee meetings and Proceedings:

A Committee shall be elected to administer the association, on a voluntary basis. It shall consist of four officers and a maximum of ten other elected members, hereinafter known as the trustees of the Association.

The officers shall be:

Chairman, Vice Chairman, Secretary and Treasurer. At least two of the officers shall be kidney patients.

The officers and other committee members shall be elected at the Annual General Meeting of the Association. At least 50% of the elected Committee members shall be kidney patients.

Ordinary meetings of the committee shall be held at least ten times in each calendar year to deal with the routine items of business, and otherwise, as required.

Dates and venues for routine meetings shall be agreed at the first Committee meeting following the Annual General Meeting each year.

Any Committee member may ask for an item to be placed on the agenda for a meeting, and an invitation to each meeting, together with an agenda and any relevant backing papers should be set to every Committee member as soon as practically possible in advance of each meeting.

The membership, proceedings and terms of reference, (including delegated powers, if any), of any sub committees must be determined by a quorate meeting of the main Committee. A quorum for any meeting of the committee shall be 50% of its total membership, (including no less than two of the then officers of the Committee).

The chairman of the Association, (or, in his/her absence, the Chairman of any meeting of the committee), shall have a second, or casting vote, in the event of an equality of votes.

In the event of any vacancy arising among the elected membership of the committee, a replacement shall be sought from among the Association's membership. Any member seeking to act as a replacement must be proposed and seconded by any other two members of the association at that time.

In addition, the Committee shall have the power to co-opt any individual, (including representatives of other kidney patient associations and similar organisations), who need not be members of the Association, but who must support its objects. Such persons may be co-opted onto the main Committee and/or any relevant sub committees, but shall not have the right to vote on any matter.

6. Annual general Meeting. (AGM):

Once in every twelve months, the Committee shall convene an AGM of the Association, within three months of the end of the Association's financial year, at which all members shall be entitled to attend and vote.

The AGM shall be for the purpose of: -

- Receiving the report of the Committee of its activities in the furtherance of the objects of the Association since the last AGM.
- Receiving, and if approved, adopting the audited accounts of the Association.
- Electing the other Committee members.
- Appointing suitably qualified reviewing accountants of the Association.
- Dealing with any other appropriate business.

7. Special General Meeting (SGM):

The committee may, at any time, at its discretion, and shall upon receiving a written request by not fewer than 5% of the current membership, hold a SGM to consider and vote on specific issues which cannot wait for an AGM. A quorum in the case of any AGM shall be 10% of the current membership.

8. Finance:

All monies raised or held by the Association shall be applied to further the objects of the Association as decided by the Committee, (or any committee thereof, under delegated powers agreed by the main Committee).

The Treasurer shall keep proper books of accounts of the finances of the Association and shall submit annual accounts to the AGM. Prior to their submission, these accounts and the underlying records will have been examined by a Chartered Accountant, who is quite independent of the Association.

There shall be bank accounts in the name of the Association, withdrawals from which accounts must be signed by any two officers, for the time being, of the Association.

The trustees shall be empowered to pay expenses reasonably incurred by the Association's members wholly in the interest of the Association.

Except with the prior written approval of the Charity Commissioners, no trustee may: -

- Receive any benefit in money or in kind from the charity.
- Have a financial interest in the supply of goods or services to the charity.
- Acquire or hold any interest in property of the charity, (except in order to hold it as a trustee of the charity).

9. Dissolution of the Association:

If the charity trustees decide that it is necessary or advisable to dissolve the charity, they shall call a meeting of the charity of which not less than 21 days' notice, (stating the term of the resolution to be proposed) shall be given. If the proposal is confirmed by a two thirds majority of those present and voting, the charity trustees shall have the power to realise any asset held by, or on behalf of the charity. Any assets remaining after the satisfaction of any proper debts and liabilities shall be given or transferred to such other charitable institution or institutions having objects similar to the objects of this charity as the members of the charity may determine, or, failing that, shall be applied for some other charitable purpose.

10. Power of amendment to the Constitution:

No alterations to the constitution may be made except at an Annual General Meeting and upon at least two calendar months' notice, in writing, being given to the Committee, of any such proposed alteration; any such notice being signed by not fewer than ten members of the Association.

The consent by a simple majority of those present at the Annual General Meeting at which such changes are considered, shall be necessary before an alteration can take effect, with the Chairman of such a meeting have a second, or casting vote, in the event of an equality of votes.

No alteration shall be made, which shall cause the Association to cease to be a charity at law.

Manchester Royal Infirmary Patients' Association Annual General Meeting Sunday 15 July 2018

Agenda

- 1 *Apologies for absence*
- 2 *Minutes of the AGM held on 2 July 2017*
- 3 *Matters Arising (Not considered elsewhere on the agenda)*
- 4 *Committee Annual Report 2017/2018*
- 5 *Annual Accounts 2017/2018*
- 6 *Appointment of Reviewing Accountants for 2018/2019*
- 7 *Election of MRIKPA Officers & Committee Members for 2018/2019*
- 8 *Any other urgent business*

