

# NEWSLETTER

I'm FREE

Please take one



Linda Maskell-Glynn 1955 - 2019

Manchester Royal  
Infirmary

Kidney Patients'  
Association

(MRIKPA)

## Summer 2019

Registered Charity Number

516871



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## Committee Members

Guy Hill	Chair	helenandguy_hill@hotmail.com	01565 654382
Steve Caddick	Committee Member	Caddicksteve@hotmail.com	0161 684 8588
Geoff Burgess	Vice Chair	geoff.burgess@hotmail.co.uk	0161 483 8141
Janet Richardson	Treasurer		07490 190492
Mike Kewley	Newsletter Editor	mikejm.kewley@gmail.com	07530 452190
John Murphy	Committee Member		
Helen Murphy	Committee Member		
Dr Arijit Sen	Committee Member	Arijitsen@hotmail.com	01706 345383
Margaret Bennett	Secretary		0161 448 1895
Wajid Iqbal	Committee Member	Wajidzz@gmail.com	07948 833 994
Barbara Taylor	Committee Member	David.taylor5557@ntlworld	0161 486 9757

# FREE sources of information for renal patients and carers

## National Kidney Federation [www.kidney.org.uk](http://www.kidney.org.uk)

The NKF is the national kidney charity actually run by Kidney Patients for Kidney Patients.

It has two roles campaigning for improvements to renal provision and treatment, and national patient support services.

It runs a FREE National Kidney Patient's HELPLINE 0800 169 09 36

## Kidney Care UK [www.kidneycareuk.org](http://www.kidneycareuk.org)

Is the leading kidney patient support charity providing advice, support and financial assistance to thousands every year.

## Greater Manchester Kidney Network (GMKIN)

<http://gmkin.org.uk>

The Kidney Information Network (KIN) is a joint venture between patients with chronic kidney disease, clinicians and the University of Salford (led by Dr Cristina Vasilica, Prof Paula Ormandy and Rob Finnigan).

KIN was initially set up in Greater Manchester (2013) as 'The Greater Manchester Kidney Information Network (GMKIN)' and in 2019 we expanded to Cheshire and Merseyside area (CaMKIN).

## Polycystic Kidney Research Charity (PKD)

<https://pkdcharity.org.uk/>

The PKD Charity was established in December 2000 by patients, professionals and members of families affected by PKD.

Their charitable aim is to promote health and to relieve those persons suffering from or affected by polycystic kidney disease (PKD) with a view to improving their conditions of life by funding research, promoting awareness and organising and publicising information to patients and carers.

Support line number: 0300 111 1234

## 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 on 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 <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 <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 <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 <a href="http://www.askaboutinsurance.info">www.askaboutinsurance.info</a>	
Insure & Go	0870 420 4162 <a href="http://www.insureandgo.com">www.insureandgo.com</a>	
J & M Ins Services (UK)	0845 230 5000	
JS Insurance	0844 848 1500 Kidney Transplant Travel insurance Kidney Stones Travel insurance	Kidney Transplant patients and patients with Kidney Stones

COMPANY	CONTACT DETAILS	COMMENTS
Just Travel Insurance	0800 542 7162 <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 <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 <a href="http://www.staysure.co.uk">www.staysure.co.uk</a>	For over 50s
The Insurance Surgery	0800 083 2829 <a href="http://www.the-insuranesurgery.co.uk">www.the-insuranesurgery.co.uk</a>	Broker
Travelbilty	0845 338 1638 <a href="http://www.travelbilty.co.uk">www.travelbilty.co.uk</a>	Disabled or pre-existing condition
World First Travel Insurance	0845 90 80 161 <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.

# 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



# Hello from your Editor

Welcome to the Summer edition of the newsletter.

In this edition we pay tribute to Linda Maskell-Glynn who many of you would have known. She edited the newsletter for many years and I knew when I took over as editor it was going to be a hard act to follow.

Linda was very helpful and supportive giving me lots of advice on how to create and publish this newsletter. She was a great inspiration to me and many others with her wit and enthusiasm for life. She will be greatly missed by many.

This edition also covers the AGM which will be held on Sunday 21 July at MRI. Please come along and support us.

You can also follow us on Facebook at MRI Kidney Patients' Association

Mike

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

07530 452190

MRI Kidney Patients' Association





# Chairman's letter

It is inevitable that we have to say 'final goodbyes' to patients, but the death of Linda Maskell- Glynn is really sad. She was a pleasure to know, a person abounding in positive energy, no matter what her body threw at her.

Many of you will be familiar with her as our Editor of this magazine for so many years. She adored exploring the medical world, to bring us articles that were both informative but also illustrative of just how much work goes on behind the scenes to help us keep well. Her example of a kidney patient going beyond their own clinical experience and helping other patients is a lesson that proves how rewarding this can be.

Dialysis patients often strive for self-worth, as their opportunities become limited. However renal transplant patients say they would like 'to give something back' using their new found freedom.

There are so many areas you can contribute to: Transplant Sport, Research with the Hospitals or Charities, sharing different experiences and raising money for Kidney charity events or joining local, regional or national groups as a patient representative. Different patients have different strengths and experiences, but I can assure you, you are well received by interested organisations that value your input.

