

Manchester Royal Infirmary
Kidney Patients' Association
(MRIKPA)

Newsletter



Autumn 2023

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Hello from your Editor

Hello and welcome to the Autumn 2023 edition. I can't believe where the time has gone. I've even seen Christmas cards in the shops.

I hope you are continuing to enjoy the newsletter and its content but please provide any feedback good or bad to ensure it's meeting your needs.

I'm really pleased to say the MRIKPA website is fully available so please take some time to have a look at it. It's for your benefit and provides useful information about renal issues.

Best wishes and take care

Mike

07530 452190

mikejm.kewley@gmail.com



MRI Kidney Patients' Association

Web address - **mrikpa.org.uk**



We've done it, with some help from our website designer, the MRIKPA website is now up and running and provides information to patients, carers and friends on a range of topics.

Its easy to navigate and includes current news, key dates for your diary, names and photographs of committee members, map of MRI, information about renal matters including dialysis, dietary tips, resources for carers plus much more.

The site has been developed for you to use as a resource and to complement the newsletters so please use it.

mrikpa.org.uk

Committee Members

Guy Hill Chair helenandguy_hill@hotmail.com

David Coyle Deputy Chair

Margaret Bennett Secretary

Janet Richardson Treasurer 07490 190492

Cassie Brzoza

Steve Caddick 0161 684 8588

Wajid Igbal 07948 833994

Mike Kewley Editor 07530 452190

John Murphy

Helen Murphy

Dr Arijit Sen 01706 345383

Manchester Royal Infirmary Kidney Patients' Association (MRIKPA)

What do we do?

The aims of the Association are to increase public awareness of issues affecting kidney patients and their families, support and help fellow kidney patients and provide formal routes to represent the patient and carers voice to the Trust and other bodies.

Is the Association a charity?

Yes. The Association is a charity and is registered with the Charity Commission. Its registered number is **516871**

Who runs the Association?

The Association is run by an elected committee. The members of the committee are fellow kidney patients who have either had a transplant or are on dialysis. They are all volunteers and apart from the Secretary receive no payment for their work. In other words the Association is run by patients for patients.

How is the Association funded?

At the moment it does not proactively fund raise due mainly to the impact of Covid -19 and limited number of members on the committee. Its main source of funds comes from charitable donations.

When do we meet?

The committee meets monthly, first Wednesday of the month. We currently use Zoom to hold these meetings. We also hold an AGM once a year around September.

Are we on social media?

Yes we are. We have a Facebook page. A website has been developed and we intend open a Twitter account.



mrikpa.org.uk



MRI Kidney Patients' Association

Contact numbers/email addresses

Renal Transplant clinic nursing team 0161 276 8721 (1.30 - 3.30 pm)

Appointments 0161 276 4471/8735

Booking appointments URTCBT@mft.nhs.uk

Main Outpatients reception 0161 276 4235

Blood results 0161 276 8721 (1.30-3.30 pm)

Renal IT 0161 276 8738

Transplant Secretaries 0161 276 8594/5496

Advanced Chronic Kidney Disease 0161 276 4440

Renal Social worker 0161 276 6521

Renal Dietitians 0161 276 4478

Renal Pharmacy 07817 136791

mft.renalpharmacy@nhs.uk

Renal Transplant ward 0161 276 4402

Renal Vascular Access nurse 0161 276 7985

British Transplant Games

**Zoe Dixon - Manchester Adult Transplant Games team Manager
07780858558**

**Kidneys for Life - Manchester Children's team
0161 276 6671**

Sources of advice

Journey planner for MRI

www.gmpte.com

National Kidney Federation

www.kidney.org.uk

0800 169 0936

Kidney Care UK

www.kidneycareuk.org

01420 541424

Greater Manchester Kidney Information Network (GMKIN)

gmkin.org.uk

Kidney Research UK

kidneyresearchuk.org

Polycystic Kidney Disease Charity

pkdcharity.org.uk

IgA Nephropathy Support UK

(Facebook site)

Dialysis Traveller

(Facebook site)

Kidney Patient Reported Experience Measure (PREM)

The annual experience survey for kidney patients, opened on 11 September 2023.

Every year Kidney Care UK asks patients to let your unit know your experience of care as a kidney patient. Your feedback is vital in influencing how your unit provides kidney care.

This year's Kidney Patient Reported Experience Measure (PREM) opened from Monday 11 September until Monday 6 November 2023.

