# NEWSLETTER

I'm FREE Please take one



Winter 2018

Manchester Royal Infirmary
Kidney Patients' Association
(MRIKPA)

Registered Charity Number 516871



# Content

2	Content	34	Quiz answers
3	Committee members	37	Pre-dialysis meetings 2019
4	Hello from your Editor	38	Dates for your diary
5	Hello from your Chairman	39	Dr Simon Jenkins MBE
7	MRIKPA - AGM	43	TRENDS update from MRI senio management
15	Travel Insurance	47	Membership form
17	British Transplant Games	48	Donations & fundraising
20	NHS Blood & Transport	49	Gift Aid
23	Renal recipes	50	Contact numbers
26	London to Paris bike ride by Guy Hill	51	Notes
29	Parachute jump	54	What we do
30	Quiz questions		
33	Electronic Newsletters		

# **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.c o.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

# Hello from your Editor

Dear all,

It's the Winter edition of the newsletter yet again, it comes around all too quickly these days.

Included in this edition we have the details of our AGM held in July, a report from the MRI team manager on the British transplant games, Guy Hill's London to Paris bike ride adventure, an inspiration to all us non-cyclists, renal recipes plus much more. As ever I hope you enjoy reading it.

To all patients and carers a very happy Christmas

Mike mikejm.kewley@gmail.com

07530 452190 MRI Kidney Patients' Association



Registered Charity Number

# Hello from your Chairman

### Dear All

For many of us Christmas is a happy time, but for dialysis patients the routine goes on, as does the lottery that is transport, to and from units. There came a point two years ago when the cry was that surely no one can do it as badly as Arriva, so the contract was handed to NWAS.

Guess what, we have reached that point again, different logo but the same people. Hiding behind a very generous 90 minute wait contract, they excuse themselves of patient misery, as time and time again a patient experiences delays in drop off and pick up. However, there is a new sinister twist in the transport woes, at the time of writing, dialysis patients in the York area have been 'reassessed' with regard to their eligibility for hospital transport to get to dialysis.

This is now the second 'attack' on dialysis patients by a CCG, Cornwall being the first and leaves us all wondering when it might come to an area near us. Fighting the injustice of it is proving difficult as neither NHS England nor the Dept of Health give us the 'right to Transport' and the local CCG confuse us with other one off PTS users and hide behind language like 'applying the rules' or' based on need'.

Dialysis is a proven life saving medical intervention that has to be applied on a regular basis, namely 3 times a week. Patients have no option but to attend and the acknowledged side effects can leave patients unfit to drive or too weak to use public transport. Removing their right to free assisted transport is both immoral and ignorant of how demanding this form of treatment is on a patient's quality of life.

Imagine facing the drama of dialysis and the difficulty of achieving enough income to support you and now facing a £300 transport bill each month.

This battle of 'morality v austerity' is being fought by our excellent National charities namely NKF and Kidney Care UK, who have access to Parliament and NHS England. Supporting and promoting them is the best way we can help stop this becoming an 'ugly precedent 'that other CCGs use to make unpalatable decisions about our services.

On a brighter note, a way around dialysis transport is to do it at home. Not for everyone, but the growth of smaller home dialysis machines is staggering. On display at the Home Haemodialysis Conference in September, were 5 smaller machines using the cassette technology.

Added to that was the fascinating talk by the very charismatic American doctor behind the artificial kidney that is small enough to be planted inside a patient. His aim is to make this available within 5 years and he is on course. He thinks he can achieve this because he is not inventing anything new, just re-thinking existing technologies and adding known bioscience. The resultant first generation kidney will not do all the subtleties of actual kidneys, like hormone and salts control but concentrate on filtering out excess water. For someone where transplant is not an option, it could be quite a breakthrough

As I threatened, myself in late August, along with 13 other Kidneys for Life supporters, we completed the London to Paris bike ride, inside this magazine is the story of the trip. The aim was to inspire people on dialysis to push their horizons and ambitions a little further, 'by doing what you can, not what you can't'. There are plenty of smaller events to try run by Kidney charities, either sedate or energetic, all designed to give you a sense of achievement and sociability that can get lost in the fog of Kidney disease.

Wishing all patients, carers and staff a Happy Christmas

# Chairman Guy Hill Helenandguy\_hill@hotmail. com

Tel: 01565 654382



# MRIKPA 2<sup>nd</sup> Annual General Meeting Minutes of the meeting held on 2<sup>nd</sup> July 2017.

**Present:** S. Rosser, G. Hill, A. Sen, J. Murphy, H. Murphy, W. Iqbal, J. Richardson, B. Taylor, P. Griffiths, K. Smith, M. Kewley and S. Caddick.

### 1. Apologies for Absence:

G. Burgess.

### In attendance: L. Ebah (renal directorate consultant) and M. Bennett (secretary)

New patients were introduced to the meeting, giving details of their renal journey. Introductions were made to the meeting for the benefit all new attendees.

## 2. Minutes of the MRIKPA 1st AGM held on 26th June 2016:

Accepted as an accurate record.

Proposer: Janet Richardson.

Sec: Wajid Iqbal.

### 3. Matters arising (not covered elsewhere on the agenda):

Psychologist: has now been appointed and the role has been split between a consultant part time psychologist (without previous renal experience) and a counsellor.

Leonard has been working closely with MK and GH, with regard to TRenDS, his presentation will explain where the process has got to, so far.

Newsletter:

- Reduced to 3 times per year.
- Reduction in number of magazines issued as Salford for example has their own magazine, so their need for our magazine has reduced.
- Next plan is to send digital copies of the magazine for consultants.

MB will inform committee about the change in constitution with regard to Edwards Veeder (accountants).