At the KPA, our fundamental role is to 'humanise' our treatment process to patients, staff and officials. Yes there is a skill in translating your own journey into a 'considered opinion ' for others to listen and take note from, but any patient can do it once they decide to get involved.

I recently attended an initiative called Kidney Patients Involvement Network (KPIN), which wants to create an internet network of 'committed Patients' who want to give back and will allow patients to connect with organisations looking for input.

As cost drives our health care it is critical that we keep our voices loud and our needs understood, for you never know when you might need that human touch in your care.

Please consider hard if you could join the KPA committee to begin that journey. Linda did, those many years ago and I know she enjoyed being involved. Thank you Linda for all that you did.

Until the Next Magazine

Guy Hill  
Chair

[helenandguy\\_hill@hotmail.com](mailto:helenandguy_hill@hotmail.com)

Tel: 01565 654382



**Linda Maskell-Glynn was the previous editor of the newsletter from 1992-2015. She sadly died earlier this year and our Chair used the following words to pay tribute to a remarkable person at her funeral.**

Linda took over the Editorship of the newsletter in June 1992, issue 54, and then continued for 16 yrs, getting to issue 139, when she had a year in hospital and then came back in 2010, doing her final issue in 2015, as she began her battle with cancer.

She was and certainly should have been, thanks to her husband's David's technical skill, proud of her magazine, both the content and the way it was displayed. I met many other KPA editors who felt it was the benchmark of a patient's magazine. Informative, not flippant but very readable and for many patients they looked forward to receiving it.

Looking back through issues, you see articles from all around the kidney world not just at Manchester but beyond.

She did this with enthusiasm, because she genuinely cared for patients and their challenges and to keep them informed in a pre-Internet world.

It showed and supported the critical link in 'trust' between clinical staff and the patients that renal is famous for and also showed how much trust doctors had in her not to misrepresent the information.

Despite a tough time, diagnosed at age of 12, on to dialysis at 21, if anyone was made to survive 47 years of renal Linda achieved it through the art of positivity. I wish it could have been bottled and handed out as the first medicine of choice.

She was such a personable character

She would talk to anyone, naturally, no matter who it was. In Linda you met 'a real thirst for life' She Believed you had 'only one life' and needed to take risks to make it a positive experience, no matter what trauma you might encounter

Despite some real setbacks in her health, she always believed she would make it through.

Even her final challenge, that seemed overwhelming to others, she believed she would pull through and didn't change her over abiding optimism.

David was her rock and when he died, you felt she might not cope but she did thanks to her determination to be 'alive'

She learnt the art of keeping herself busy, never to dwell, her card making hobby was a delight to receive.

She loved community and her desire to celebrate at any opportunity, especially if it meant dressing up. I know 'down the pub' that she and David did an incredible

As editor, she wouldn't be thanked and yet renal patients, who knew her or not, have a lot to thank her for. Amusingly she once quietly let it drop, she dreamed of being on the Queen's honour list, imagine David's horror. It was not really for recognition, but she fancied writing an article all about it. If there was to be gong then it would have to be an MBE, well known colloquially as the award for 'my bloody effort'

So thank you Linda, sadly we failed you on your honour, but now you are back with your beloved David. I suspect keeping busy and already editing GOD's own 'newsletter' to heaven and he will honour you as a **FSA** .....fully signed up angel. Back on earth, on behalf of all of us at the KPA, it was a pleasure being your renal friend.

Guy Hill  
Chair

# N W R K P A

The North West Region Kidney Patients' Association

N E W S L E T T E R

*I'm back!!*



Spring 2010 Issue 139

Registered Charity No. 516871

# MRIKPA Annual General Meeting Sunday 21st July 2019

*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 21 July 2019 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 2018/19 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.

<b>I/we will be attending the MRIKPA AGM on Sunday 21 July 2019</b>	
<b>Name/Names:</b>	
<b>Address:</b>	
<b>Telephone number:</b>	<b>Number of people attending:</b>
<b>How many people will require CAPD facilities?</b>	

If you wish to nominate someone to stand as an officer on the next (2018/2019) 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.

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

# MRIKPA Annual General Meeting Sunday 21 July 2019

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 30 June 2019**

**3rd 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.

**2019/2020**

Nominee	Proposer	Seconder	Prosposer 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		
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 21 July 2019

## Agenda

- 1 *Apologies for absence*
- 2 *Minutes of the AGM held on 15 July 2018*
- 3 *Matters Arising (Not considered elsewhere on the agenda)*
- 4 *Committee Annual Report 2018/2019*
- 5 *Annual Accounts 2018/2019*
- 6 *Appointment of Reviewing Accountants for 2019/2020*
- 7 *Election of MRIKPA Officers & Committee Members for 2019/2020*
- 8 *Any other urgent business*

## Programme

<i>9.30 a.m. to 10.00 a.m.</i>	<i>Arrival, Refreshments &amp; 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 &amp; questions</i>
<i>11.50 a.m. to 12.00 a.m.</i>	<i>Closing remarks from the chairman elect from 2019/2020</i>
<i>12.00 a.m.</i>	<i>Depart</i>

# Annual Accounts

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

# DRAFT

## MRIKPA 3<sup>rd</sup> ANNUAL GENERAL MEETING Minutes of the meeting held on 15<sup>th</sup> July 2018

**Present:** G. Hill, J. Richardson, W. Iqbal, J. Murphy, H. Murphy, M. Kewley, G. Burgess, B. Taylor and S. Caddick.

All present were welcomed to the meeting.

