

Newsletter

Manchester Royal Infirmary
Kidney Patients' Association
(MRIKPA)



Winter 2020/2021



Content

2-3	Content & Committee members
4-10	Editor, Chair comments & Accounts
11	Poem
12-13	Renal Remembrance service
14-17	Remembering Geoff Burgess
18-22	Electronic newsletter & Hope KPA caravan
23-25	British Transplant games 2019
26	New organ donation law
26-28	Editors Morecambe Bay Charity walk 2019
29-32	Potassium food levels, quiz, recipe and answers
33	Membership form
34-35	Donations
36	Gift aid form
37	Useful numbers
38-39	Sources of advice & notes
40	What we do

Committee Members

Guy Hill Chair helenandguy_hill@hotmail.com

Steve Caddick 0161 684 8588

Janet Richardson Treasurer 07490 190492

John Murphy

Helen Murphy

Dr Arijit Sen 01706 345383

Margaret Bennett Secretary

Wajid Iqbal 07948 833994

Mike Kewley Editor 07530 452190

Hello from your Editor

I write this as we continue to struggle with the impact of Coronavirus and the effect it is having on our daily lives. We must say a massive thank you to all the medical staff who are risking their lives to care for us at this very difficult time.

At the time of writing the two vaccines are being rolled out across the country but it's particularly important for renal patients to follow current Government guidelines and also the advice of clinicians at Manchester Royal Infirmary (MRI). We need to continue to stay safe at this worrying time.

The keen eyed readers will have noticed that this is the first newsletter since the Summer 2019 edition. There are three reasons for this:-

Firstly I was not well during 2019 mainly down to Norovirus and because of my illness I was unable to work on the newsletter.

Secondly my transplant of 14 years and 11 months failed earlier this year and I'm now a home hemo-dialysis patient. I must say a huge thank you to the staff at Altrincham hospital particularly on the training team for their help and support in preparing me for home dialysis.

Thirdly I had some technical difficulties with the software package so I'm using a new one so its all a bit of a learning curve for me at the moment.

Anyway at least I've produced something and I hope you continue to enjoy the newsletter.

If there's anything you want to see in the newsletter drop me a line.

Best wishes for 2021.

Mike

07530 452190

mikejm.kewley@gmail.com



MRI Kidney Patients' Association



Hello from your Chairman

Dear Members,

Since the last magazine, all our worlds have been restricted by the COVID crisis. For those that have followed the figures published by the Renal Association, sadly in the NW, Covid has proved to be a significant risk to all renal patients and to the end of November 2019, 749 (11% of our 6458 NW renal patients) have been hospitalised with a 26% mortality rate. As I write, the vaccines have arrived and renal patients are on the 4th tier of priority, so hopefully by spring we should be able to restore our lives to a more normal pattern, however until then, I am afraid the advice is more of the same with regard to shielding.

For those that have had Covid, we appreciate as a charity that 'Long Covid' is a real issue and we will look very favourably on any requests for financial help for patients who are struggling with its consequences. We are also concerned about pre-dialysis patients who are waiting at this time for dialysis resources and may well need to change their homes to suit a home based therapy. Thankfully the transplant programme has re- started but this year's totals are going to be significantly down and this directly affects the availability of dialysis provision.

I am pleased that both our national charities have kept up a dialogue with NHS England about the COVID effects on renal patients and their websites are both informative and updated on the latest guidance.

On the 3rd August 2020, very sadly Geoff Burgess, our Vice Chair, died peacefully at home. Our deepest sympathy goes to his wife Hilary and her family. Geoff had been on the committee for 22 years and had done stints as chairman as well. There is a tribute to him in the magazine. But from a very personal point of view I will really miss him and all the help he gave us.

The greatest tribute to him would be to find new members who would step forward and join the committee and continue his work.

At the heart of any KPA, you need committed committee members, who are level headed, capable of seeing all views, caring and very understanding of other patients viewpoints . Geoff was all these and a real servant to the KPA. We will always remember him for his great humour and his stories. A real tonic when the kidney journey for all of us has so many up's and down's.