### 4. MRIKPA Committee Annual report: 2016/2017:

GH: presented his report to the meeting. See attached.

• One minute silence was held in memory of Simon Jenkins and Dennis Crane in grateful thanks for their work and commitment to the lives of renal patients.

#### 5. MRIKPA Annual Accounts: 2016/2017:

Janet Richardson presented the accounts to the AGM. She reported:-

- She took the AGM through the report. Income in excess of £8000, through a legacy and 'Just Giving'. Expenses include GMKin, British Transplant Games and Renal Social Workers and Printing and distribution of magazine.
- She explained about the auditors. Edwards Veeder no longer audits charity accounts.
- There was a discussion about GMkin. The site is developed, but it is not yet activated.

Proposer: BT Seconder: WI

### 6. Election of MRIKPA officers and committee members for 2017/2018:

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.

Proposed: S. Rosser Seconded: K. Smith

Further nominations were requested from the floor. There were none received.

### Agenda item for next meeting

### 7. Extraordinary item: auditing of accounts:

"The committee proposes amendments to the constitution at point 6, in line with the changes in auditing rules from the Charity Commissioners. The constitution and its aims will not be fundamentally changed in any way."

There was a discussion. Proposed: S. Caddick Seconded: H. Murphy

### 8. Any other urgent business:

The MRIKPA has received a letter from S. Jenkins' daughter. She is wanting to fund raise on behalf of the MRIKPA. She has asked for any suggestions with regard to: -

- a sponsored event and
- where the money raised might go.

Discuss this at the next MRIKPA meeting.

### TRenDS- L. Ebah

L. Ebah presented his report about the arrangements so far. See attached.

After the presentation, AGM members raised issues about: -

- Staffing and the Stockport model
- Lines versus fistulas
- The efficiency of the start of dialysis
- Lines do not provide quality dialysis, committee would like to see some research/data to show the difference, for patients.
- We have to have faith in what they are wanting to achieve.

# **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.

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.

# MANCHESTER ROYAL INFIRMARY KIDNEY PATIENTS ASSOCIATION BALANCE SHEET AT 28 FEBRUARY 2018

## **Accumulated Fund**

28.2.17		28.2.18
98832.33 -8062.29 20741.01	Balance sheet at 1 March 2017 Gain/deficit for the year to 28.2.18 Charity walk funds	91210.04 -6672.03 20301.01
111511.05	Represented by:	104839.02
	Nat West Bank PLC	
1745.53 109725.52	Current Account Deposit Account	5050.41 99748.61
	Stamps	
40.00		40.00
111511.05		104839.02

Accounts approved

Chair mrinst

10/5/18

# MANCHESTER ROYAL INFIRMARY KIDNEY PATIENTS ASSOCIATON RECEIPTS AND PAYMENTS ACCOUNT FOR YEAR ENDED 28.2.18

28.2.17	RECEIPTS	28.2.18
8443.96	Donations	3,307.47
41.92	Bank interest and bonuses	23.09
0	Refund of bank charges	12.27
0	Gift Aid	1,345.13
8,485.88		4,687.96
	PAYMENTS IN PURSUIT OF ASSOCIATION'S OBJECTIVES	
2,000.00	Amenity Fund	2,000.00
276.00	NKF Conference Subsidies	281.00
4,712.99	<b>Newsletter Printing &amp; Distribution Costs</b>	6,952.79
830.74	Books & Equipment for MRI & Hope NHS	-
216.00	Just Giving Charges	216.00
3,200.00	Transplant Games Grants	200.00
300.00	Holiday Dialysis	440.00
4,000.00	Website Development	_
•	Trends Meetings	412.20
15535.73		10,501.99
	ADMINISTRATION COSTS	
99.06	Insurance	101.33
101.89	Postage, Stationery & photocopying	77.38
760.00	Secretarial costs	660.00
51.49	AGM costs	19.29
1,012.44		858.00
<u>-8062.29</u>		- 6,672.03

### TREASURER'S REPORT FOR THE FINANCIAL YEAR ENDING 28TH FEBRUARY 2018

### Income

We have received £3307.47 in donations this year, including £350.00 in memory of our previous chairman, Dr. Simon Jenkins. This donation has paid for the new TV in the dayroom in ward 9. I have also amended our charity's information with HMRC and have claimed Gift Aid of £1345.13, which represents the last three years. HMRC transferred this amount to our bank in June.

The interest rate on our Business Reserve Account was increased in September from 0.01% to 0.05%. The amount we received each month previously was approximately 90p, now it is approximately £4.

#### **Expenditure**

Our expenditure this year is £11,359.99. This includes our usual major costs:

Newsletter printing and distribution £6952.79

Amenity fund grant £2000.00

The newsletter costs are more than last year because we have paid for three newsletters, whereas last year we only paid for printing for two. This was because of the payment dates for the Questbond invoices.

This year, our chairman has incurred expenses amounting to £412.20 for his attendance at numerous Trends meetings. The committee agreed that he should be reimbursed as he has been an important voice for the patients we represent.

We have had to transfer £10,000.00 from our Business Reserve Account into the Current Account in order to meet these expenses. The Reserve Account balance is currently £99748.61, of which £20401.01 represents the charity walk funds. This fund has been reduced this year because we have paid £340.00 for patient holidays.

We have made a loss this year of £6672.03 but trying to reduce our costs is challenging. We have reduced the grant to the Amenity Fund to £300.00 per quarter with effect from April 2018. We have already reduced the number of newsletters from four to three per year. Reducing to two a year is an option, but would need some discussion before a decision is made. Newsletter distribution costs are quite high at £1475.79 this year, which is approximately 21% of the total newsletter cost. Trying to reduce that cost would help.