Programme

<i>9.30 a.m. to 10.00 a.m.</i>	<i>Arrival, Refreshments & Registration</i>
<i>10.00 a.m. to 10.40 a.m.</i>	<i>MRIKPA Annual General Meeting</i>
<i>10.40 a.m. to 10.55 a.m.</i>	<i>Break for refreshments</i>
<i>11.00 a.m. to 11.50 a.m.</i>	<i>Guest speaker & questions</i>
<i>11.50 a.m. to 12.00 a.m.</i>	<i>Closing remarks from the chairman elect from 2017/2018</i>
<i>12.00 a.m.</i>	<i>Depart</i>

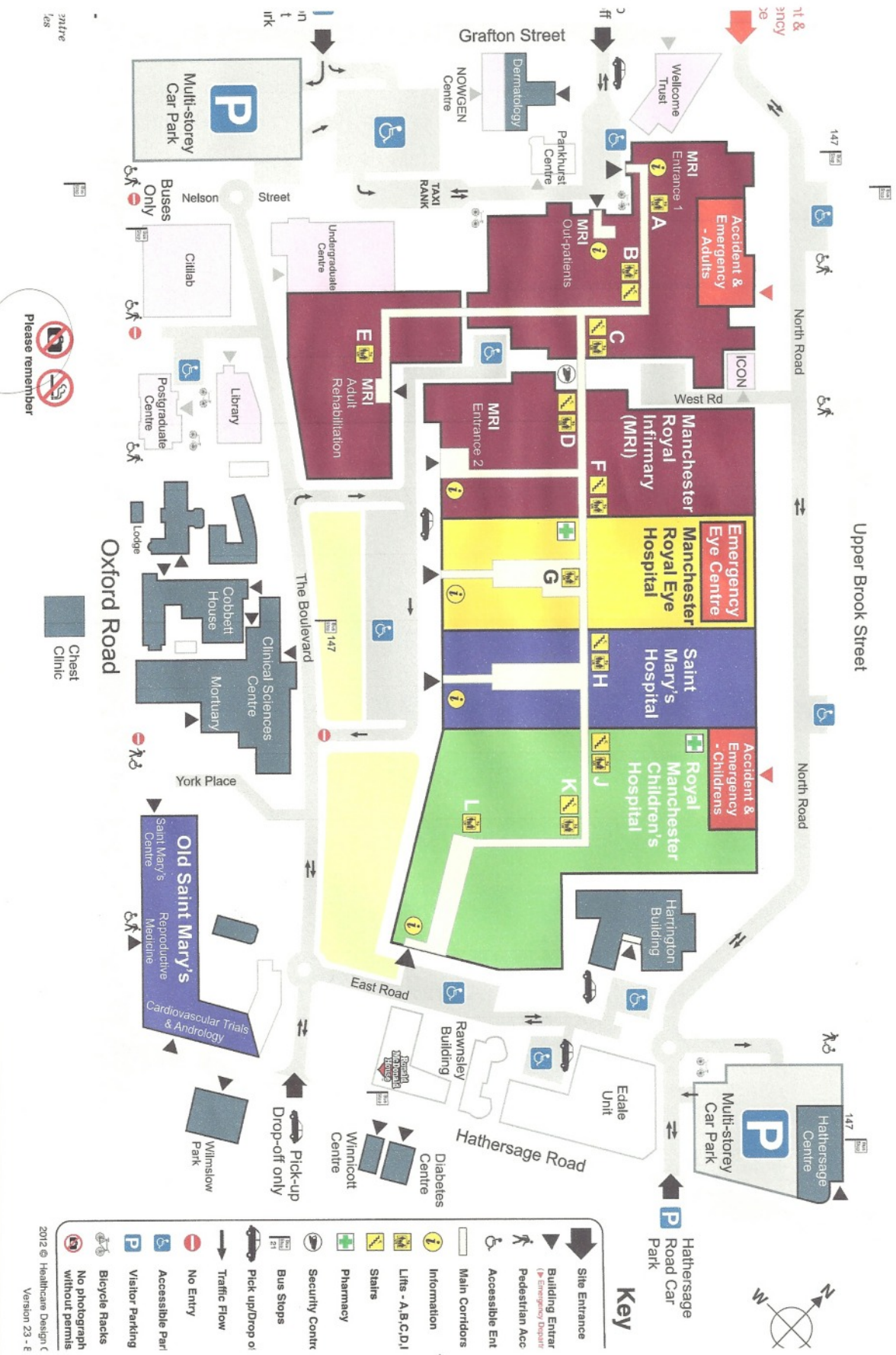


Central Manchester University Hospitals NHS Foundation Trust, Oxford Road, Manchester M13 9WL. Website: www.cmfh.nhs.uk

Tel: 0161 276 1111



Central Manchester University Hospitals



Annual Accounts

These will be made available at the AGM and published in the next newsletter

Manchester Royal Infirmary

Transformation of Renal Dialysis Service (TRENDS)

The plans to transform renal dialysis services across Manchester, Tameside & Glossop, Stockport, South Trafford, and East Cheshire continue to take shape and make progress. We should start to see real benefits from the plans by the summer.

The vision is to create a range of high quality renal dialysis care that makes use of the latest technology and based in modern community settings wherever possible.

Work on the new community dialysis units in North and Central Manchester continues to make good progress. The new premises will provide patients and staff with a modern and comfortable environment with state-of-the-art equipment which will contribute to an improved patient experience.