Registered Charity number 516871

Our committee role is two-fold, one to allocate our charity resources and two, to try and understand why the NHS makes the decisions it does, which are very rarely black and white but usually grey. To translate that into a patient's renal journey and see where the problems are and try and get the service to react to those shortcomings and help patients who have fallen through the cracks. Sometimes it can be about getting sandwiches for renal dialysis patients, other times, it is a major overhaul of the service. For our charity funds we react to any staff referral where a patient is in need, be it a late night taxi fare to go home from hospital or social grant for someone who is struggling on benefits.

Many members of Staff move on and as patients we can be sad but pleased that their skills have often gone elsewhere in the NHS to help others. But when one dies suddenly, it is very hard both for us and the staff. Sadly Noel Hastings has died pre-maturely. To me, he was a person who just 'cared'. As you can read in Wayne's obituary, he had been all around the renal department in various Admin roles. His final contact with patients was as Dialysis Holiday Co-ordinator. Ever cheerful, you presented him with a wish to visit an exotic or even mundane place; he would find a way to dialyse near it. And from everyone who met him during his many years in renal, it was that cheerful approach that left you just a bit more comfortable in the challenges of being a renal patient.

His poem he wrote about loss is inspirational and our thanks and our good wishes go to his wife Caroline and his children for allowing us to print it. After a deeply moving memorial service at the hospital by Rev Sarah Brewerton, I know he is sorely missed by all his colleagues.

On a different issue, all medical based charities are constantly concerned about 'relevance' to their patient bodies. Our big national patient charities, the National Kidney Federation and Kidney Care UK are both currently trying to understand how to engage and more importantly make a difference to patients in their challenges. As a KPA we are no different, we are the best conduit of patient views and feedback up the system and back down. There are so many opportunities to engage as a patient be it to give something back or get help, but sadly in this 'privacy' driven world patients do have to make the first step.

If you genuinely want to know more, then an email to anyone on the committee will put you on the right path. As a KPA we want to engage with you, because since any of us took that step, we have found it a fascinating kidney world and it has been rewarding to make a contribution.

Covid restrictions made it impossible to have an AGM this year, so the existing committee carried forward to 2020-21. Our Accounts have been qualified and registered with the Charity Commission as per their COVID AGM Cancellation Guidance. Details below. All our committee meetings in 2020 have been virtual but with minutes taken. I trust as members you find that acceptable in these frustrating times.

On a restful note, once we are able to travel again, I am very pleased that Hope KPA have invited us to join in with the use of their very smart patients caravan located at Staining near Blackpool. It is on a very quiet site but with excellent facilities and creates a superb opportunity for a short break. All the details are in this magazine and we hope that you will enjoy its use.

Wishing you good health in 2021

Kind regards

Guy Hill

Chair MRIKPA

A tribute to Noel Hastings

I first encountered Noel when he worked in X-ray almost 19 years ago.

He was enquiring about the job coming up working on Ward 23 and CAPD with me. He eventually got the job and we became a bit of a double act on Renal, similar sense of humour, socialisers and all round comedians.

We were always looking for the best wind ups and he stitched me up many times. I'll never forget the banter he always had with the porters in the social club when he worked behind the bar, always happy and helpful. He introduced me to amateur dramatics at one point which I never thought I'd get involved with and he got me involved in a whole new world I never knew existed.

This led to doing extra work, with Noel making appearances on Corrie and Emmerdale Farm. For some reason they were always looking for blokes in the background with beards! I could tell you loads of funny stories about what we got up to, karaoke in his local pub, a wild weekend in Grassington at my parents caravan, music gigs at The Apollo, a fancy dress barge trip in Yorkshire with the renal technicians, the list goes on.

He was always hilarious but also had a serious side when it came to his wife Caroline and daughters Niamh and Erin who he always talked about with fondness. I met a great friend in Noel and he will be missed in many ways by all the people he touched.

Wayne Carey

Treasurer's report for the financial year ending 29th February 2020

Income

We received donations of £3249.60. Along with a Gift Aid refund of £127.82 and bank interest of £187.88, our total income for the year is £3565.30.

Expenditure

Compared with the last few years, we have spent very little. As can be seen from the accounts, the main item of expenditure is the newsletter. Unfortunately, due to illness, we have only published one issue.

There is still money in the amenity fund, amounting to just less than £3000. We are no longer paying money into it however. It is worth noting that although this happened after the financial year end, Dr. Vardan now knows about the fund and has "spread the word" amongst nursing staff to try and ensure the money is used to good effect.

We have not needed to transfer any money from our Deposit Account this year so our bank balance is healthy and we have made a small profit for the year of £408.33.