Our Reserves Policy is to have the equivalent of three years expenditure in reserve and we are currently well within that amount, but we must continue to review our expenditure.

Janet Richardson

MRIKPA Treasurer

12th April 2018

# Chairman's report 2017

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 is further fire-proofed. However, from the open day, it is clear that patients once settled can enjoy an excellent facility.

We celebrated 50 years of transplants in March, put together by the amazing Kidneys 4 life team and it was impressive to see the turnout of patients at the Principle Hotel to show their appreciation 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 compromised 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 14th and is open to all and also gives you a chance to feedback into your association.

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.

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. Panicking 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 Guy Hill

# **Holiday Insurance**

This information has been reproduced from the National Kidney Federation Website . where you can always find the most recent information <a href="http://www.kidney.org.uk/help-and-info/holidays/holidays-tips-insure/">http://www.kidney.org.uk/help-and-info/holidays/holidays-tips-insure/</a>.

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.

co.uk	Specialise in travellers with medical conditions  Worldwide  Europe/America/Canada  Europe  UK, Europe & Worldwide. Tel: Mon-Fri 8.30 am - 5.30 pm (Sat 9 am - 12 noon)
co.uk	Europe/America/Canada  Europe  UK, Europe & Worldwide. Tel: Mon-Fri 8.30 am - 5.30 pm (Sat 9 am - 12
co.uk	Europe  UK, Europe & Worldwide. Tel: Mon- Fri 8.30 am - 5.30 pm (Sat 9 am - 12
co.uk	Europe  UK, Europe & Worldwide. Tel: Mon- Fri 8.30 am - 5.30 pm (Sat 9 am - 12
co.uk	Europe  UK, Europe & Worldwide. Tel: Mon- Fri 8.30 am - 5.30 pm (Sat 9 am - 12
co.uk	UK, Europe & Worldwide. Tel: Mon- Fri 8.30 am - 5.30 pm (Sat 9 am - 12
co.uk	Fri 8.30 am - 5.30 pm (Sat 9 am - 12
ance.com	All types of medical conditions up to a high level of severity.
ince.	
m	
	Kidney Transplant patients and patients with Kidney Stones
_	ravel insurance

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

# BRITISH TRANSPLANT GAMES 2018 BIRMINGHAM 02 - 05 August Manchester Adults Team Report

The Manchester Adults Team enjoyed a fantastic weekend at the Transplant Games in Birmingham and this summer's glorious sunshine actually stayed with us too! With both experienced and new competitors in the team we had 16 Transplant competitors and 1 Live Donor competing in 32 different events across 14 sports and with wonderful encouragement given by our supporters who themselves were able to take part in many social sports on offer. The team achieved a total of 29 medals (8 Gold, 13 Silver and 8 Bronze) over the four days and medals or not each and every competitor is truly 'Winning at Life!'

On the first evening all the teams paraded through Birmingham city centre into the Opening Ceremony, held in the stunning Symphony Hall, where the record for the number of people with transplants in one room was broken with a new Guinness World Record of 723 (still going through the intricate verification process as I write this). The surprise special guest for the evening was the amazing comedian Jasper Carrott OBE, who was hilarious as ever!

The four days saw transplant athletes compete in a range of sports from Archery to Volleyball and many in-between including Cycling, Lawn Bowls, Swimming, Athletics, Darts, Snooker, Ten-Pin Bowling, Golf, 6 A-side Football and various Racquet sports. There were also social events for supporters, such as the Football, Golf, Basketball, Netball and the Donor Run.

The Games Village set-up with campus accommodation and the majority of sports being held using Birmingham University sports facilities made for a magnificent atmosphere and enhanced the social and networking aspects of the Games including an outdoor festival with a BBQ and Hog Roast on the Saturday evening of the Donor Run. This was my 18<sup>th</sup> consecutive British Transplant Games and the hosts at Birmingham University certainly made it one of the best yet. The weekend culminated with a Gala Celebration event held at the International Convention Centre.

Very well done to all our competitors this year:-

Connor Ellis; David Jones; Beth Morris; Guy Hill; Holly Loughton; Judith McEwen; Juliet Lewis; Kelly Chadwick; Khalid Bostan; Mark Smith; Paul Reynolds; Sam Clarke; Scott Mackenzie; Stewart Jones; Zoë Dixon; Wesley Winder and his Dad and Live Donor Philip Winder. Also to Lesley Dunn who could not compete due to injury but still came along to support us, thank you!

On behalf of the whole team I would also like to say a massive thank you to our sponsors this year. To Kidneys For Life for our fabulous new team polo shirts and to Kidney Care UK for funding all the competitor registration fees and helping with our accommodation costs. Your support and generosity made such a difference to the team, helping each and every one of us to take part.

The whole team spirit is fantastic and like all the competitors, I'm always so grateful that I am actually able to take part and it is only possible because of the brave decision a family made to donate their loved one's organs. To compete is to give thanks to our donor families and living donors, demonstrate the benefits of transplantation, raise awareness of organ and bone marrow/stem cell donation and to celebrate the gift of life.

Next year's British Games will be held in Newport, Wales, 25 – 28 July 2019. We very much welcome new team members so if you are interested in taking part please do get in touch with me. I can guarantee you will enjoy the most amazing experience that is the Transplant Games!

The World Transplant Games is to be hosted in the UK, NewcastleGateshead 17 – 24 August 2019.