**In attendance:** M. Bennett R. Shrigley and P. Griffiths.

1. **Apologies for absence:** A. Sen.

2. **Minutes of 2<sup>nd</sup> AGM held on 2<sup>nd</sup> July 2017:** Were accepted as an accurate record.

**Proposed:** Janet Richardson

**Seconded:** Pam Griffiths

3. **Matters arising (not covered elsewhere on the agenda):** None except 2 AOB items.

4. **MRIKPA Committee Annual report:**

G. Hill read out his report and started this with a minute's silence in memory of R. Jenkins. For the contents of this report please see attached. There were questions about: -

- Marginal kidneys: Where the kidney is felt to be ok but the donor does not have a clean bill of health, or might have had complications with their health, such as diabetes, cancer (but not of the kidney) etc.
- Biopsy: Cambridge has one of the smallest waiting list because they have been doing biopsies with reference to older donors and is dealt with on a progressive chart. There is now a national biopsy scheme that is being trialled. Manchester has signed up for it too.
- Shortlist choices: Transplant blood people want patients to be involved too for 3<sup>rd</sup>, 4<sup>th</sup> and 5<sup>th</sup> choices on shortlist. Conservative choices that are made by some units are picked up by other units, due to the biopsies. This is beginning to have a detrimental effect on people's choices for transplant.
- Thanks were given to renal social workers for their work this year.

G. Hill was thanked for his report.

**MRIKPA Annual accounts: 2017/2018:**

J. Richardson gave the AGM a breakdown of the accounts for this year. Please see attached.

**Proposed:** Barbara

**Seconded:** Wajid

There was a discussion about the cost of the magazine. There are members who receive online in addition to hard copies. There was a discussion about the cost of printing and delivery of the magazine and how this might affect the reserves policy.

Magazines are no longer delivered to Salford, as they have a very good copy of their own.

M. Bennett asked:

- Is there any way we can find out what the uptake is through GMKin?
  - Facebook: Can we put a link on for GMKin through FB, when the magazine comes out? The clicks on FB seem to have increased. W. Iqbal confirmed that this had increased due to a recent post on organ donation, so a link might be a good idea and is possible to do.
- There was a discussion about the reserves policy and an explanation about the 3 years reserves stipulated within it: -
- It provides evidence of sustainability and forward planning of the Association.
  - Protects the Association from hoarding money unnecessarily.

There have been no requests for transplant games because kit has been provided by KforLife, this year.

6. Election of MRIKPA officers and committee members for 2018/2019:

AGM was informed that the committee members are willing to stand again for this forthcoming year. For the committee to be accepted en bloc there needs to be a proposer and seconder. Further nominations were requested from the floor. There were none received.

Proposed: P. Griffiths

Seconded: R. Shrigley

7. AOB:

Constitution: due to a recent change in the law from Charity Commissioners there is no longer a requirement for accounts to be audited under £25,000. As the KPA is below this, the constitution needs to be revised to reflect these changes. It was recommended to add, if appropriate according to charity commissioners' rules, in Section 15 (d) para 1.4 so the constitution will now read Section 8:

Prior to their submission these accounts and the underlying records will have been examined by a chartered accountant, if appropriate according to charity commissioners' rules, who is independent of the association.

Proposed: R. Shrigley

Seconded: S. Caddick

Plaque for TV: Has been bought for ward 9. Irene Chambers is to organise the plaque, she has asked for the wording to be agreed.

Suggestion:

In memory of Dr. Simon Jenkins OBE, Kidney patient at MRI. This is to be sent to Dr Deborah Joseph for approval.