Janet Richardson

Treasurer

27th April 2019

**MANCHESTER ROYAL INFIRMARY KIDNEY PATIENTS ASSOCIATION
RECEIPTS AND PAYMENTS FOR THE PERIOD ENDING 29.2.20.**

<u>28.2.19</u>	RECEIPTS	<u>29.2.20</u>
4,223.00	Donations	3,249.60
109.09	Bank Interest and bonuses	187.88
0.00	Refund of bank charges	0.00
0.00	Gift Aid	127.82
<u>4,332.09</u>		<u>3,565.30</u>

PAYMENTS IN PURSUIT OF ASSOCIATION'S OBJECTIVES

1,200.00	Amenity Fund	0.00
773.00	NKF Conference Subsidies	75.00
7,184.21	Newsletter Printing & Distribution Costs	2,025.27
392.34	Books and Equipment for MRI and Hope NHS	555.00
198.00	Just Giving Charges	0.00
1,400.00	Transplant Games Grants	0.00
0.00	Holiday Dialysis	0.00
0.00	Trends Meetings	0.00
	Contribution to cost of Linda Maskell Glynn funeral	300.00
<u>11,147.55</u>		<u>2,955.27</u>

ADMINISTRATION COSTS

101.33	Insurance	101.33
73.62	Postage, Stationery & Photocopying	100.37
0.00	Secretarial Costs	0.00
0.00	AGM Costs	0.00
<u>174.95</u>		<u>201.70</u>

-6,990.41

408.33

**MANCHESTER ROYAL INFIRMARY KIDNEY PATIENTS ASSOCIATION
BALANCE SHEET AT 29 FEBRUARY 2020**

<u>28.2.19</u>	Accumulated Fund	<u>29.2.20</u>
84498.01	Balance sheet at 1 March 2020	77557.10
-6990.41	Gain/deficit for the year to 28.2.19	408.33
20301.01	Charity walk funds	20301.01
<u>97808.61</u>		<u>98266.44</u>
	Represented by:	
	Nat West Bank PLC	
3950.91	Current Account	4221.36
93857.70	Deposit Account	94045.08
0.00	Stamps	0.00
<u>97808.61</u>		<u>98266.44</u>

Accounts approved

CHAIRMAN

VICE CHAIRMAN

signature and date

signature and date

Remembrance - by Noel Hastings 2009

I enjoyed our walk today over the hills
where splendid colours danced on leaves,
the smell of wet trees and daffodils,
the confident kiss of summer's breeze.

We sat for a while, drank cold tea and laughed
remember, the radio played a song by Cliff,
"Poor man's Elvis" you said, acting daft,
but these 'miss you nights' are the longest.

I asked if you were happy to which your smile replied
and all at once my soul was light,
soaring high from the pain inside
.....love in perpetual flight.

Don't think I could love you more than this day
said I, like a blind man to the lark,
yet, I know tomorrow's song will be as gay,
I hear absence doth make a fond heart.

We spoke of the children, and holiday treats
of far away lands with kaleidoscope birds,
"A week in the Lakes is more up our street"
and I shrunk in the warmth of your words.

The sky, now a canvas of shameless cerise,
cast skinny shadows on the land
and as the sun ebbs away past evening's trees
we'll walk down the hill hand in hand

I know that we'll part when we get to the weir
and slowly, I'll start up the track
to sit and stare at the empty armchair
to sit and wish you back, but.....you see
when a butterfly lands in a field on a flower
then changes its mind and flies to the sun
a pastiche of nature's delicate power
do we embrace its arrival or sigh when it's gone?

Of course, they think I'm mad, put it down to the sorrow
Who gives a figsame time tomorrow?

A Service of Remembrance

For

Patients of the Renal Department Manchester
Royal Infirmary

Sunday 15th November 2020

Due to Covid restrictions the service could not be held at the Lowry. Instead a virtual service was conducted. You can view the service at:

vimeo.com/mftrenalremembrance



Geoff Burgess

Geoff sadly passed away in August 2020. He was a long serving member of the KPA and below Guy has written a short obituary in his memory followed by Margaret Bennett our Secretary and close friend of the family.