Zoë Dixon MBE
Manchester Adults Team Manager
Tel: 07780858558
e-mail: zoe dixon@tiscali.co.uk

www.transplantsport.org.uk www.britishtransplantgames.co.uk





# NHS - Blood & Transplant

# Pre-Implantation Trial of Histopathology In renal Allografts (PITHIA)

28th September 2018

# **Dear Kidney Patient Associations,**

We are writing to inform you about a new clinical trial for kidney transplantation – which is called the PITHIA trial. All the kidney transplant centres in the UK are taking part in this trial and it will introduce a national biopsy service (for the assessment of kidneys, prior to transplantation, from deceased donors aged 60 years or older). A biopsy is where a small sample of the kidney tissue is taken so that it can be examined under a microscope. This biopsy will happen at the donor hospital and before the kidney is transplanted.

# Why are we doing the PITHIA trial?

The aim of PITHIA is to allow doctors to perform higher numbers of good quality transplants using kidneys from older donors. Many potential kidney transplants are from donors aged 60 years or older, and many of the kidneys from these donors are not used (due to worries about how these kidneys may work). But we are aware that age alone is not a good predictor of kidney health and so many good kidneys may be discarded rather than transplanted. The PITHIA trial will allow doctors to look at each kidney in more detail (using a biopsy). The biopsy service will hopefully allow doctors to identify more good kidneys for transplantation.

# **Key points:**

- Doctors will be providing information about the trial to patients on their kidney transplant waiting list.
- Not all kidneys (from donors aged 60 years or older) will be biopsied this will only be performed where the transplant surgeon thinks it is necessary.
- The biopsy will take place before the recipient is called into hospital.
- If a biopsy has been performed on a kidney, this will be discussed with the recipient before they consent for the operation.
- This trial does not affect the recipient's right to decline any organ that they feel is inappropriate.

Clinical Trials Unit

Long Road

Cambridge

CB2 0PT

The trial will start on 1st October 2018 and will last for two years. Every four months a randomly-chosen group of UK kidney transplant centres will be given access to the national biopsy service (PITHIA is a 'stepped-wedge cluster randomised trial'!). We will inform your group again once your local transplant centre has the biopsy service.

By the end of the trial, all centres will have the biopsy service, and we will then compare the before and after the biopsy service was made available. We anticipate that this comparison will show that biopsy availability increases the use of kidneys from donors aged 60 years or older by about 11% (which would mean an additional 120 kidney transplants could be performed in the UK each year).

If the trial results show that biopsies are beneficial, we will present the case to the National Health Services England, Scotland, Wales, Northern Ireland) to request funding for pre-transplant biopsies – so that they become standard practice. Biopsies are already in routine use at Addenbrooke's Hospital (Cambridge), which has provided the evidence-base for the PITHIA trial.

We would appreciate it if you could help us by sharing this information with all members of

your support group, and on social media where appropriate. Further information about the trial can be found on the website (www.pithia.org.uk) or by contacting PITHIA@nhsbt.nhs.uk.

Kind Regards,

**Gavin Pettigrew** 

**Chief Investigator** 

**Emma Laing** 

Trial Manager

# **Kidney Kind Christmas Recipes**

## **Cheese and Onion Pie**

(Serves 4)

# Ingredients

# Pastry:

450g/1lb plain flour
2 tsp baking powder
120g/4½oz unsalted butter
1 egg yolk
50g/2oz parmesan cheese, grated
120ml/4fl oz water
1 egg, beaten, for glazing

## Filling:

1 medium potato, peeled, cut into cubes and par-boiled 2 onions, finely sliced 1 tbsp plain flour 50ml/2oz whole milk 50ml/2oz double cream 150g/5½oz mature cheddar cheese, grated ½ tsp English mustard ½ tsp cayenne pepper Freshly ground black pepper



### Method

- 1. For the pastry, rub together the flour, baking powder, salt, butter and egg yolk in a bowl until the mixture resembles breadcrumbs. Add the grated parmesan and stir together.
- 2. Add the water, mixing continuously until the mixture forms a dough (you may not need to use all of the water). Roll the dough into a ball, wrap it in cling film and chill in the fridge for an hour.
- 3. Meanwhile, par-boil your potato pieces, drain and set aside.
- 4. Separately boil the onions for 2-3 mins, or until soft and drain well.
- 5. Add flour to onions in the pan and stir well. Add the milk and cream and stir over a medium heat for 3-4 minutes or until smooth and has thickened slightly. Add the cooked potato pieces, grated cheese, mustard and black pepper (to taste), stir well and set aside.
- 6. Preheat the oven to 180C/Gas 4 and grease a deep pie tin with butter.
- 7. Roll out two thirds of pastry ball onto a clean, floured work surface. Using the rolling pin, lift the pastry and lay it over the pie tin to line the base and sides. Gently press the pastry into the corners of the tin, trimming off any excess, then prick the base of the pastry case several times with a fork.
- 8 Bake the pastry for 10-15 minutes, until golden-brown. Remove from the oven and set aside to cool. Once cool, pour the pie filling into the pastry case.
- 9 Roll the remaining pastry out onto a clean, floured work surface. Brush the rim of the cooked pastry case with some beaten egg and place the pastry lid on top of the pie. Seal the pastry lid to the pastry case using a fork.
- 10. Brush pastry lid with remaining beaten egg, then transfer to the oven and bake for 25-30 mins, until golden-brown.