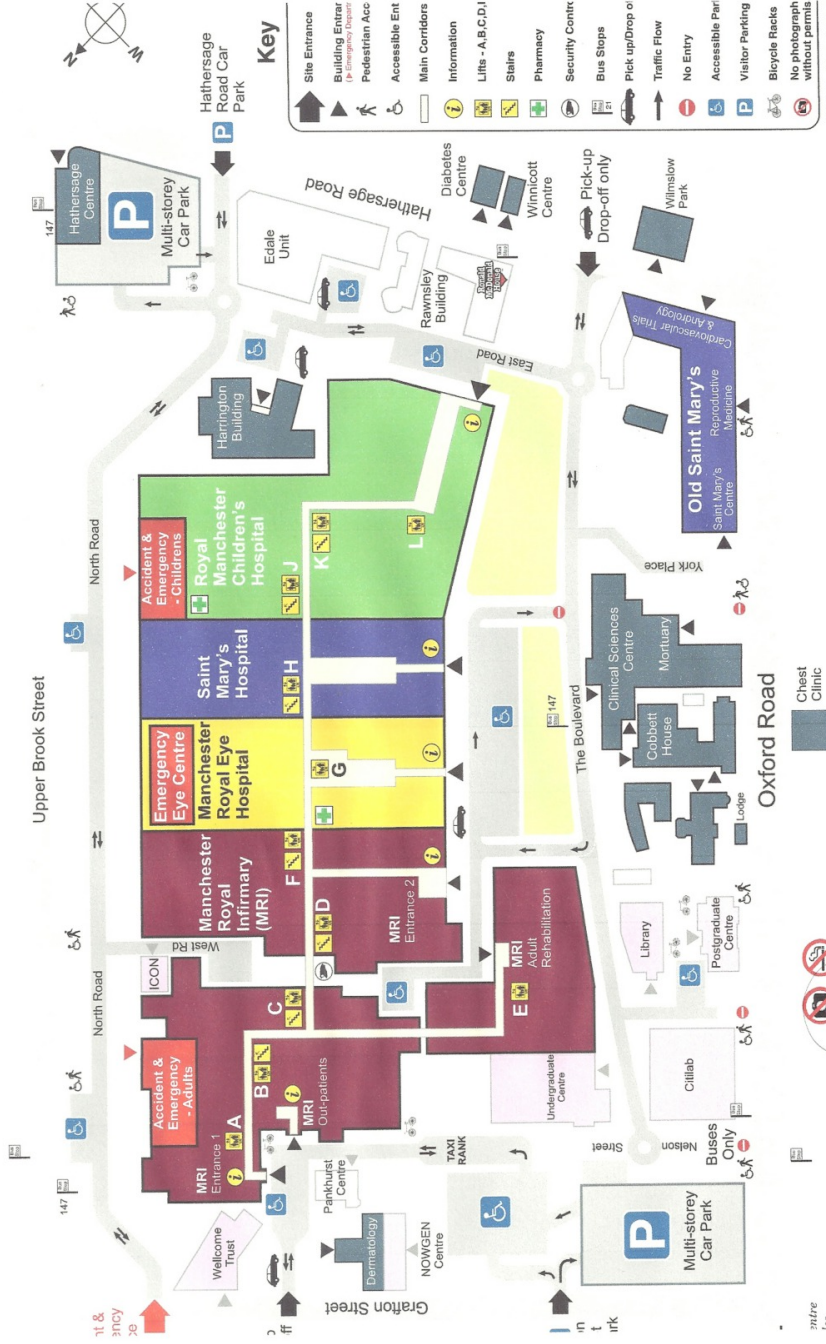


# Central Manchester University Hospitals

Central Manchester University Hospitals NHS Foundation Trust, Oxford Road, Manchester M13 9WL. Website: [www.cmfh.nhs.uk](http://www.cmfh.nhs.uk)

Tel: 0161 276 1176

Nominence



Please remember

Centre for



# Haemodialysis & Fistula's

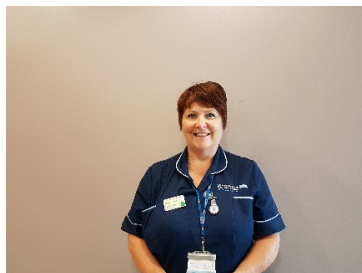
(This article is published with consent from)  
[www.kidneycareuk.org](http://www.kidneycareuk.org)

The 2017 PREM (Patient Reported Experience Measure) survey, co-ordinated by Kidney Care UK and the UK Renal Registry, had good and bad news for kidney units. While most of the 11,027 kidney patients completing the survey highly rated their overall care, many haemodialysis (HD) patients were dissatisfied with their experience of needling—i.e. how often the kidney team inserted needles with as little pain as possible. Satisfaction with needling also varied widely between kidney units.

“This highlights that vascular access is one of the most important—and challenging—aspects of kidney care. Vascular access is a patient’s lifeline because good dialysis depends on it. Access must be ready for the start of dialysis, and then looked after to make sure that it’s functioning correctly,” says Alayne Gagen. Alayne is the Renal Vascular Access Nurse Specialist for Manchester University NHS Foundation Trust (MFT), and recently became Co-Chair of the British Renal Society Vascular Access Special Interest Group (BRS VA).

Alayne recommends discussing vascular access as soon as possible — certainly when eGFR is declining towards 15 — and it should at least be broached in the pre-dialysis or low-clearance clinic. The prospect of dialysis can be unnerving, and Alayne believes that every patient deserves a great deal of empathy.

“Health professionals need to take a step back and understand each patient as an individual. Some people may not want to talk about access. This applies especially to those with acute kidney injury (AKI) or who have been diagnosed without warning with kidney failure and need to start dialysis immediately, as they have so much to absorb. And some patients do not feel ill even with very poor kidney function, while others see access as a step towards dialysis and feeling better. And every patient has lots of other concerns, such as the future of their family, job and other commitments,” she says.



## Fistula first

There are four types of vascular access, but an arteriovenous fistula (AVF) is the gold standard. One reason is that it gives a good blood flow, which increases the effectiveness of dialysis, in turn improving health and wellbeing. Alayne adds: “Since a fistula is made from your own blood vessels, you do not have a foreign body permanently inside you. Compared with other types of access, there is less risk of clotting and infection, so you are less likely to need hospital stays and antibiotics. A fistula also enables you to continue most of your daily activities. You can have a deep bath or a long, hot shower, and go swimming—none of which are advisable with a central venous catheter (CVC) or line.”

According to Alayne, the main drawback with a fistula is that it might not work, or can stop working: the vein can become narrow (stenosis) or it can clot and become blocked. It can also be difficult to balance the restrictions of a limited fluid allowance against maintaining the hydration needed for a good blood flow—a problem in very hot weather, or during any illness that causes diarrhoea or vomiting.