Geoff joined the Kidney Patients' Association committee in 1998, while he was already on dialysis at home. This was a time when the KPA was very active around the region and in Manchester because many of the specialist nurses we have today didn't exist and particularly the journey onto dialysis just happened. Whereas today, many patients undergo a comprehensive pre-dialysis period where the in's and outs of the next stage are explained and patients prepared for.

In fact Geoff has been a permanent fixture at the pre-dialysis evenings for what seems for ever. Gently explaining to new patients that it is all very survivable and on occasions there could even be humour. Geoff should certainly know as he often recalled to us how he cajoled, tinkered with, hit in just the right places, a very old dialysis machine to get it to work. I am sure his wife Hilary has a wealth of memories of 'those moments' when it all just went wrong.

Despite being told for years he was a very poor prospect for transplant, he benefited from a change of heart by the matching system to prioritise long term dialysis patients and he won the transplant lottery and had a successful one. This gave him renewed energy and in 2009 , Geoff became chair of the KPA and was very able at getting the doctors and specialist staff to come and see the KPA and explain what was happening in renal and why. Sadly his constant battle with cancer forced him to step down to vice chair , where he offered me invaluable support .

In his real life Geoff was a policeman in the Cheshire constabulary, a real Dixon of Dock Green character whose local knowledge and friendly advice was his weapon of choice. Those days and his move to traffic police on Cheshire roads gave him an endless source of barmy stories of people's antics. He quite often found those 'above him' baffling , none more strange than when he alone was ordered to protect Cheshire from the top of Mobberley church tower during an airport alert, armed with just a rifle left over from WW2. Retiring from the police due to kidney issues, he went on to work as a lorry driver while on home dialysis. In actual retirement, his transplant allowed Geoff and Hilary to see the world, usually from a ship and as he was a larger than life character, he would light up any deck bar with his friendliness.

Thank you Geoff for being a friend to all of us; we will really miss you in so many ways. Our deepest sympathies go to his wife Hilary, Andrew, Wendy, Michael and Philip his children and their families.



Geoffrey Burgess - for you!

I want to start with a quote from John and Helen Murphy, who are current committee members of the MRIKPA.

“...Geoff was a friendly person, who worked hard for the KPA. He was knowledgeable about the working of the Renal and Transplant Departments.”

Shirley Wallwork, a past member of the committee said, “...He was generous with his time, supporting the KPA and pre-dialysis meetings at MRI – sharing his story and experience...giving patient’s reassurance and confidence to face the future...”

I have known Geoff for the best part of 22 years through the KPA. At that time Dennis Crane was Chairman. I had been asked if I would like to come along to a meeting with a view to becoming the Secretary – the rest as they say “...is history.” Geoff would stand in the doorway of the boardroom, present a joke, make us all laugh and I would say to myself – who is this man?

At that time Geoff was driving HGVs after having retired from the Police Force, was on home haemo-dialysis and waiting, which was for /Geoff, a long wait for a transplant. There was a saying at the KPA at that time, “get on the Committee and you get a transplant.” Geoff’s patience paid off and he received his transplant in 2006.

Geoff’s early career in the KPA began as a committee member and a counsellor. As a long standing dialysis patient, also dialysing at home, meant that he could reassure, encourage and offer advice, (non-medical of course) and signpost patients to the relevant departments/staff for support.

The onset of the pre-dialysis meetings, which the committee involved itself in, meant that counselling ceased. Geoff always maintained that this was a good thing. It showed that these pre-dialysis meetings were responding to patient, and just as importantly, carer needs.

“Far better,” he would say “...to give people all the information at the beginning of a renal journey, than in the midst of confusion, panic and fear that patients, embarking on a renal life, often feel.”

Geoff attended these meetings, as a speaker, advocating that there is life after renal failure.

A quote from Janet Richardson, our current treasurer says just this: “I can remember Geoff at a pre-dialysis meeting in 2001. Withington patients had just been transferred over to MRI and I was feeling very unsettled and scared about dialysis. He said that, “...you dialyse to live, not live to dialyse...” I felt more confident after that evening and that phrase...became something of a mantra.”

A quote from Mike Kewley our current Editor of the MRIKPA magazine says this. “Geoff always made me laugh with his many stories, but I remember most when he attended the pre-dialysis meetings as an expert patient. He would talk about holidays in France as a dialysis patient. How much easier it was to dialyse over there, but he made us laugh when he explained if the nurses hurt you, when needling you – ‘ow’ meant the same in any language! Just made I laugh, but he inspired me to go and do it...”