# Trifle (Serves 6)

# Ingredients Base

500g/1lb 2oz frozen fruit (raspberries, blackberries, strawberries) 50g/2oz caster sugar, or more to taste 500ml/18fl oz cloudy apple juice 5 sheets leaf gelatine 250g/9oz madiera cake

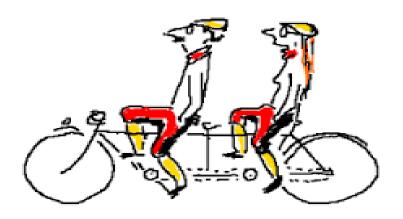
## Custard

250g/9oz mascarpone 500ml/18floz ready-made vanilla custard **Topping** 300ml/½ pint whipping cream 5 glacier cherries chopped in half, to serve



### Method

- Place fruit into a saucepan, add the sugar and cook on a low heat until the sugar has dissolved. Remove half of the berries and juice to a bowl then set aside to cool.
- 2. Add the apple juice to the fruit in the pan, and bring to a simmer and cool
- 3. Soak the gelatine leaves in a bowl of cold water for five minutes, until soft.
- 4. Add the gelatine to the fruit in the pan and stir until it has completely dissolved. Remove from the heat, and transfer the jelly mix to a bowl. Allow to cool, then chill in the fridge until the mix has set.
- 5. Cut the madeira cake into thin slices
- 6. Layer the cake, jelly, fruit and juice in the bottom of a trifle dish
- 7. For the custard layer, put the mascarpone into a large bowl then add the custard. Whisk together until creamy and smooth. Spoon the custard over the fruit and sponge.
- 8. Whip the cream, then spoon over the top of the trifle, starting from the outside and working in. This will avoid the cream sinking into the custard.
- 9. Chill the trifle for an hour before serving.



# London to Paris - Kidney for Life Bike ride

For me this challenge began in April, when I wanted to build on the 1000 cumulative miles I had walked in 2017. However, being on dialysis, just getting to the start line seemed daunting enough, and completing the 300 miles over 4 days, just looked ridiculous. Not being a keen solo road biker didn't help, so when my blind friend (amusingly also called Guy) enthused about doing it on a tandem, I seemed to have an answer to getting a little help for all those miles.

We were generously lent a tandem by a Charity called Charlotte's Tandems who help the 'inflicted'. Fast forward, by end of July, the 2 GUYS had achieved 500 training miles, in some beautiful localities and I had certainly proved that stamina could be gained with careful nutrition, hydration and dialysis management. While Guy K had once again enjoyed the sense of the open road and aerobic exercise, deprived of as his eye sight started failing over the previous 2 years.

At the start on Tuesday 27<sup>th</sup> August , we joined a motley crew of MRI staff, including Afshin our friendly MRI surgeon, Mike Picton a well known face in Nephrology and other nurses. Us, mother of a kidney patient and friends of a kidney patient made up the peloton. Looking at the start line, there was certainly mixed ability and definite lack of training in some cases, I was not really sure all were going to make it! In pleasant sun, we began Day 1 by following the arrows put out by the organising team of Chapeau Events, due south, over the North Downs and onto the flatlands of the Kent Weald and ending the 84 miles up on the South Downs, to take the long descent into Dover and onto the ferry for a very well deserved fish and chips and overnight stop in Calais.

Day 2 started to rain at 8 am and wasn't to stop until 6pm. For me though it wasn't a problem, as I handed the tandem over to Neale 'our domestique!', I took the train up to Arras to have a dialysis session at Arras hospital. I rejoined my bedraggled fellow cyclists that evening, who recalled tales of cycling 80 miles in horrendous conditions, while I was sat on my dialysis bed, looking out of the window, thinking 'who's a lucky boy then!'

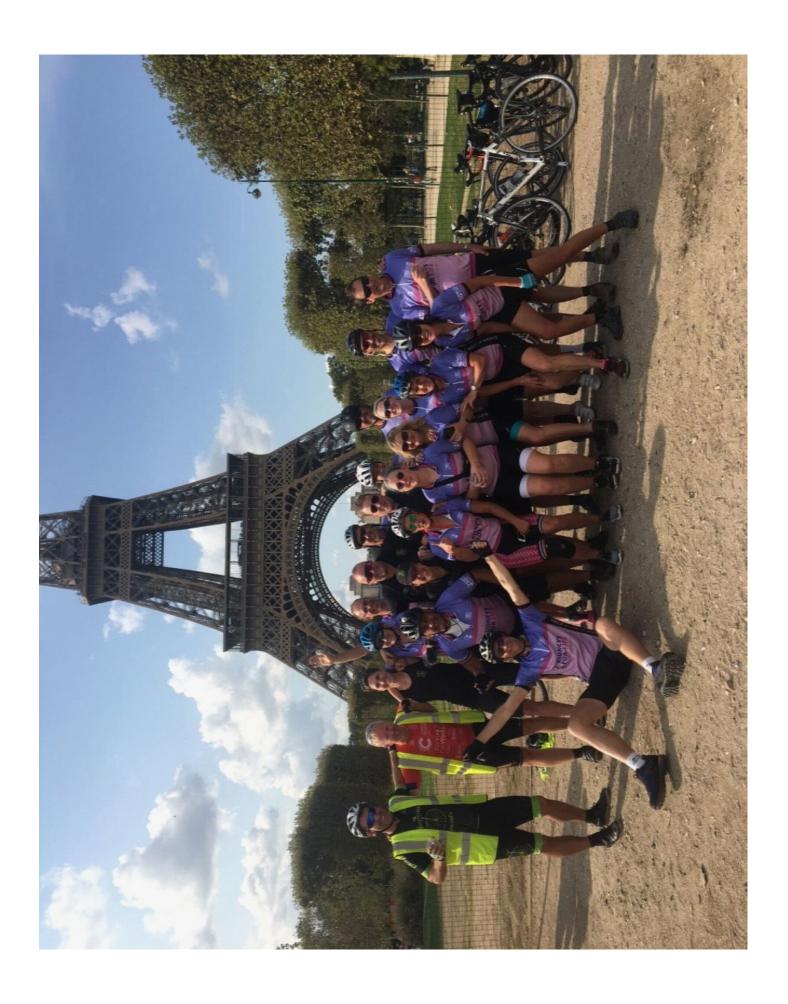
Day 3, with the sun back out, we pedaled through the Somme valley and all its connections with the First World War and to the magnificent memorial at Thievpal for the fallen and then passed numerous cemeteries. A demanding 89 miles brought us into Compiegne.