The survey can help you share your praise and concerns about the main areas of your care with your unit (anonymously). This helps your kidney team to understand how you and the other kidney patients they care for feel about your experience of care.

If you are over the age of 17 and living with chronic kidney disease (CKD), you can take part in the ADULT kidney PREM. This includes those attending a UK hospital renal unit or satellite unit but not yet on renal replacement therapy and anyone who has received a kidney transplant.

If you are a child/young person with CKD aged between 12 – 16 years old, you can complete the PAEDIATRIC kidney PREM. If you are a parent or carer of a child/young person of any age with CKD you can complete the PAEDIATRIC kidney PREM by proxy, answering in relation to the care your child receives.

To complete the survey go to www.kidneycareuk.org/news-and-campaigns/news/kidney-prem-2023/

New Chairman of the National Kidney Federation - our very own David Coyle

David Coyle is Vice-Chair of the MRIKPA committee and has recently been elected the new Chairman of the National Kidney Federation (NKF). Here are his thoughts for the future of the NKF -

No stranger to the NKF, as an officer for Manchester Royal Infirmary KPA, or indeed to renal disease, I am very pleased to be taking up the role of Chairman for NKF. I'd like to thank Jim for all his hard work over the years as I pick up the baton.

It's my intention to help further develop the NKF into a strong and prosperous organisation by supporting the KPAs and the NKF team's work so we continue to influence national strategy. As a small charity we are helping make change and improvement happen for the benefit of people living with kidney disease and their families.

In my working life as Patient Lead for the National Institute for Health and Care Research (NIHR) Devices for Dignity I have been involved in ensuring the patient's voice is both heard and acted upon in research. I believe very strongly that co-production with patients and carers is a vital component of kidney research and service improvement.

The value of our Federation is the change and improvement we can achieve working at a local level with our clinicians and their renal teams, and at a national level working with policy makers. I am an advocate for patient involvement and I will continue to bang that drum during my tenure as Chair for the NKF.

We have important work to do over the coming years to grow our family of KPAs as we continue the work of our Federation, keeping the needs and requirements of the renal community high on the health agenda and making the case for the welfare of kidney patients and their families.

World Transplant Games

Perth, Western Australia

15th - 21st April 2023

It was a brilliant World Games, Perth were amazing hosts and the GB&NI team topped the medal table with 121 Gold, 96 Silver and 71 Bronze medals, a total of 288 medals, including those won by Juniors and Live Donors.

Our Manchester Adults did brilliantly.

Juliet Lewis won bronzes in the doubles badminton and also doubles pétanque.

David Jones won 3 Silver medals, in the 5km Run Individual and Team and in Squash and a Bronze in Badminton Singles.

Arthur Taylor at his first World Games excelled himself to win Gold in Ten-Pin Bowling and Silver in Lawn Bowls.

Zoë Dixon MBE, in her 10th World Games was delighted with her performances and times too. She came 5th in the 10km Individual Time Trial and 6th in the 30km Road Race in a very competitive age category and a challenging course for the Cycling. She had to withdraw her team for the Ladies Team Time Trial, where we likely would have medalled, as her cycling partner was not well enough to ride. It was the right decision as no one race is worth risking health and her partner later recovered ok, thankfully.

A fantastic time was had by all and the Manchester Adults would again like to thank Kidneys For Life and the MRIKPA for your wonderful support in helping us to raise awareness of transplantation on the world stage.

Zoë Dixon MBE



Left to right - Arthur Taylor, David Jones and Zoe Dixon with the River Swan in the background



Arthur Taylor on the podium with his Gold medal in the Ten Pin bowling

Juliet Lewis far right winning bronze



BRITISH TRANSPLANT GAMES 2023
COVENTRY
27 - 30 JULY
Manchester Adults Team Report

The Manchester Adults Team enjoyed a fantastic weekend at the Transplant Games in Coventry and despite it being one of the wettest July's on record we were blessed with intermittent sunshine until the Sunday afternoon rain! With both experienced and new competitors in the team we had 10 Transplant competitors (a further 2 had to withdraw beforehand for different reasons) and 1 Live Donor, competing across 11 different sports and 18 events types. Also we had competitors in all of the age categories, from 18-29 adults right through to 70+, now that's quite something!