Dennis Crane’s illness and ultimate death meant that there was a new chapter in the life of the KPA. Geoff was raised to the dizzy heights of vice chair for 10 years, with a break for 2 years as Chair. It was during these 12 years that I met Hilary and began to meet at their home. If didn’t feel like work at all and Hilary always fed me delicious teas. It was at the table that Geoff would regale us with his many exploits as a policeman and make us laugh. I sneakily think that he wanted to tap my brains with regard to computing technology. He was to begin his amazing journey on the computer, typing, copy and pasting, creating documents, filing (which was one of his favourites!). I’d say “..have you filed it Geoff?” He’d say “Yes I know I did, but don’t ask me where!” It would then be my job to try to find things. Gradually, he did get better and began to learn short cuts. Pathways were always recorded, so he didn’t have to remember them.

Fast forward a few years and Geoff graduated from tower and screen to laptop. This, I feel was the turning point. Emailing and, dare I say it, Social Media? The filing of photos of his hobby- Meccano and of Geoff and Hilary's amazing holidays. It was at this point that we called ourselves 'The Dream Team.' This was our 'coming of age' as a working partnership. Together we changed formats and some of the working practices of the KPA. E was very canny because he processed change without people really realising and so there were no objections.

Geoff's interaction with Social Media presented its own unique problems. One evening, after having been and Geoff and Hilary's, I got a phone call.

"Margaret," he said "something strange has happened to my FB page." I gave him my usual response... "Which button have you pressed now Geoff and what does it say on the screen?"

He replied, "I can't tell you, it's in Russian!"

My youngest son, Philip, just looked at me and said, "What's he done now mum?" He got his laptop out, so we had the same screen – we directed Geoff to the relevant tab to get English back as the default. Do you know, I had to change my preferences on FB wall, so that the 'naughties' that had previously found their way onto my page could be approved, or not, as the case may be. Geoff and Nick Biddiss were terrible rogues: in more recent years, Geoff proved himself adept at 'Skyping', I was very proud of him for that.

Geoff was a good proof reader. He re-worded my 'typos', one memorable one, and Hilary will remember this 'Islets of Langerhans'. His joke was that his spelling and grammar was better than mine and me being a teacher too and him receiving his education in a Church of England Primary School.

There was simplicity in his style of leadership, saying what he needed to say, without offence. His operational approach meant that changes were made that improved the running of the KPA. Any new venture had to be sustainable and not onerous. He was acutely aware of the voluntary nature of the committee. Practical benefit for the patients and their carers was his goal and perseverance: he needed it, because the wheels of the NHS are very slow, when it comes to the donation of equipment.

During Geoff's years as chair, he operated a 'tight ship'. Everyone had their say, but decisions were made based on common sense, patient need and practicality. He always had his eye on the ball as a custodian of funds and together Geoff and Anwar, our previous treasurer, worked tirelessly to ensure this. The introductions of timed agendas ensure pacy meetings that gave everyone a chance to speak, for there to be a discussion- but I tell you, Geoff's reign ensured the shortest meetings, meaningfully led and decisions made. A quote from Arijit Sen, a committee member, "...Geoff and I had our transplant in the same year, after a long wait, so I felt a closeness with similar experiences...I personally feel Geoff, as chairman of the KPA did excellent work..."

I want to leave you with an analogy. A picture of Geoff as a KPA member, committee member, Vice Chair and Chair. I want you to think of the colours **Green** and **Yellow**, with 'G' and 'Y' being the first and last letters of his name. I now want you to think of an electrical plug. In a way, I think an electrical plug is quite fitting for a man who loved trains, a Meccano man from a tender age, building machines that move that are not static.

We all know, in a plug, there are three wires: the 'Live' and the 'Neutral', which form the complete circuit, and the **Green** and **Yellow** of the 'Earth', which doesn't usually form the circuit, but rather acts as a safety wire.

Geoff was that 'Earth wire'. The safety wire which provided the KPA with a safety net. I do feel that this stems from his life as a policeman. He knew the law inside out. You could tell he'd trained officers for Sergeant's exams. The safety net that he provided comprised of a series of questions: -

- What are we wanting to achieve?
- Does it comply with the KPA constitution?
- Does it fit with the Charity Commissioners?
- Are we taking sensible steps?
- What are the practical benefits for patients and carers?
- Is it sustainable?