Day 4 - 67 miles Compiegne to Paris - in perfect weather, we do the 56 miles to lunch via coffee and cakes at Ognon and a tortilla lunch on the banks of the Seine, Then a processional ride into a very busy Paris along the Seine to the Bagatelle Park in centre of Paris. Then with horns blaring, singing, we process to the Arc de Triomphe and onto the Eiffel Tower. 3 celebratory laps in the Eiffel Tower Park is followed by champagne and pictures, with all the emotion of a long but superb journey that had bonded the group in a unity of determination.

So completed a trip that had seen me, and my fellow riders, overcome many challenges. Not just in the previous 4 days but over the preceding 4 months. The trip had been splendidly arranged and catered for by Dave and his team, the organising company Chapeau Events on behalf of K4L. I can but recommend one of their rides, as they think of everything and so you just have to pedal!

For the 2 GUYS, we followed this epic with the Coast to Coast, Morecambe to Whitby ride, with the help of Keith Pennington from Hope KPA driving the support car, to complete 1000 miles on the tandem in 2018. Of course it doesn't end there, we have started planning a ridiculous attempt on 'LeJoG', (Lands end – John O'Groats), 980 miles up Britain in 2019!

# **Guy Hill**





# Parachute jump for Kidneys for Life

Last year a good friend, Colin Smith, did his first ever 5km run for Kidneys for Life at the age of 71. You may remember the article. This year he went one better and did his first ever tandem parachute jump for the charity.

Before signing up for the jump he ensured his doctor gave him the all clear and the jump was arranged at the Black Knights Parachute Centre based at Hillam Lane, Cockerham, Lancashire.

Having turned up for the jump the instructor was a bit surprised at his age and asked him to take a short physical test to see if he was fit enough to complete the jump. He passed and was soon in the plane with his skydiving instructor and several other skydivers climbing to a height of approximately 15000 feet ready for the jump.

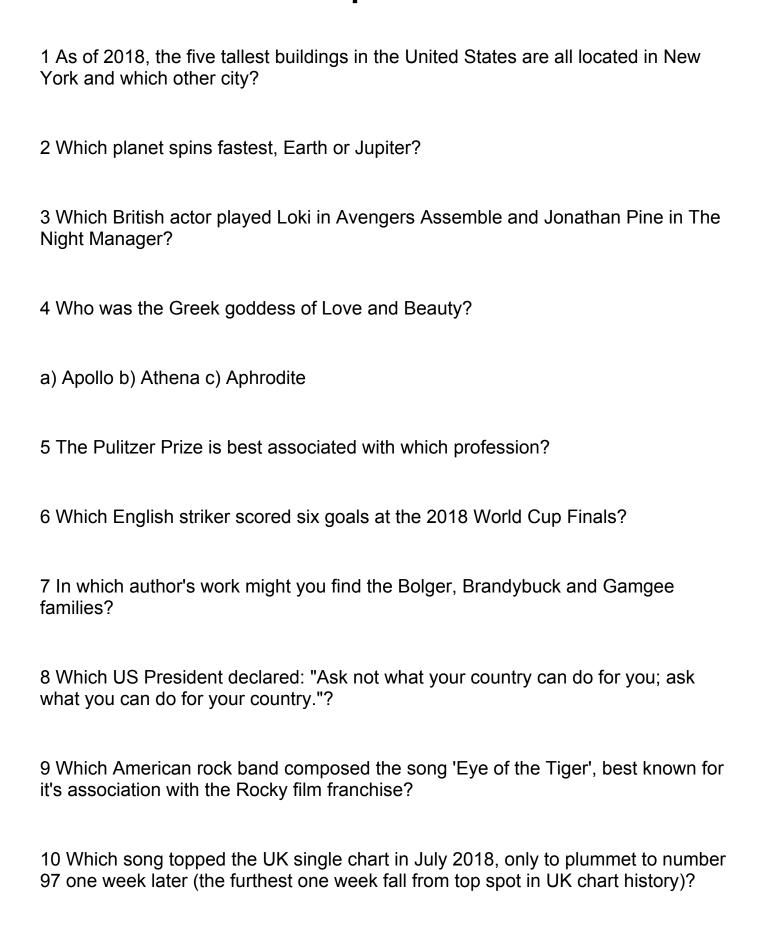
Colin said that once he was out of the plane it lasted all too briefly. 'Once the parachute had opened' he said 'it was a very silent and the views were breath taking'. The instructor let him steer for a short while and before he knew it he was coming into land.

He said it was a fantastic experience and a wonderful day and raised £270.00 for the charity.

As for next year he joking said he would swim the English Channel, mind you last year he said he would do a parachute jump and nobody believed him!!

Mike Kewley (Transplant patient)

# **Quiz questions**



# **ANAGRAMS**

The following are all famous scientists with clues given by their notable inventions:

Demo Astonish (Light Bulb/Motion Picture Camera)

Oil Gale (Made improvements on the Telescope)

Jolt Hurtle (Seed drill and horse-drawn hoe)

Uncle Will Mail (Basis of first refrigerator)

Tamest Jaw (Improved on Newcomen's Steam Engine)

Breaches Lab Gab (First mechanical computer)

Blend Ale Relax (First practical telephone)

Natural Gin (Computer science pioneer)



# Christmas Quiz questions

Who created Rudolph the Red Nose Reindeer?



What is the opening line of 'The Christmas Song' by Nat King Cole?