Some people also worry about the fistula's appearance. "Patients tell me that they do not want 'those lumps' on their arm. The usual cause of lumps or aneurysms is area puncture—i.e. the fistula is needled or cannulated in the same place every time. 'Rope laddering' or the needling along the length of the fistula is recommended and will help to reduce the likelihood of aneurysms," says Alayne.

Buttonholing is a newer method of needling that is less likely to cause aneurysms. Instead of sharp-pointed needles, blunt needles are inserted at the same two positions each time to create a tract or tunnel into the fistula—like the hole in the skin created by a piercing. It takes about six sessions to form buttonholes suitable for dialysis.

"At MFT, we train all our home HD patients to buttonhole. It can be difficult to use buttonholing in a dialysis centre unless the staff have received specific training. However, patients can learn the technique and do their own needling within the main unit—something we do encourage at MFT. This is because, in order to form the tracts, the same person must do the first six initial cannulations with the sharp needles, and we cannot always guarantee this in a busy dialysis unit," explains Alayne.

## **Fistula surgery**

When you are ready to go ahead with your access, the usual procedure is to be referred to a vascular surgeon for a consultation - at MFT the wait is four to six weeks. "It can then take up to six months from being referred before you can needle your fistula. In the meantime, if you have to start dialysis you will need a line. This highlights why your fistula needs to be created in a timely fashion," says Alayne.

At the one-stop appointment with the surgeon, your veins are 'mapped' with ultrasound to see if they are suitable for a fistula, either at the wrist (radial fistula) or at one of two positions at the elbow (brachial fistula). One of the latter may involve a second operation called superficialisation, which should be discussed during the consultation.

At MFT, the fistula operation takes place three to four weeks after the one-stop appointment, lasts for 30-45 minutes and is usually done under local anaesthetic. A general anaesthetic is possible if you cannot face being awake, but this means a longer wait for surgery because of the need for pre-operative assessment and possibly an overnight stay in hospital.

You can go home after the operation when the surgeon is happy with your recovery, usually after four to six hours with local anaesthetic. After your operation, you should not drive or lift heavy objects for two weeks. Your kidney unit should advise you when and how to start exercising your fistula arm to improve blood flow and help your fistula to develop.

From now on, check the appearance of your fistula and feel for the thrill (the buzzing sensation under the skin) every day. Contact your kidney unit at once if the thrill stops, or the fistula feels hot, looks red, or is painful.

"I strongly advocate that patients learn to be experts about their fistula. Sometimes I suggest that buying a cheap toy stethoscope so that you can get used to listening to sound of the thrill or bruit," says Alayne.

## Starting dialysis

At the follow-up appointment six to eight weeks after the operation, an ultrasound scan checks the depth, diameter and flow of blood of your fistula to see if it can be needled (called maturation). Should a superficialisation be needed, it will be booked after the follow-up appointment, and is generally done under a general anaesthetic. Pre-operative checks should have already been done, but if not, an appointment will be sent before the operation date is given.

The early days of needling a fistula are often a worrying time for patients. According to Alayne: "We sometimes cannot avoid infiltration (when a needle goes into the fistula and out the other side, or nicks the vein wall). If the vessel wall is still fragile, the fistula may blow - i.e. the area will swell and pressure needs to be applied quickly, as it will cause bruising under the skin. It is the job of professionals to support patients through this experience".

"Vascular access is a patient's lifeline because good dialysis depends on it"

Alayne stresses that pain should never be problem when needling a fistula or graft. "I always advocate that patients should have some form of local anaesthetic if they wish (at MFT we offer three types). Health professionals would not have dental treatment without anaesthetic and it is unacceptable to needle a fistula without offering pain relief, especially at the first of needling of the fistula," she says.

Unfortunately, fistula surgery sometimes fails and not everyone is suitable for a fistula or graft. Your artery walls may have become hardened due to deposits of calcium, while your vein can be too narrow. And sometimes blood vessels are too small or have been damaged due to other diseases like diabetes. This will be explained when you see the surgeon, who will then discuss your options for access.

According to Alayne, it is possible to dialyse long-term with a line, providing it is well cared for and is checked carefully at every dialysis. She also sees no objection home haemodialysis with a line as long as you have been thoroughly trained to identify and cope with any problems. Improving vascular access care

The BRS VA are working with colleagues to improve vascular access care across the UK. Initiatives include clinical practice recommendations to improve needling technique, tools to improve safety, and a national survey of the structure of vascular access services. "By optimising vascular access services throughout the UK, our aim is to raise standards, which will in turn improve patients' wellbeing and the safety of their kidney care," concludes Alayne.

## Janet's story

Janet Loftus is 59 lives in Manchester, and has been dialysing for five years. She dialyses at a hospital unit for four hours three times a week, and has started to self-care. At present, she sets up her dialysis machine and dressings table and is hoping to start inserting her own fistula needles.

Three months after starting dialysis with a line, Janet underwent her fistula surgery at the one-stop vascular clinic in Manchester. She says: "I hated dialysing with a line and could not wait to have it out and use my fistula."