The team took home 21 medals in total (5 Gold, 7 Silver and 9 Bronze), with everyone taking home one or more medals, which is fantastic! Wonderful encouragement was given by our amazing supporters who themselves were able to take part in the social sports on offer and many of ours participated in the Donor Run on the Saturday evening. Medals or not, we're all just so grateful we're actually able to do this and enjoy it so much, every competitor is truly inspirational and winning at life!

On the first evening all the teams gathered inside the Cathedral ruins where the Impact Steel Band also performed for us, before we all paraded into Broadgate in the City Centre for the Opening Ceremony held outside. We were very proud to wear our new royal blue team kit, (organised by our Team Manager!), which looked great! As always the biggest appreciation and applause was for the remarkable Live Donors and Donor Family Network members as they entered the ceremony.

The four days saw transplant athletes from all teams 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 the Racquet sports. There were also social events for supporters, such as the Football, Golf, Basketball, Netball and the Donor Run. The weekend culminated with a Gala Celebration event held at the Warwick University Campus Student's Union.

Very well done to all our competitors this year:-

Arthur Taylor; David Jones; Guy Hill; Khalid Bostan; Lenka Novakova; Paul Reynolds; Zoë Dixon. Also our new team members, who absolutely loved the whole experience and were brilliant – Katherine Murray; Graham Taylor and Hafeez Ahmad and our wonderful Live Donor, Nikki Oosthuizen. Also Mark Smith and Wil Marklew, we were sorry you couldn't compete but look forward to you and everyone returning next year!

On behalf of the whole team I would also like to say a massive thank you to the MRIKPA for their generous support, helping each of us to participate this year.

The whole team spirit is fantastic and like all the competitors, I'm always so grateful that I am actually able to take part (this was my 21st British Games) and it's 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 Nottingham 01 – 04 August 2024. 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!

Also take a look at the Transplant Sport website to see more events taking place throughout the year and also find out more about the British Games at the British Transplant Games website.

Zoë Dixon MBE
Manchester Adults Team Manager
Tel: 07780858558
e-mail: zoe_dixon@tiscali.co.uk
www.transplantsport.org.uk

Children's team
Contact Kidneys for Life
0161 276 6671
fundraiser@kidneysforlife.org





Left to right - David Jones, Guy Hill, Khalid Bostan and Paul Reynolds







David Jones & Guy Hill





MANCHESTER
CHILDRENS

MANCHESTER
CHILDREN'S
TRANSPLANT
GAMES TEAM

Sponsored by
**KIDNEYS
FOR LIFE**
HELPING PEOPLE TO THRIVE

**Kidney
Care UK**

TRANSPLANT
GAMES

Manchester
Children's Team

Quiz

- 1 Which European country with a population similar in size to Uruguay will adopt the euro as its currency in 2023?
- 2 Now kept in Edinburgh Castle, which stone is to be used for the coronation of Charles III at Westminster Abbey?
- 3 The coronation was planned for years using which code name?
- 4 Officially opened by Her Majesty the Queen in 1973, October 20th sees the 50th anniversary of which iconic building?
- 5 The 2023 Rugby World Cup is taking place in which country? And which country were reigning world champions?
- 6 Which country is projected to surpass China in 2023 to become the world's most populous country?
- 7 Which two countries hosted the 2023 FIFA Women's World Cup?
- 8 Amazon Prime Video will release a second season of Clarkson's Farm in early 2023. What is the name of this farm?
- 9 Which month in 2023 marks a whole year since Russia invaded Ukraine?
- 10 December 16, 2023, is the 250th anniversary of which historic event?
- 11 Tata Consultancy Services sponsored what on the 23 April 2023
- 12 How many litres of water can a home dialysis machine use in a week?
- 13 The fourth instalment of which film series hits cinemas in 2023 after a two-year delay caused by COVID-19?
- 14 Which country has the highest life expectancy?

Chairs Annual Report 2022/23

Thanks to Ruth Shrigley we have an exact starting date of this KPA of Saturday 11th June 1983, in its former guise of NWRKPA. Therefore we now have 40 years of continuous activity of working on behalf of patients to better their journey through the challenges of kidney disease. As a change to our minutes silence, I suggest a round of applause for all the patients, carers and staff who have contributed to the KPA over these 40 years would be appropriate.