The staff are keen to work with patients to increase the availability of self-care and home dialysis and there will be training areas at both sites for patients who wish to pursue independent dialysis. The North Manchester dialysis unit, located in Hexagon House, is due to open soon. All patients who receive dialysis treatment in North Manchester will transfer to the new unit. The unit provides dedicated free parking for patients.

Dialysis patients had the opportunity to look round the new facilities in North Manchester on Tuesday 8th and Wednesday 9th May. This was designed to accommodate patients either before or after their dialysis session to make it more convenient. I visited the unit and took some photo's which you can see on the next few pages.

The Central Manchester dialysis unit, located in Octagon House, is now due to open on 25th June. A clinical review is currently underway of all patients who currently dialyse at Manchester Royal Infirmary to see which patients would be suitable to transfer to the new community unit. Every effort will be made to accommodate patients in their current slots. Patients will be notified in early June of the outcome of this review and where the most appropriate place is for their continuing dialysis care. Octagon House will provide dialysis care for 80-90 patients.

Update on the new workforce model

Good progress also continues to be made with the new workforce model.

33 new dialysis assistants have been recruited across the Manchester, Altrincham and Tameside units. Only 6 vacancies now remain and recruitment continues to appoint to these posts.

Newly appointed dialysis assistants undergo a comprehensive 12 week training programme to ensure they are fully trained to deliver safe, patient-focused treatment and are fully integrated into the existing teams.

The clinical educators in the training team organised an away-day on 1st May for new recruits and existing staff to reinforce the integration process.

Dialysis assistant Julie Davies from the North Manchester unit gave her views on her new role:

How are you getting on in your new role? I'm really pleased that I applied for this role and welcome the new challenge it brings. I enjoy the one-to-one patient care and am looking forward to continuing in this role. I definitely made the right choice.

How have you found the dialysis training? I've found the training to be very good, with more hands-on experience on the unit than in the training school. The patients have been very receptive and supportive.

How easily have you been integrated into the dialysis team? All the staff on the unit have been very supportive and welcoming, from the housekeepers to the ward manager. They're an excellent team to work with. Having the training on the unit has also helped.

Are you looking forward to moving to the new community dialysis unit? Yes. The current environment is far from ideal – it's old and cramped, with insufficient space for trolleys and equipment. I'm looking forward to working in a brand new unit with new equipment and up to date technology.

What do you think the benefits of the new environment will be? The main benefit will be being able to provide a better patient experience in a modern environment with new equipment. A dialysis patient in North Manchester commented on her experience of the new dialysis assistant role: "They're lovely girls, always there if I need help with anything and always ready to give the other staff a helping hand."

And what about moving to the new unit? "I'm looking forward to seeing the new unit and having nice new equipment. I hope the staff will still have the time to be as supportive as they always have been in the past."

Success of home dialysis roadshow

In early March, dialysis patients had an opportunity to find out more about home dialysis and how it might work for them at three roadshow events held to coincide with World Kidney Day.

The three events, held at Tameside Hospital, the Stockport dialysis unit, and Manchester Royal Infirmary, attracted around 90 patients and their families and friends. Not only could patients meet the experts, they were also able to talk to patients who already dialyse at home about the benefits.

Patients dialysed live from a camper van to demonstrate how flexible dialysis could be. About 30 patients have decided to choose or swap to home dialysis instead of their in-centre option and staff will be following up on this expression of interest. The roadshow was so successful it is hoped to make it a regular annual event in the future.

If you have any suggestions, concerns or questions, our clinical director, matrons and ward managers will be happy to discuss these with you. We will continue to keep you updated on further developments and progress of the project.

**Diane Comer, TRenDs Project Team Lead diane.comer@mft.nhs.uk
Tel: 0161 276 4411 April 2018**

Hexagon Hse - maintenance unit



Hexagon Hse - share care unit



Hexagon Hse - Fresenius 5008s
used by home haemodialysis patients



Home Dialysis - Awareness



Home dialysis is not for every dialysis patient. There may be family or other health reasons that prevent patients from dialysing at home.

However; there are a number of myths that have built up over the years that may stop dialysis patients from considering home dialysis. Some of the myths are mentioned below.

1. I have to have a Arteriovenous (AV) fistula (AVF) before I can do it at home
2. Can't do Home HD if you live alone or have no carer
3. Can't do home HD if you have other co morbid conditions (in many cases actually better for you – especially if you have poor heart function or low BP problems – may suit 5/6 times per week so gently removing small amounts of fluid/toxins each session, less fluid gains/more stable dx/ better for heart etc)
4. Can't have home HD if you rent a property (in many cases if property is rented long term and as long as an agreement from landlord can have home HD). Also with NX stage machine minimal changes needed to the property
5. Have to have home HD in a separate bedroom
6. Nocturnal dialysis not safe (concerns mainly about needle dislodgement – safe taping procedures should make this virtually impossible. There are also alarms to detect that can be utilised for reassurance if required). Better recovery time also post dialysis (no “dialysis hangover”)
7. Will have poor sleep on nocturnal dialysis. Often the opposite happens. Once the patient learns to relax that they are attached to a machine they often actually sleep better, particularly on non-dialysis nights. Dialysis patients often have insomnia and restless legs. Better dialysed patients generally sleep better. There is a school of thought that larger or middle molecules that contribute to these problems are removed better on long/slow dialysis.
8. It's safer in hospital. Although this may be correct if you're on hospital dialysis there is limited time/frequency which may result in hypotensive episodes, there is also the issue of transport to and from dialysis and the patient may suffer with “dialysis hangover” i.e. be on more medication etc.