After her operation, Janet exercised with a squeeze ball to strengthen her fistula, and still uses one every day to maintain the blood flow. In the early days of dialysis, Janet's fistula blew a few times, but since then there have been no problems.

Janet says: "My fistula is amazing: it gives me a higher pump speed, so I feel much better than with a line. I can also do more. Before my kidneys failed, I used to go swimming with my granddaughter and she was devastated when she found out I could not swim with a line. Now I have my fistula, she is happy that we are back in the pool.

## Renal Recipe

Let's Spring into shape for the Summer!!

Hopefully we can soon expect some better weather including a bit of Summer sunshine! For many it might be the time to start to focus on diet and lifestyle with the promise of eating healthier or starting a new fitness regimen?

Healthy eating choices start at grocery shopping. Supermarkets these days offer endless varieties, packet sizes, serving suggestions- all of which can be daunting and a bit like hard work.

Please see below for some top tips for when you go shopping:

Choose fresh ingredients as much as possible

Limit processed meats such as sausages, ham, salami and bacon and choose fresh meat, poultry and fish where possible

Limit packet/tinned/cuppa soup and choose carton soups or homemade soups

Limit readymade/microwave meals and other products and prepare your own meals from fresh ingredients as much as possible

Choose tinned fish in spring water or oil rather than brine

Look for tinned vegetables and pulses without added salt

Try to avoid high phosphate drinks such as Cola drinks, Dr Pepper, Oasis, hot milky drinks, beer, coffee, iced tea, drinking yoghurt, milkshakes, energy drinks

Choose Weetabix, Rice Krispies, porridge oats rather than instant porridge, Cheerios, Coco Pops

What about trying this tasty easy to prepare recipe.

Spring Stir fry – serves 2

Ingredients:

150g lean lamb steak

8 spring onions

2 cloves garlic – crushed

1 tsp grated ginger – fresh or from jar

1 large carrot

½ red pepper

½ yellow pepper

100g bean sprouts

Marinade for meat = 2 tablespoons apple juice, 1 tsp spoon soy sauce, 1 dsp sweet chilli sauce and 2 tsp corn flour.

## Method:

1. Cut lamb into thin slivers and place in marinade. Leave for at least ½ hour.
2. Chop all the other ingredients into matchstick size pieces roughly the same size.
3. Heat 1 tbsp oil in a wok or large frying pan
4. Add lamb to pan drained of marinade and fry for about 5 minutes until the meat is sealed and browned.
5. Add garlic, onions, ginger, peppers and carrots to pan and fry for a further 5 minutes
6. Add bean sprouts and cook for 5 min
7. Add remainder of marinade and cook until reduced down
8. Serve with boiled noodles or rice



# Patientview

*A number of patients have asked me: what is Patientview ??*

PatientView allows renal patients to view their latest test results online, along with clinic letters and information about diagnosis and treatment. You can set up alerts, monitor your symptoms and download your records. You can view PatientView from anywhere in the world and share your information with anyone you want.

PatientView is available to patients if their hospital or renal unit has signed up to it. At present that is most renal units in the UK, plus it is now becoming available in some places for patients with other conditions.

## **What's needed?**

Your local unit or health organisation must have joined. MRI has.

PatientView started out as a service for kidney patients in the UK, but can now work for others too.

## **How does it work?**

Information comes directly from existing records, for example hospital and GP records, or may be entered directly or via other apps. Secure messaging functionality is included.

You can find out more information at [www.patientview.org](http://www.patientview.org)

or contact 0161 276 4414

# **BRITISH TRANSPLANT GAMES 2018**

## **BIRMINGHAM**

### **02 - 05 August**

## **Manchester Adults Team Report**

The Manchester Adults Team includes kidney/kidney-pancreas transplant recipients and bone marrow/stem cell transplant recipients (see also eligibility conditions at the end of this article) from Lancashire and South Cumbria, Manchester, Greater Manchester and North Cheshire or further afield as long as you were transplanted or receive your post-transplant care in the region.

We welcome new members of any age or sporting ability, it might even inspire you to take up something new! It is a unique opportunity to share in giving thanks to our donor families and living donors, demonstrate the healthy and active lifestyle that can be achieved after transplantation, raise awareness of organ donation and bone marrow/stem cell donation and to celebrate the Gift of Life!

Over the four days athletes compete in age groups across a range of sports from Archery to Volleyball and many in-between and can take part in 4 competition events across the 4 days of the Games, limited to one sport per day (look at the full schedule through the website links provided below). So in sports with multiple events you can enter more than one event in that sport and these will count towards your 4 events. The competition sports are:-

Archery; Badminton Doubles (Male and Female); Lawn Bowls; Cycling (5km TT and 10km RR); Darts; 6-A-Side Football; Golf; Snooker; Squash; Swimming (50m Back, Breaststroke, Butterfly and Freestyle, 100m Breaststroke and Freestyle; 200m Freestyle and a mixed 4x50m relay); Table Tennis (singles); Tennis (singles); Volleyball and Track and Field. The Track and Field includes 100,200,400,800 and 1500 metres; 4x100m mixed relay; 3km walk; Ball Throw; Discus; High Jump; Javelin; Long Jump and Shot Putt.