Which town, beginning with letter N, was Jesus raised as a child?

What is the time difference between Lapland, Finland and London, UK in December?

Can you name two of the three song titles of the 1990's UK Christmas Number Ones by the Spice Girls?

Who is the Patron Saint of Children?

According to the Christmas carol, which king last looked out on the feast of Stephen?

Who plays Juliet in the Love Actually movie?

Which famous Christmas poem was written by Clement Clark Moore?

What is the name of the fictional town in How the Grinch Stole Christmas?

# 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

Mike Kewley

**Editor** 



# Quiz answers

- 1 Chicago
- 2 Jupiter
- 3 Tom Hiddleston
- 4 c) Aphrodite
- 5 Journalism
- 6 Harry Kane
- 7 J. R. R. Tolkien
- 8 John Fitzgerald Kennedy
- 9 Survivor
- 10 Three Lions



# **ANAGRAM ANSWERS**

**Thomas Edison** 

Galileo

Jethro Tull

William Cullen

**James Watt** 

Charles Babbage

Alexander Bell

Alan Turing



# **Christmas Quiz Answers**

Robert L. May Chestnuts roasting on an open fire Nazareth 2 hours (Finland is 2 hours ahead of the UK) 2 Become 1, Too Much, Goodbye Saint Nicholas Wenceslas Keira Knightley Twas the night before Christmas (originally called A visit from St. Nicholas) Whoville

# 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.

## Thurs 24th January

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

### Tues 23rd April

18:00-20:30 Post Graduate Building. Staff - Lindsay, Krisha, Fiona

# Tues 30th July

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

### Thurs 24th October

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

Pre dialysis team 0161 276 4440

# Dates for your diary 2019

World kidney day - 14th March 2019

UK Kidney Week - 3rd - 5th June 2019 Hilton Brighton Metrop

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

MRIKPA AGM - Sunday 21st July @ MRI (fudetails in the next newsletter)

British Transplant Games - Newport, Wales, 25 - 28 July 2010

**World Transplant Games** - England - Newcatle - Gateshead 1 August 2019

### **Dr Simon Jenkins MBE**

As some of our readers will know Dr Simon Jenkins MBE was a long term member of the KPA. He sadly died in March 2017 and his family wanted his name and all his excellent work to be remembered.

In November 2018 a television paid for by the family and plaque paid for by MRIKPA was officially unveiled in Ward 9 at MRI.

His daughter also wrote a tribute to her father which is produced on the following pages.



Simon's family with Geoff Burgess Deputy Chair MRIKPA (far right)



Simons daughter, Deborah, with members of the nursing team



### Dr Simon Jenkins MBE

Since March 17<sup>th</sup> last year there hasn't been an hour pass by where I haven't thought about Dad. It has been an extremely difficult and emotional task to try to pull together all my thoughts and squeeze them into a few short minutes.

As a Dad and a Papa his enthusiasm and passion for medicine inspired both myself and Zak to follow in his footsteps. Dad would relay stories to Zak of being a junior doctor in Birmingham and they would compare notes. I'm quite sure though that it wasn't Zak who rode a Lambretta scooter a quarter of a mile down the hospital corridor at night to deliver a baby. Or "got" volunteered in a medical trial which involved having a bone marrow biopsy taken from his sternum without any anaesthetic.

The Jenkins family although disparate is still very much connected and Dad thought it so important to keep in contact and loved to take a keen interest in the lives of his daughter in law Wendy, nieces Liane Sally, Sarah and Ruthanna, nephews Daniel and Andrew and Adam and cousins, Maureen, Henry and Ann. Mum and Dad used to live next door to Mum's sister Linda and her husband Ronnie when they lived at the Westlands keeping our families firmly bonded.

Dad held numerous positions both professionally and voluntarily and was a highly regarded doctor and held in high esteem by his colleagues. For many years he was a GP trainer and helped junior doctors fulfil their potential but even when they had finished their training he still provided them with his lifelong support.

Dad had such a brilliant mind and a broad spectrum of skills. He was actively involved in medicopolitics and was a fellow of the BMA. He was one of the first GPs in the country in the 1980s to establish the creation of computing expertise in general practice. In later years he was a true silversurfer sending and receiving hundreds of e-mails and sitting at home in his armchair updating his Caring Bridge blog on a daily basis.

His positive outlook meant that he always saw the **best in** people. Despite a very difficult three years on dialysis following acute renal failure at the age of 60 he was eager to make a difference to the lives of his fellow renal patients, and before long was Chairman of the Kidney Patients Association. Howard and I are attempting to cycle from London to Paris in August for the charity 'Kidneys for Life' to raise money in his name. Dad was known to do a bit of cycling himself in his youth. The story of him cycling from Birmingham up to the Scottish Highlands, age 14, with 3 of his school friends, in a pre-mobile phone world, makes for fascinating reading, especially the part about him having to find a blacksmith on the way to mend his broken bicycle frame. That early intrepid spirit never left Dad and even though he wasn't in the best of health, at the age of 75, he insisted on travelling to China alone for the World Kidney Conference.

And finally, to me, Dad, was my personal and professional role model. He put me on a pedestal and only ever showed me love and respect, care and consideration. He told me that I was his guardian angel. He taught me to treat everyone as an equal, to work hard and strive to do my best and that the most important things in life are your family and friends. You can have all the money, all the titles and all the status in the world but those things are temporary. What matters most is the mark that we make on the world and the legacy that survives us.

Dad set us all an example and the best way we can remember him is by trying to live our lives as well as he lived his and try to leave this world a better place.

# Transforming Renal Dialysis Services (TRenDS) MRI - Newsletter - December 2018

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.