If you want to speak to your home dialysis team to discuss the possibly of home dialysis their contact details are

0161 276 4440

available from 10.00am to 3pm every day



Afternoon Tea Celebration Event

On Sunday 22 March 2018 a 50th anniversary of the first kidney transplant at MRI took place at The Principal Hotel, Oxford Road, Manchester M60 7HA. There was a selection of sandwiches and cakes, and tea or coffee was also served.

The event was organised by members of the Kidneys for Life team based at MRI.

A few of the MRIKPA committee members and their partners attended the event along with 400-500 patients, carers, families, renal donors, clinicians and nurses.

It was an inspirational and emotional event for all. Some of the renal transplant patients attending had had their transplant for more than 25 years.

Afshin Tavakoli renal clinician gave a talk summarising the work and technical innovation and development of renal transplant over the past 50th years. He also highlighted the work of the clinicians, nurses and importantly the people working behind the scenes in the support teams who arrange and book our appointments.



Patients, family and staff enjoying afternoon tea



Summer renal recipes

The following summer renal recipes have been provided by Jade Reilly, Renal Dietitian, Nutrition & Dietetics at MRI.

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## Pasta with Butternut Squash and Sage Sauce



**Serves 2**

**Ingredients**

**4 tbsp olive oil**

**2 garlic cloves**

**4 tbsp chopped fresh sage**

**200g (7oz) butternut squash, peeled, seeds removed,**

**finely chopped**

**200ml (7fl oz) white wine (optional – or try low salt stock)**

**200ml (7fl oz) double cream**

**75ml (3fl oz) hot water**

**300g (11oz) penne pasta, cooked according to packet instructions**

**Black pepper (sprinkle) (optional)**

### ***Method***

1. Heat olive oil in a frying pan over a medium heat. Add garlic and sage and fry for 1-2 minutes, until golden.
2. Add the butternut squash and fry for 3-4 minutes, until golden.
3. Add the white wine and cook for one minute (optional)
4. Add the double cream and water, bring to the boil, then reduce the heat to simmer for five minutes, until the butternut squash is soft and cooked.
5. Add the cooked pasta, toss together and add black pepper and serve.

# Citrus spiced salmon

**Serves 4**

## **Ingredients**

**1/2 tsp ground cumin**

**1/4 tsp ground cinnamon**

**1/2 orange, zest only**

**1/2 lime, zest only**

**4 x tbsp olive oil**

**4 x 100g/3½oz skinless salmon fillets**

**Black pepper**

**4 x wedges of lemon**

## **Method**

1. Preheat oven to 180C/Gas 6. Line a baking tray with non-stick baking paper.
2. Combine the ground spices, orange zest and lime zest in a small bowl. Add the olive oil and stir well to form a wet marinade for the salmon.
3. Rub each salmon fillet well with the marinade and place it on the prepared baking tray. (At this stage you can cover with clingfilm and leave overnight in the refrigerator to marinate, if you wish). Once all the fillets are well coated in the marinade, season them with black pepper.
4. Bake for 12-15 minutes, or until the fish is cooked through. Serve with lemon wedges in addition to e.g. flat breads or rice.



# The General Data Protection Regulation (GDPR)

The new EU data protection regime, effective from 25<sup>th</sup> May 2018, covers any organisation established in the EU regardless of whether the company or body is based in the EU or not. If it processes personal data in connection with selling goods or services to EU subjects or monitoring their behaviour. This means that UK non-profit bodies must comply which includes charitable organisations.

## **Does it apply to the MARIKPA?**

Yes it does. As we hold names and addresses of our members we need to ensure that your personal data continues to be held securely and in line with the new regulations. We will continue to treat data fairly, securely and with respect.

## **What are we doing to meet the requirements?**

We have reviewed our activities, and selected the most appropriate lawful basis which applies to us.

## **Why do we hold personal data?**

We hold personal data purely to be able to send out the regular newsletter to our members. We **do not** directly market members for information either by email, post or phone. We have reviewed and checked that the processing and storing of this data is necessary for the relevant purpose, and are satisfied that there is no other reasonable way to achieve that purpose.

## **Membership details**

**If you no longer wish to receive future newsletters complete box 4 on page 39 and return the completed form to**

**M Kewley, 11 Canterbury Road, Hale, Altrincham, Cheshire  
WA15 8PL**

or

email to - [mikejm.kewley@gmail.com](mailto:mikejm.kewley@gmail.com)

Phone - 07530 452190

# Quiz questions

Outside which New York building was John Lennon killed?

Which character does Morgan Freeman play in Bruce Almighty?

Complete the advertising slogan for FedEx: 'When there is no..'

Wellington is the capital city of which country?

What letter is located between letters X and V on a standard keyboard?

Which famous astronaut once said, "That's one small step for man, one giant leap for mankind!"?

How many megabytes are there in 1 gigabyte?

During which decade did Elvis Presley die?

How many of Snow White's seven dwarfs have names ending in the letter Y?

As of 2016, which athlete had won the most Olympic medals?

'I Know Why the Caged Bird Sings' is the autobiography about the early years of what inspirational African-American writer and poet?