The programme also includes events for Live Donors and Donor Families, this year these are Track 100 metres; Ball Throw; Long Jump; Swimming 50 metres Freestyle; Badminton Doubles; Obstacle Relay. Entrants can take part in 3 of these events.

In addition there is a social sports programme which you and your supporters can enter and so get more involved in the weekend. These include 6-A-Side Football; Golf; Adult Short Tennis; Basketball (3 on 3 format) and Netball.

The weekend is rounded off with a fantastic social celebration event on the Sunday evening, which this year will be at the fabulous Celtic Manor Resort venue.

It's the taking part that counts and the whole experience is a celebration and is about fun, friendship, great camaraderie between teams and living life to the full! We very much welcome new team members so if you are interested in taking part please do get in touch.



## **British Transplant Games Eligibility Conditions:-**

### **Organ transplant:**

Individual must have received an organ from someone else and be on immunosuppressants post-transplant.

### **Bone Marrow recipients:**

Individuals who have received a bone marrow or stem cells transplant from a donor and are on, or, have been on immunosuppressants post-transplant.

### **Organ Failure post-transplant:**

Eligibility for participants with a failed organ transplant that is stable on the following supportive therapies –

Kidney –on dialysis

Pancreas – by insulin

Heart – artificial heart pump

Small bowel – total parenteral nutrition

In all cases of failing transplanted organs participation will depend on residual capacity and current physical fitness.

**You will compete in the age group that corresponds with your age on 30th June.**

Adults 18-29

Seniors 30-39

Super Seniors 40-49

Veterans 50-59

Super Veterans 60-69

Super Super Veterans 70+

Contact Details:

Zoë Dixon MBE

Manchester Adults Team Manager

e-mail: [zoe\\_dixon@tiscali.co.uk](mailto:zoe_dixon@tiscali.co.uk)

[www.britishtransplantgames.co.uk](http://www.britishtransplantgames.co.uk)

[www.transplantsport.org.uk](http://www.transplantsport.org.uk)

# **The Manchester Adult Athletes competing at the World Transplant Games**

## **Newcastle Gateshead, UK**

### **17th – 24th August 2019**

This August Newcastle Gateshead will warmly welcome approximately 3000 participants from around 70 countries, aged from 4 to 80+ for the World Transplant Games 2019. The World Games are held every two years and represent the largest organ and bone marrow/stem cell transplant awareness event in the World and is our Transplant Olympics!

The following Athletes from the Manchester Adults Transplant Games Team will be competing for Great Britain and Northern Ireland. We would all like to thank both the MARIKA and Kidneys for Life for their generous support to help us to represent our country on the world stage whilst promoting awareness and celebrating the Gift of Life. As the UK is the host nation, it will be particularly special to compete in this time.

**Bernard Capper** – I suffered from hereditary Polycystic Kidney Disease which caused my kidneys and liver to grow rapidly, rendering me inactive, in constant pain and with my weight ballooning, as a consequence I had given up sport at the age of 40. I had both kidneys removed and then in 2015 was blessed to receive a kidney transplant from an altruistic donor.

After taking part in my first British Transplant Games in Liverpool 2016 and seeing what other transplant recipients could achieve, I realised I could honour my donor and make the most of this amazing gift by taking up sport once again. Now aged 57, I have been selected to compete in both Football and Volleyball at my first World Games. I hope to inspire other transplant recipients to become active and encourage more people to support organ donation whilst proving how life changing this gift can be.

**Connor Ellis** - I received my kidney transplant in 2004 when I was 9 years old and attending the British Transplant Games over the years, as a child and now an adult, has been a big part of my life. I've met some amazing people, and made many friends. Now that Archery is part of the World Games, I'll be competing for the first time this year. I look forward to continuing to support organ donation awareness and meeting even more like minded and supportive people from around the world!

**David Jones** - This will be my second World Games after receiving my stem cell transplant in 2014. I did well in Malaga two years ago, achieving a Gold, Silver and Bronze in racquet sports. I'm also adding the 5km run to my usual Squash, Tennis and Badminton this year and am optimistic of doing well again. The Games are a magnificent showcase of what can be achieved by people fortunate enough to be given a second opportunity in life, yet there are still many waiting to be given this chance and I want to do all I can to raise the profile of organ donation of all types. Stories from fellow athletes are humbling and an inspiration in overcoming adversity to make the best success of their new lives.

**Elizabeth Morris** - When I was 17 months old I was diagnosed with acute lymphoblastic leukaemia. After fighting the disease for several years I had a bone marrow transplant at the age of 5. This is the 6th World Games that I have been selected to go to, with great success in previous Games. It is a privilege to represent my country and promote organ and tissue donation. I will be competing in the Cycling 10km Time Trial and 30km Road Race; the 5km Road Run and two individual Swimming events as well as the relay and also the Virtual Triathlon. My donor gave me a second chance at life, you could help give someone theirs.

**Frances Wright** - 2019 marks the 40th Anniversary of my kidney transplant. I was 14 when I received the call that a tragic car accident of a young girl from Newcastle meant that I had the opportunity of a transplant. I have competed in 3 previous World Transplant Games winning gold medals in swimming and athletics and still hold a world record in the 50m backstroke from Vancouver in 1993 (my last Games). I couldn't resist competing once more in this year's Games - in the 40th year of my transplant AND in the birth place of my kidney, Newcastle. I was delighted to be selected for the team in athletics.