Thank you

Despite the lifting of COVID restrictions, Direct contribution to the Renal Service and the patients has remained challenging throughout the year. Inside the hospital and all the satellites, the renal service has been in constant flux, as one pressure after another has created a whole host of changes to how patients' pathways are working. However the hospital is certainly open to all procedures which is good news.

The new challenge is a whole host of unaccounted 'new patients' needing dialysis that has come from vascular failures, resulting from poor medical management during COVID MRI has needed to find 10% i.e. 60 new dialysis slots fairly instantly, which is unprecedented. Nationally the transplant waiting list has risen 2000 in a year, from the steady 5000 to 7000. A Simple knock on effect is no holiday dialysis in Manchester for the moment.

Our biggest focus since COVID has been on the transplant clinic, which has been through a variety of transformations. And it is pleasing to report that this has now settled down into an efficient methodology that sees patients processed quickly.

The permission of the Trust to 'release blood results for renal patients early' on MyMFT has helped ease concerns for patients, although we all mourn Patient View, which was in retrospect, simply brilliant. The one thing many of the patients observe is how hard the renal staff are working on the front line, to try and protect vulnerable patients from the poor decisions made elsewhere. We have reported our observations and balanced feedback from social media to the renal service where changes are creating issues.

This whole COVID scenario has continued to emphasised where we want the KPA to be, helping both patients and the Renal Service; to arm patients with useful knowledge about their predicament and to liaise with the service on the pathways and application of the service from the patient's point of view.

As long as I can remember in my 25 years of KPA involvement, the KPA has made great efforts for this but it's been done in an informal way, through personal contacts and a service that was relaxed over patient interaction. However today we have a far bigger patient body to squeeze through a tighter resourced service, with a Trust and NHS, very focused on costs and controlled communication. A scenario that many people interacting with public bodies find in today's world.

As a KPA to get 'impact', we are still in transition to harness the internet as a driver of communications,

to then link back into personal communication to help patients with grants, advice and personal contact to make the challenges of kidney disease less daunting.

On the patient side, we have social media, that finally allows patients to interact in real time and not geography dependent but has the ability to point out very quickly, failings in any service but has a habit of being a poor method at listening to explanations, understanding context and separating fiction from truth.

For the KPA, we recognise that any organisation wanting to engage must have formality and skills to be noticed. Therefore, beyond our other, we have built on last year challenge to ourselves to formulate a strategy that identifies all the areas we can contribute and the skills and resources needed to help both patients and the service. There is no question that 'patient energy' is an underused resource, which structured right, can really help patient journeys.

We need to regularise an open communication with the clinical directorate. Support a return to pre-dialysis meetings. Build on the process of peer support to patients training for home Hemodialysis and shared/self care in units.

The next task is to progress this to engage with the other key areas for a renal patients pathways, so that we can take the KPA to another level in its work. We do need more **volunteers** to engage with the KPA. Having launched a website at mrikpa.org.uk the intention is to build patient communication and interaction with the renal service through it. Initially it is a static site that ensures a presence on the web for contact etc and has a membership sign in.

Content wise we are sign posting to other sites for explanations of processes like dialysis. However we will start to add approved MRI specific detail where appropriate. We have started to use social media to inform when changes are explained by the Renal service and together they present a good source of information for patients, especially when the NHS changed to all secondary care funding changed in April 2023 and will start to change services in the region

I hope this will help our biggest challenge which is 'finding patients to help' to do all the things we envisage. We have 450 signed up members, who receive regular communication as well as over 2000 MRI kidney patients who use the service, so there is plenty of potential helpers. We are hoping anyone reading this report, who would like to give something back to a service, will consider volunteering some time for the KPA.

Now to my annual thank you. I have been able to meet more frontline staff during the year and been able to thank them then. However to all the staff at the MRI your dedication to us as patients has been exemplary and despite your pressures, still do an amazing job of being there for us when we need you. On behalf of all of us, thank you.

To the national Kidney Charities, also a big thank you. They have continued to work hard to keep patients informed of the COVID situation and kept us highlighted to NHS England and the Government that we are still a very vulnerable body of patients and need special consideration.

This year's activity has been around the new 'renal transformation programme' that will define renal as it goes to regional NHS funding. Last year we gave the National Kidney Federation (NKF) £500, this year we have 'lent' them David Coyle our Vice Chair, and must congratulate him on his role as Chairman of the NKF. He has certainly moved the NKF to directly support KPA's in the work they do and there is certainly a sense of 'like minded' thinking in what the NKF does and a KPA does.