Who is lead singer of the Foo Fighters?

What are the two main ingredients of a 'screwdriver' cocktail?

What is the tallest breed of dog in the world?

Who is the author of The Hunger Games trilogy?

# Renal transplant patients and antibiotics

Don't get caught out by being prescribed the wrong or incorrect antibiotic by your GP. Ask for specialist advice before starting the following medicines.

Clarithromycin

Rifampicin

Erythromycin

Aliopurinol if also taking Azathioprine

Rosuvastatin if also taking Ciclosporin

More than 10mg daily of Simvastatin or Atorvastatin if also taking Ciclosporin

Fluconazole

Amiloride

ACE inhibitors

Nitrofurantoin

Spironolactone

Trimethoprim

Verapamil

Oral Contraception

Phenytoin

Diltiazem

NSAIDS

Carbamazepine

This is not an exhaustive list. For further advice consult the renal pharmacy team on 0161 701 0880

## Holiday Insurance

This information has been reproduced from the National Kidney Federation Website . where you can always find the most recent information

<http://www.kidney.org.uk/help-and-info/holidays/holidays-tips-insure/> .

The NKF and MRIKPA cannot accept responsibility for information out holiday insurance which covers you for a 'pre-existing medical condition' (see 'Warning' opposite). Most standard policies do not provide this type of cover and, below, is a list of companies that may be able to help if you have problems obtaining insurance.

| COMPANY                                       | CONTACT DETAILS                                                                            | COMMENTS                                                                    |
|-----------------------------------------------|--------------------------------------------------------------------------------------------|-----------------------------------------------------------------------------|
| Able2Travel                                   | 0845 839 9345                                                                              | Specialise in travellers with medical conditions                            |
| All Clear Ins Services                        | 0870 777 9339                                                                              | Worldwide                                                                   |
| ASDA Insurance                                | 0845 300 7131                                                                              |                                                                             |
| Avanti Travel Insurance                       | 0800 066 5604<br><a href="http://www.avanti.co.uk">www.avanti.co.uk</a>                    |                                                                             |
| Direct Travel Insurance                       | 01903 812345                                                                               | Europe/America/Canada                                                       |
| Free Spirit                                   | 0845 230 5000                                                                              | Europe                                                                      |
| Freedom Ins Services                          | 01223 454 290<br><a href="http://www.freedominsure.co.uk">www.freedominsure.co.uk</a>      | UK, Europe & Worldwide. Tel: Mon-Fri 8.30 am - 5.30 pm (Sat 9 am - 12 noon) |
| Goodtogoinsurance.com                         | 0844 334 0160<br><a href="http://www.goodtogoinsurance.com">www.goodtogoinsurance.com</a>  | All types of medical conditions up to a high level of severity.             |
| Holiday and Medical Insurance (Mr Mike Smith) | 01773 769406<br><a href="http://www.askaboutinsurance.info">www.askaboutinsurance.info</a> |                                                                             |
| Insure & Go                                   | 0870 420 4162<br><a href="http://www.insureandgo.com">www.insureandgo.com</a>              |                                                                             |
| J & M Ins Services (UK)                       | 0845 230 5000                                                                              |                                                                             |
| JS Insurance                                  | 0844 848 1500<br>Kidney Transplant Travel insurance<br>Kidney Stones Travel insurance      | Kidney Transplant patients and patients with Kidney Stones                  |

| COMPANY                      | CONTACT DETAILS                                                                                                                                                                                          | COMMENTS                                                   |
|------------------------------|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|------------------------------------------------------------|
| Just Travel Insurance        | 0800 542 7162<br><a href="http://www.justthecover.co.uk">www.justthecover.co.uk</a>                                                                                                                      | Bespoke policies which cover 98% of all medical conditions |
| Medici Travel                | 0845 8800168<br><a href="http://www.medicitravel.com">www.medicitravel.com</a>                                                                                                                           |                                                            |
| MIA Online                   | 01268 782745                                                                                                                                                                                             |                                                            |
| RIAS PLC                     | 0845 234 0011                                                                                                                                                                                            | For over 50s                                               |
| Staysure                     | 0844 692 8444<br><a href="http://www.staysure.co.uk">www.staysure.co.uk</a>                                                                                                                              | For over 50s                                               |
| The Insurance Surgery        | 0800 083 2829<br><a href="http://www.the-insuranesurgery.co.uk">www.the-insuranesurgery.co.uk</a>                                                                                                        | Broker                                                     |
| Travelbility                 | 0845 338 1638<br><a href="http://www.travelbility.co.uk">www.travelbility.co.uk</a>                                                                                                                      | Disabled or pre-existing condition                         |
| World First Travel Insurance | 0845 90 80 161<br><a href="http://www.worldfirst.co.uk/home/travelinsurance/medical-problems/medicalscreening.aspx">www.worldfirst.co.uk/home/travelinsurance/medical-problems/medicalscreening.aspx</a> | Medical Travel Insurance                                   |

Note: Insurance companies can and do change their Terms & Conditions - always ensure you have current information on policies. Also note that insurance companies usually take each case on its merits; it is usually a case of phoning around and finding the one that is the most suitable for you.

Remember that, in Europe, in addition to the correct holiday insurance, you should also carry a European Health Insurance Card (EHIC) (see NKF website for more details).