#### Octagon House

As detailed in our September newsletter, the North Manchester patients will continue to dialyse on this site until Hexagon Tower opens in 2019 (see update below). As previously reported, this team are working within the new workforce structure. A recent patient survey has been completed which gave us some great feedback (Results at the end of newsletter). In addition, we successfully transferred 30 patients from the renal dialysis unit on the main MRI hospital site on 5th November. Both patients and staff from the main unit have settled in well and are enjoying the new facilities.

We would like to thank our North Manchester patients and staff who are travelling further during this interim period. We hope to get you established in your new building as soon as possible (see update below). Your continued patience and understanding is greatly Appreciated.

We aim to complete the transfer of the remaining patients from the renal dialysis unit on the MRI hospital to Octagon House from mid-April to mid-May next year. This timescale is in line with the completion of the dialysis assistant training programme at this site which will enable both units to function under the new staffing structure and deliver the new clinical model.

#### **Hexagon Tower**

Much work has been underway since the initial meeting with Greater Manchester Fire Service back in May regarding the lift specification for the new renal dialysis unit in Hexagon Tower. It has taken time to ensure that the lift provision in the new unit meets the requirements of our patients and staff and is completely safe.

A number of concerns were raised with regard to the specification which resulted in a meeting being arranged with the Greater Manchester Fire Service and all stakeholders at the beginning of November 2018. The specification has now been revised and a management plan produced, both of which are with the landlord for approval.

Once this has been confirmed, we will be able to go ahead with the planned work of the lift being upgraded to meet evacuation standards for both patients and staff, with a view to completing the work by mid-April to mid-May 2019.

We will continue to update you on progress with this key development.

#### **Altrincham**

The training of the remaining dialysis assistants should be finalised by March 2019 which will enable the new workforce structure clinical model to be delivered.

#### **Tameside**

The Tameside dialysis unit has been operating under the new Fresenius contract for buildings and equipment since 2017. The workforce structure was introduced in July 2018 but the new clinical model has not yet fully started due to supporting Altrincham, and the main dialysis unit with staff ,whilst the dialysis assistants in these areas complete their training. The new model should be ready for implementation early next year.

#### **Patient survey**

We conducted a patient survey at both the Tameside and North Units in November due to the fact that both these units are now operating under the new contract and staffing model.

The overall feedback for both units was extremely positive with a large number of patients commenting that access to treatment time is more timely and efficient.

For those patients at North Manchester, whilst there is additional travelling time at the moment, a high percentage of patients are happy with the new and clean environment.

Tameside unit (total 125 completed)

Category Score out of 125

Transport 81

**Environment 120** 

Comfort 113

Communication 108

Medical care 84

Nursing care 124

Nutrition 98

Punctuality of access to dialysis time 114

Infection control 124

Involved in decision 119

Improvements over last 6 months New machines, new and improved televisions, cleanliness, accessing dialysis, session in a more timely manner

Suggested improvements for the future Larger waiting area, staff not to be sent to other units leaving Tameside short, improved transport services, same person to prepare and set up dialysis tables, refreshments provided whilst waiting for transport.

#### **North Manchester (Octagon House)**

Category Score out of 80

Transport 16

**Environment 80** 

Comfort 70

Communication 79

Medical care 44

Nursing care 80

Nutrition 75

Punctuality of access to dialysis time 72

Infection control 80

Involved in decision 77

Improvements over last 6 months Better environment, clean and spacious, friendly and welcoming, more timely access to dialysis session, staff helpful and cheerful, better facilities.

Suggested improvements for the future Transport, more medical cover and access to doctor, move to Hexagon as soon as possible to reduce travel times, Tegaderm dressings to be made available, toast to be provided.

#### Clinical model

With the infrastructure and staff now in place, in January 2019 we will move to implement a clinical care model that will help achieve the best outcomes for all patients. We will endeavour to provide every patient with the best possible start to their haemodialysis journey through the introduction of a Haemodialysis Transition Unit.

The Haemodialysis Transition Unit is designed with patient empowerment at its core. It willaim to equip dialysis patients with the knowledge and the attitude to take an active role in self-managing their kidney disease. This is our goal for all patients receiving dialysis treatment, as this self-management offers patients successful adaptation to kidney failure and the best clinical outcomes for patients.

We would expect to see about 15 patients join the Haemodialysis Transition Unit every month, with bespoke multidisciplinary dialysis care plans for individual patients. We are in a position to also implement the use of state-of-the-art dialysis machines within this setting in a phased manner. In addition, we are also working towards a new model of care that will increase the availability of training and support to our existing patients.

We are looking forward to a bright future for patients and staff alike in all dialysis facilities in 2019

### 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
☐ I consent to the MRIKPA contacting me by post
$\ \square$ I am already a member of the MRIKPA and have changed my name, address and/or phone number
$\ \square$ 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
☐ I would like to receive my newsletter electronically
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 MRIPKA 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. M. England £100.00 16.5.18

In memory of Brian Broadbent £575.00 16.5.18

Mrs. C.R. Potts, in memory of Mrs. Kath Hogg £20.00 25.6.18

Prof. N. Malick £500.00 30.7.18

Mrs. L. Myers, in memory of David James Myers £50.00 11.9.18

Mr. & Mrs. L. Shaw £250.00 15.10.18

John Hartle £30.00 15.10.18

Mr. S. Mistry £100.00 15.10.18

Alan Benster £25.00 30.10.18

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.



# Gift Aid declaration -for a single donation

Name of charity or Community Amateur Sports Club
Please treat the enclosed gift of $\mathfrak L$ 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

# Notes

# 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



Printed by Questbond Limited Tel: 0161 202 6100 Fax: 0161 202 4331 Email: info@questbond.co.uk