Finally, to all those patients who have been involved in KPA work and especially my committee that keeps the KPA going and relevant, an enormous thank you.

Guy Hill

Chair MRIKPA



MANCHESTER ROYAL INFIRMARY KIDNEY PATIENTS ASSOCIATION

TREASURER'S REPORT 1.3.22 - 28.2.23

Income:

£1587.53, made up of £1253.00 donations, £334.53 bank interest.

Our Business Reserve Account interest rate fluctuates. At the end of the period, the bank interest rate was 1%. At the beginning, it was 0.10%.

Expenditure:

£6775.88, mostly the cost of printing and distribution and we have given a contribution to the Transplant Games team.

These figures mean we have made a loss of £5188.35 in the year. As can be seen from the balance sheet however, at the financial year end, we had a balance of £9176.40 in our current account and £94,443.48 in the business reserve account. This is a healthy position and more than meets the requirements of our reserves policy.

Janet Richardson

Treasurer

24th June 2023.

MANCHESTER ROYAL INFIRMARY KIDNEY PATIENTS ASSOCIATIOⁿ
BALANCE SHEET AT 28.2.23

£	89,023.49	Balance Sheet at 1st March 2022	£	88,507.22
-£	516.27	Gain/deficit for the year to 28.2.23	£	5,188.35
£	20,301.01	Charity Walk Funds	£	20,301.01
£	<u>108,808.23</u>		£	<u>103,619.88</u>

Represented by

Nat West Bank PLC

£	14,699.28	Current Account	£	9,176.40
£	94,108.95	Business Reserve Account	£	94,443.48
£	<u>108,808.23</u>		£	<u>103,619.88</u>

RECEIPTS AND PAYMENTS 1.3.22 - 28.2.23**28.2.22 RECEIPTS 28.2.23**

£	2,458.45	Donations	£	1,253.00
£	9.44	Bank Interest	£	334.53

£ 2,467.89 £ 1,587.53

PAYMENTS IN PURSUIT OF ASSOCIATION'S OBJECTIVES

£	1,931.90	Newsletter Printing and Distribution Costs	£	3,855.10
-		Books and Equipment for MRI and Hope NHS	£	-
		Transplant Games Donaton	£	2,000.00
		NKF Donation	£	500.00
		2022 AGM Patient Information letter	£	280.78

£ 1,931.90 £ 6,635.88

ADMINISTRATION COSTS

£	131.88	Insurance	£	140.00
£	20.38	Domain name renewal	£	-
£	900.00	Website development	£	-

£ 1,052.26 £ 140.00

-£ 516.27

-£ 5,188.35

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.

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.

Donations list to 3.8.23

Charities trust 22.12.22 £36.00

Charities trust 31.01.23 £12.00

Charities trust 16.02.23 £138.00

Charities trust 31.03.23 £13.00

L Myers & G Edwards 01.06.23 £50.00

08.06.23 £150.00 in the
memory of Ken Saunders

Charities trust 16.06.23 £29.00

My Tandem Skydive for Kidneys for Life

April 2023

Well I did it!!

Yes that's me on the following page harnessed to a British Parachute Association instructor at 15,000 feet falling at 120 miles per hour free fall for approximately a minute. I tried combing my hair for the photograph but it was impossible!!

After that minute the parachute opened and we slowly and very quietly drifted down to land about 5 minutes after jumping out of the plane. Below you can see Morecambe Bay.

The morning started off grey and overcast but by 12 noon the sun started to appear and by the time I did my jump in the early afternoon it was clear and sunny. So while drifting down to land I had wonderful views on Morecambe Bay, the Pennine hills and in the distance Scotland and the Isle of Man.

7 people jumped on the day for Kidneys for Life and overall there were about 45 people jumping either for other charities or themselves.

To make it even more special my kidney brother Paul Reynolds and his daughter surprised me and came to offer their support.

I raised a fantastic £2057.68 for Kidneys for Life.

It was an amazing experience. Would I did it again?? - Yes, in a heart beat.

Mike



**BLACK
MIGHTS**

PARACHUTE CENTRE



FOREIGN TRAVEL INSURANCE pre-existing medical conditions



It can be difficult to know where to start looking for travel insurance with a pre-existing medical condition such as dialysis or a kidney transplant.