**WARNING** - Many insurance companies take on new policies without asking any medical questions. They are able to do this because they rely on a clause in the small print which says that they will not cover pre-existing medical conditions. Patients must realise that such policies do not give them insurance cover, and that any claims as a result (both directly and indirectly) of existing kidney disease under such a policy would not be honoured in the event of a claim. Whether you were accepted (without disclosing existing illness) and are paying the premium, is irrelevant in such cases. To travel abroad without insurance that covers you for your pre-existing medical conditions could be catastrophic financially.



## Grafton Street Car Park - operated by ParkingEye

If you use the Grafton Street car park when attending your clinic appointments it now uses number recognition technology. This means it takes your registration number on the way into the car park and you pay when you exit the car park by punching in your registration number into the pay machine and pay the required amount.

Patients have been caught out by the lack of clear signs regarding the change and faced a penalty for not paying on exit.

MRI is unable to request parking charge notices are cancelled. You must appeal in writing within 28 days from the date of the original correspondence direct to ParkingEye to either Appeals Department, ParkinEye, PO Box 565, Chorley, PR6 6HT or <https://portal.parkingeye.co.uk>

## Oxford Road

You are only allowed to drive down this road at certain times of the day. Drivers face fines for not complying with this requirement. Your editor is one of those people!!

I understand to date approximately £9 million has been taken in fines for drivers not adhering to this new rule.



# Dates for your diary

2018

## **Pre-Dialysis - Patient Education Meetings**

Tues 31<sup>st</sup> July 18:00-20:30 Post Graduate Building  
Lindsay, Fiona, Krisha

Tues 30<sup>th</sup> October 13:30-16:00 Post Graduate Building  
Lindsay, Susie, Jackie

## **Events**

UK Kidney Week 19<sup>th</sup> – 21<sup>st</sup> June 2018 Harrogate  
Convention Centre

Annual Renal remembrance service - Sunday 8<sup>th</sup> July 2pm @  
the Pier 8 Room at the Lowry Theatre, Manchester

**MRIKPA AGM - Sunday 15<sup>th</sup> July @ MRI**  
(further details in the next newsletter)

British Transplant Games - Birmingham Thursday 2<sup>nd</sup>  
August - Sunday 5<sup>th</sup> August

National organ donation week - 5<sup>th</sup>-11 September 2017

# Quiz answers

The Dakota Building

God

Tomorrow

New Zealand

Letter C

Neil Armstrong

1000

The 1970s

Five: Dopey, Grumpy, Sneezzy, Sleepy, Happy

Michael Phelps

Maya Angelou

Dave Grohl

Vodka and orange juice

The Great Dane

Suzanne Collins

## **Obituary**

### **Dr Madan Mohan Gupta** **JP MBBS DTD DCH DIH MRCGP FIAMS FODA**

**8<sup>th</sup> December 1934 – 19<sup>th</sup> December 2017**

Dr Madan Mohan Gupta of Oldham sadly passed away on the evening of 19<sup>th</sup> December 2017 from an acute myocardial infarction. He was a renal patient under the care of the Manchester Royal Infirmary.

Madan was born in Arrah, Bihar. He graduated in medicine from the Prince of Wales Medical College in Patna in 1957.

He travelled to the United Kingdom in 1964, and after initially pursuing a career in paediatrics, he opted to become a general practitioner. In 1972 he settled in Oldham, Lancashire and excelled as a general practitioner (GP) there. He maintained a special interest in paediatrics and child health. He was much respected by patients and colleagues. He achieved numerous postgraduate qualifications. He was one of the first Asian GPs to pass the Membership of the Royal College of General Practitioners (MRCGP) exam, and to become a GP trainer. He successfully grew his practice from a single handed practice to a group training practice.

He continued to keep strong links with India and spoke at symposia and conferences on general practice and community medicine there. For his continuing work in India he was made a Fellow of the Indian Association of Medical Specialists.

He was also politically active. He was a founder member, past president and Fellow of the Overseas Doctors' Association (ODA) (now the British International Doctors' Association - BIDA). Through his work with the ODA/BIDA, he successfully campaigned to bring about very much needed changes which have ensured that international doctors in the UK are treated fairly.

He was also a founder member, past president, and patron of the Bihar Jharkhand Medical Association (UK).

He worked tirelessly for charities, and the community. He was a Rotary Club member and a Justice of the Peace (JP).

He had strong connections with the Indian Association of Oldham, and was a past president and trustee. He was integral in the association securing a purpose built temple in Oldham. He also contributed to charitable activities in Bihar, India.

Socially he was very active. He was always well connected with family and friends all over the world.

Madan was a renal patient at Manchester Royal Infirmary since 1964. He had chronic renal failure. He diagnosed himself as having renal impairment during a laboratory test on his own urine specimen when he was a medical student in India. When he arrived in the UK he became a patient of the renowned renal department at MRI and over the years has seen the retirement of several eminent Consultant Renal Physicians.