Khalid Bostan - I received my kidney transplant in November 2014, to say that my family and I will always be eternally grateful is an understatement. Over the last 4 years it has given me my life back, as well as giving a father back to my children. This will be my second World Transplant Games, I'm very proud to have been selected again and am looking forward to once again representing Team GB. My chosen sport is Badminton. I'm hoping to come home with a medal, having won Silver in the British Transplant Games (Liverpool 2016) and a Bronze (Birmingham 2018). As well as all the other competitors both donors and recipients, I want to show that transplants do work and give thanks to my donor and donor family as well as the fantastic NHS teams that make it all happen.

Sam Clarke - I received my kidney transplant in 2003. I have competed in two previous World Games (Argentina and Malaga) and two European Transplant Games (Finland and Sardinia) in the past 5 years and with some medal success. I am proud to have been selected again as an athlete to be representing Team GB in our home country and also to have the honour of being the Ten-Pin Bowling Team Captain. I will also be competing in Petanque and Discus and hope to continue with my successful performances, make new friends and raise awareness of organ donation.

Stewart Jones - In 2008 I received a kidney from my amazing Dad. From that moment I knew it was up to me to look after my gift and was determined to get back to full health. I took up running and ran my first half marathon at the Great North Run in 2013. I enjoyed it so much I ran my first marathon in 2014 and since then have run a total of 11 marathons. I have competed at four British Transplant Games since 2014 winning Gold, Silver and Bronze medals in Track and Field. I feel very honoured to have been selected to represent Team GB in Athletics at my first World Games and back where my running journey started, in Newcastle. I aim to do my Dad proud and show the world what organ donation can achieve.

Wesley Winder – I received a live donor kidney transplant from my Dad in January 2018 and took part in my first British Transplant Games just 6 months after that, in Birmingham, where I took part in the Football tournament and won a Gold medal with the winning team. I enjoy sport and Football in particular so was delighted to be selected to represent Team GB at my first World Games this year where I hope we will make the finals of the Football and come home with a Gold medal once again!

Zoe Dixon MBE - I received my kidney transplant in 1999, so this is my 20th Anniversary year and what better way to mark it than to give thanks to my Donor and Donor Family for the Gift of Life at the World Transplant Games. I will be competing in the Cycling 10km Time Trial, 30km Road Race and potentially also the 20km Team Time Trial. This will be my 9th consecutive World Games, having first competed in 2003 and I am honoured to again be selected to compete for Team GB. I hope to maintain my record of winning medals at every World Games but most of all I'm just always so grateful that I'm actually able to take part and continue to promote awareness and demonstrate the benefits of transplantation.

Wish us luck and I will be sure to let you know how we all get on!

Zoë Dixon MBE

<http://worldtransplantgames.org/>

# Pre-dialysis meetings

## 2019

These are informal meetings where patients and their carers can find out more about the various dialysis options and talk to “expert patients” about their experiences of living with kidney disease.

### **Tues 30<sup>th</sup> July**

18:00-20:30 Post Graduate Building. Staff - Lindsay, Chris, Susie

### **Thurs 24<sup>th</sup> October**

13:30-16:00 Mint Seminar Room. Staff - Lindsay, Jackie, Krisha

**Pre dialysis team 0161 276 4440**

# Dates for your diary 2019

**UK Kidney Week** - 3rd – 5th June 2019 Hilton Brighton  
Metropole

**MRI Annual Renal remembrance service** - Sunday 14th July  
2pm @ the Pier 8 Room at the Lowry Theatre, Manchester

**MRIKPA AGM** - Sunday 21st July @ MRI (further details in the  
next newsletter)

**British Transplant Games** - Newport, Wales, 25 – 28 July  
2019

**World Transplant Games** - England - Newcastle - Gateshead  
17 – 24 August 2019

# World Kidney Day

## 14 March 2019

On World Kidney day myself and Zoe Dixon the Manchester Adult Transplant games team manager helped Carol Boham and Ann Lewis on the Kidneys for Life stall opposite the CAPD suite

We helped sell homemade cakes made by nurses and sell raffle tickets to raise money for Kidneys for Life. It was also an opportunity to raise awareness of kidney disease with other patients and visitors to the hospital.

Kidneys for Life also had a stall in the children's area of MRI also selling cakes and raffle tickets.

I'm pictured with Carol later on in the day, when all the cakes had gone!!



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

Membership of the Manchester Royal Infirmary Kidney Patients' Association (MRIKPA) 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 and receive its free electronic newsletter via email
- I do not want to be contacted by email but consent to be contacted 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 for my details to be sent to the National Kidney Federation

My Name

E-mail address

or

Address

Postcode

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***

Mr.D.J. & Mrs.J.B. Hudson £10.00 7.12.18

Alan Proctor in memory of Lynn Proctor-Bradshaw £100.00 12.12.18

In memory of Mr. John Ashton £605.00 7.2.19

Paypal Giving Fund 7£0.00 4.2.19

In memory of Mr. John Elliott £880.00 28.2.19

Jim Smith £100.00 28.2.19

Paypal giving Fund £18.00 28.2.19

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.**





## 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.*

# Notes

# 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)

**Renal Pharmacy Service** 07817136791

**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

# 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*