MoneyHelper provides free and impartial money and pensions advice for people across the UK. It's part of the Government's Money and Pensions Service. They also provide information and advice on travel insurance.

On their website under Insurance they provide a **Travel Insurance Directory** of specialist providers for people with pre-existing medical conditions.

Website - www.moneyhelper.org.uk

Phone - 0800 0113797

If you are considering a holiday abroad its worth reviewing the Travel Insurance Directory of providers. I found it extremely useful when searching for my foreign travel insurance.

YOUR ENERGY SUPPLY PRIORITY SERVICE

You may remember in the Spring newsletter we had an article about the energy supply priority service that helps utility companies take care of those who are in vulnerable situations.

Kidney Care UK is working in partnership with several water companies including United Utilities to ensure that people living with chronic kidney disease (CKD) in their regions receive the support they need.

As part of this partnership Kidney Care UK has delivered training to front-line call staff so they can better deal with inquiries from customers living with CKD and those on dialysis, ensuring they can offer the best support, especially to those on home dialysis - a machine can use 7500 litres of water every week, the equivalent of almost 80 showers.

The Priority Services register.

It is a free of charge system that helps suppliers to ensure the correct support is given to its most vulnerable consumers. This can include advance notice of planned power cuts for customers who depend on their energy supply for medical reasons and priority in an emergency.

For more information go to either

www.ofgem.gov.uk/get-help-your-supplier-priority-services-register

www.kidneycareuk.org/utility-partnerships

Quiz - the answers

1 Croatia

2 The Stone of Scone, also known as the 3 Stone of Destiny

3 Operation Golden Orb

4 The Sydney Opera House

5 France are the hosts. South Africa the previous winners.

6 India

7 Australia and New Zealand (Portugal won)

8 Diddly Squat Farm

9 February

10 The Boston Tea party

11 London Marathon

12 See previous page

13 John Wick (Chapter 4)

14 Hong Kong

Managing your fluid and salt levels

If you are at home you will need to monitor your own fluid allowance, with the help of your kidney team. You may like to create your own fluid balance chart so you can keep track of how much fluid you have each day. Your dietitian can help you with this.

It is important to try and keep to your recommended fluid allowance as best as you can as it has been calculated to keep you in the best condition of health.

How can I control my fluid allowance?

You may find it hard to keep to your fluid allowance at first, especially if you have to limit the amount of fluid that you drink. It is important to discuss any concerns you may have with your kidney doctor, nurse or dietitian. The following tips may also help:

Measure your fluid allowance into a jug at the start of the day. Every time you drink, take that amount of volume away from the jug so you know what you have left to drink

Use a small cup (*I used an espresso cup it's 100mls*) and spread your drinks throughout the day

Take small sips rather than big gulps of fluid

Freeze a drink in a plastic bottle and sip it as it defrosts

Suck on ice cubes as they last longer than water. Try freezing them with fruit squash

Chew sugar free gum, suck on boiled sweets or aqua drops

Rinse your mouth with mouthwash

Choose cold rather than hot drinks to quench your thirst

Take tablets with food instead of water

For extra support, tell your friends and relatives that you are on a fluid allowance

How can I reduce my salt intake?

A high amount of salt in your diet can make you feel thirsty which may increase your need to drink more than you have been advised.

The following tips will help you reduce the amount of salt in your diet:

Avoid adding salt at the table.

Avoid very salty foods e.g. burgers, sausages, bacon, cheese, smoked fish, crisps, salted biscuits.

Avoid tinned soup as these are high in salt and contribute to your daily fluid allowance

Try to cut down on ready-made meals, packet sauces and sauces in jars as well as takeaways. These are high in salt and other additives. Replace these with home-made foods where possible.

Experiment with other seasonings such as herbs, spices, garlic, vinegar, pepper.

Limit your use of stock cubes as these are very salty

Check food labels – foods with more than 1.5g salt or more 'per 100g' are high in salt. Look for alternatives or choose less of these.

'Lo salt' products are not be suitable as they contain a salt substitute, potassium which can be harmful for people with kidney disease.

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

Name

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)*

Donations and Fundraising

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



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

Cheque's should be made payable to: MRIKPA

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

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

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

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

giftaid it

Gift Aid declaration –for a single donation

Name of charity or Community Amateur Sports Club

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

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

Donor's details

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

Surname -----

Full Home address -----

Postcode -----

Date -----

Signature -----

Please notify the charity or CASC if you:

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

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