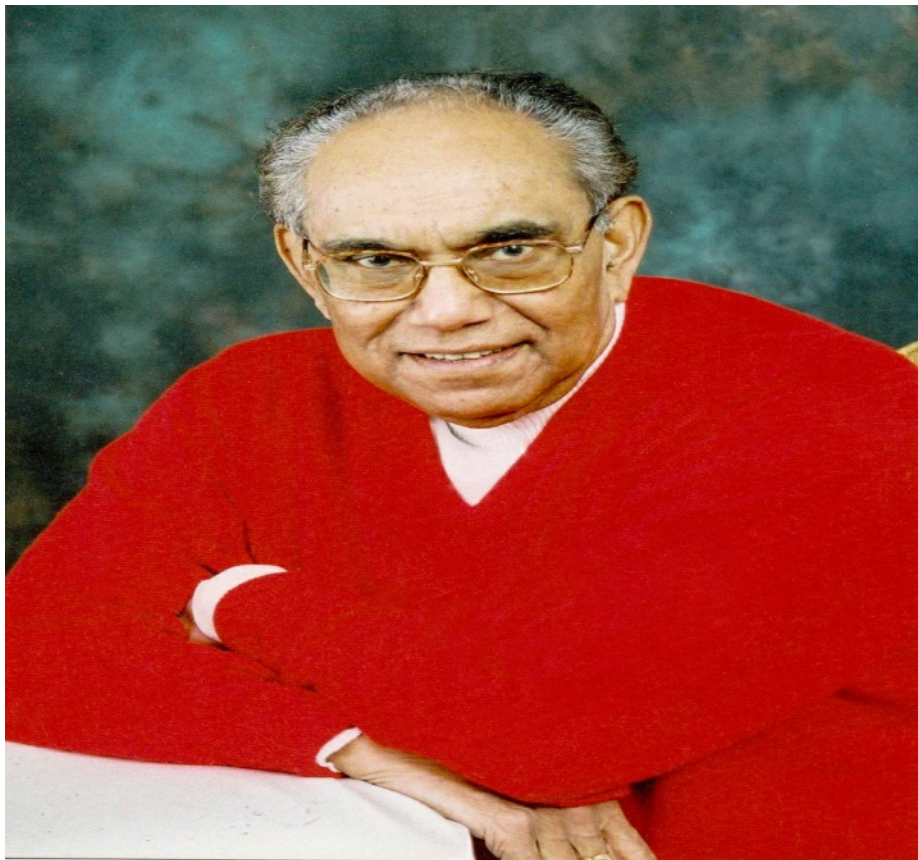
In 1999 he was commenced on peritoneal dialysis and later the same year was very fortunate to receive a cadaveric renal transplant. He was informed that the donor was an elderly man who also had a degree of renal impairment and thus it was felt that the transplant kidney only had a limited life-span. Madan suffered a number of complications, including an acute rejection, fluid overload, pulmonary oedema and anaemia immediately post-transplantation. He however recovered from these and apart from some “hiccups” along the way the transplant kidney served him well until his death.

He was always very grateful to the donor (and his family) of the kidney that he received and for the care he received at MRI. In addition he valued the support of the MRI Kidney Patients Association. When he and his wife Prem Shila celebrated their 50<sup>th</sup> Wedding Anniversary in 2014 they requested friends and family to give donations to the MRIKPA in place of giving gifts and similarly at his funeral, Prem Shila and their children requested friends and family to give donations to the MRIKPA in place of bringing flowers.

Madan was a successful, but humble, and unassuming man. He went out of his way to help others and has touched many lives. He is very much loved and respected by his family and many generations of doctors, patients and friends.

He leaves behind his wife, 3 children and their spouses and 5 grandchildren.

Rajat Gupta  
Binoo Rastogi  
Jaya Kedia



**Dr Madan Mohan Gupta**

# MRIKPA Newsletter

## Fancy receiving a copy electronically?

With increasing printing and distribution costs the MRIKPA Committee have been reviewing how we can reduce some of the costs of producing the newsletter.

In this ever increasing electronic age I was wondering if readers would prefer to receive the newsletter in an electronic PDF format. Some readers have already requested a copy electronically.

Whilst I appreciate many readers would prefer to have a hard copy to read there are benefits of receiving the newsletter electronically. Firstly you can easily share copies with family and friends, secondly you can print off certain pages to either read or retain and thirdly you can easily store back copies.

If you would like to receive it electronically drop me an email at [mikejm.kewley@gmail.com](mailto:mikejm.kewley@gmail.com)

Mike Kewley

Editor





the **Westfield** Health  
**BRITISH**  
**TRANSPLANT**  
**GAMES**  
Birmingham 2018

Birmingham welcomes you to the 41st edition of the Westfield Health British Transplant Games which will be held across the region from Thursday 2nd August to Sunday 5th August 2018.

Birmingham, with a population of 1.1 million people is one of the UK's most vibrant, energetic and diverse cities. The area has excellent transport link and should prove a popular destination for participants and their families in 2018.

The Westfield Health Transplant Games are making a 3rd visit to Birmingham and will take their place in the sporting calendar alongside the 2018 IAAF World Indoor Championships (1st-4th March), the Yonex All England Open Badminton Championships (14th-18th March 2018) and the Investec 1st Test between England and India.

The Westfield Health British Transplant Games will make use of several of the outstanding facilities across the city including the Symphony Hall, the ICC, Alexander Stadium and the recently opened University of Birmingham Sport and Fitness Centre. The Games will also enjoy the support of Birmingham City Council, University of Birmingham, Queen Elizabeth Hospital Birmingham Charity, Birmingham Children's Hospital Charity and Sport Birmingham.

The Games will also shine a light on the hard-work, dedication and talent of the doctors and nurses who work in hospitals across the region who bring hope to families and individuals from all over the UK undergoing transplant surgery, Birmingham performs more Transplants than anywhere else in Europe and recently celebrated its 5,000th Liver Transplant.

So if your not participating you can always go along and support the Manchester children's and adult's teams.

## ***MRIKPA Membership Application Form***

Membership of the Manchester Royal Infirmary Kidney Patients' Association (MRI) is completely free. It is open to kidney patients, their relatives & friends, hospital staff and to anyone who is interested in the welfare of kidney patients. Members receive, free of charge, a regular newsletter.

**Please tick as appropriate and then complete the form below**

- I would like to join the MRIKPA
- I consent to the MRIKPA contacting me by post
- I am already a member of the MRIKPA and have changed my name, address and/or phone number
- I no longer wish to remain a member of the Association or to receive the newsletter. Please remove me from your mailing list.
- I consent to receive the National Kidney Federation (NKF) magazine

My Name

Address

Postcode

Telephone/Mobile

***Please send this completed form (or a photocopy if you prefer) to:  
Mike Kewley, 11 Canterbury Road, Hale, Altrincham Cheshire WA15 8PL***

***I would like to make a donation to the MRIKPA and enclose  
a cheque for £ ..... (Membership is free but if you would like  
to make a donation we would be very grateful)***

### **Important - Data Protection Information:**

The MRIKPA and the National Kidney Federation keep your data for the sole purpose of distributing your magazines.

If you do not wish your data to be held on computer, please tick this box:

However, if your name and address are not on our computer we will be unable to send you the newsletter.

# *Donations and Fundraising*

Mrs. E. Jenkins in memory of Dr. Simon Jenkins £350.00 29.1.18

Janet Richardson £10.00 1.3.18

David & Rita Potts in memory of Mrs. M. Nezabi £20.00 1.3.18

In memory of Dr. Madan Mohan Gupta £710.00 1.3.18

Mrs. M. England £100.00 20.3.18

Please send whatever donation you can afford, large or small to support your association. As a charity, we rely entirely on the generosity of our members and supporters to continue our work for the benefit of kidney patients in the region.



**Please send your donations to:  
Janet Richardson  
12 Carrington Lane, Sale M33 5ND**

**Cheque's should be made payable to: MRIKPA**

You can telephone Janet on 07490 190492 to ask about ways you can make a bequest or donate through gift aid.

**Monies donated are used solely for the benefit of kidney patients. Your Committee are all volunteers and do not receive any payment from your donations or from any other source for the work that they do.**

**Donations are received at different times and as a result may miss the deadline of the newsletter.**

**Therefore, the total amount raised may not be shown in one newsletter but shown over two issues.**



giftaid it

## Gift Aid declaration –for a single donation

### Name of charity or Community Amateur Sports Club

-----

Please treat the enclosed gift of £ ----- as a Gift Aid donation.

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

### Donor's details

Title ----- First name or initial(s) -----

Surname -----

Full Home address -----

-----

Postcode -----

Date -----

Signature -----

### ***Please notify the charity or CASC if you:***

- *Want to cancel this declaration*
- *Change your name or home address*
- *No longer pay sufficient tax on your income and/or capital gains.*

*If you pay Income Tax at the higher or additional rate and want to receive the additional tax relief due to you, you must include all your Gift Aid donations on your Self Assessment tax return or ask HM Revenue and Customs to adjust your tax code.*

# Contact numbers

## **Renal Transplant Outpatients**

Monday Suite E 0161 276 4147

Tuesday Suite D 0161 276 4239

Wednesday Suite B 0161 276 4115

Thursday Suite E 0161 276 5004

Friday Suite E 0161 276 4167

**Transplant clinic room** 0161 276 8721 (after 1pm)

**Transplant office** (appointments) 0161 276 4492/3646

**Blood results** 0161 276 8721 (1-3pm)

**Ward 9 & 10** 0161 276 4518/4402

**Pre dialysis team** 0161 276 4440

**Renal Social worker** 0161 276 6521

**Renal Dietitians** 0161 276 4478

**Renal Vascular Access nurse** 0161 276 7985

## **Transplant Games**

Zoe Dixon - Manchester Adult Transplant Games team Manager -  
07780858558

Denise Roberts - Manchester Children's Team Manager  
0161 701 7708

# NOTES

# What do we do?

- ❑ *We promote the welfare of persons receiving treatment at MRI, for disease or illness affecting the kidneys, irrespective of where they were referred from.*
- ❑ *We hold an Annual General Meeting each year.*
- ❑ *We finance an Amenity Fund which provides for patients in need.*
- ❑ *We send out up to four magazines free of charge each year.*
- ❑ *We supply items to improve the comfort of patients in hospital.*
- ❑ *We campaign on behalf of kidney patients to improve facilities and increase public awareness of issues affecting kidney patients, particularly the need for transplants.*
- ❑ *We work with other organisations interested in renal disease and its treatment and we are a member of the National Kidney Federation.*
- ❑ *We give equipment to Hospital Renal Units - items that are not supplied as a statutory provision.*
- ❑ *We will pay (at the reduced rate) for up to twelve members per year to attend the National Kidney Federation Conference for a weekend*



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