So long as we ticked all of the above, Geoff was happy.

A huge man with a huge heart and equal spades of humour, which was as Guy Hill, our present chair stated, "... a humour that was a real tonic, when we had our ups and downs, whether that be personally or as a committee." Guy is right when he says that "...Geoff was a man who was level-headed, capable of seeing all views, caring and very understanding of other patient viewpoints..." guy is right when he says that "...Geoff was a real servant to the KPA and we will miss you in so many ways..."

Thank you Geoff for being a friend and colleague. For being the KPA's 'safety net'. Arijit Sen is right when he says that

"...we will miss your presence..."

However, I have been thinking about this over the last couple of days, we have a bonus:

"...a bonus of the most amazing memories."

Thank you.



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



Holiday caravan for Patient use

Located: Newton Hall Holiday Park, Staining Road, Staining, Blackpool, FY3 0AX.



Sleeps 6, in one double bedroom and there are 2 other bedrooms containing 2 single beds in each and a separate toilet & washbasin.

The site has a number of amenities including a newly installed pool, sauna, indoor bowls, fishing lake, children's play facilities, restaurant etc.

There is a 'heavy duty' mobility scooter for use by guests as required.

The current charge is £35/night for the Caravan, inclusive of heating costs etc.

The local bus service provides transport direct to Blackpool & Lytham from the site entrance.

The caravan is provided courtesy of Hope KPA and all details and booking is via a phone call to Ann Hunt, 07769 713087(M) or email granyanny04@hotmail.com.





BRITISH TRANSPLANT GAMES 2019
NEWPORT, WALES
25 - 28 July
Manchester Adults Team Report

The Manchester Adults Team enjoyed a fantastic weekend at the Transplant Games in Newport which began with the hottest day of the year and record breaking temperatures in the UK. With experienced, new and returning competitors in the team we had 12 transplant athletes competing across the 23 sports on offer and with wonderful encouragement given by our supporters who themselves were able to take part in many of the social sports. The team achieved a total of 16 medals (3 Gold, 6 Silver and 7 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, almost 1000 transplant athletes, gathered for the Opening Ceremony at Newport Football Club and were welcomed by local community groups including cheerleaders, brownies and cadets. As always the appreciation to all our donors is prevalent and there were standing ovations, tears and applause for the Live Donors and the Donor Family Network as they entered the stadium. Following the speeches, the flag handover from Birmingham to Newport and the lighting of the Transplant Flame, the Games were officially declared open!

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. Social events for supporters included the Football, Golf, Basketball, Netball and the Donor Run. Also events for Live Donors and Donor Families this year were Track 100 metres, Ball Throw, Long Jump, Swimming 50 metres Freestyle and Badminton Doubles.

The weekend culminated with a Gala Celebration at the amazing Celtic Manor Resort with delicious food and fabulous entertainment, including live music performed by The Valli boys!

Very well done to all our competitors this year:-

Arthur Taylor; Bernard Capper; Connor Ellis; Beth Morris; Holly Loughton; Joseph Wright; Lesley Dunn; Lynsey Wilkinson; Mark Smith; Rumel Rahman; Stephanie Robinson and Zoë Dixon.

On behalf of the whole team I would also like to say a massive thank you to Kidneys For Life for our fabulous 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.

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



New organ donation law in England already saving lives

Friday 20 November 2020 marked six months since Max and Keira's Law (Organ Donation (Deemed Consent) Act 2020) came into effect in England and saw the country shift to an 'opt out' system for organ donation. The new law, which saw England change to an opt out system alongside Wales and Jersey, means that people in England are now considered as willing to donate, unless they have opted out, are in one of the excluded groups or have told their family they don't want to donate.

For the first time since the new law came into effect on 20 May 2020, NHS Blood and Transplant are publishing initial data which highlights the positive impact the new law has had to date in helping to save lives through the gift of organ donation. Initial figures collated up until 31 October 2020 show that so far 135 people have donated their organs, after being considered as willing to donate as they had not expressed an organ donation decision during their lifetime. These donations account for 26% of all donations that took place during the same time period and resulted in a total of 341 organs transplanted.

Anthony Clarkson, Director of Organ and Tissue Donation and Transplantation, at NHS Blood and Transplant, says: *"Although the law change came into effect in the midst of the first lockdown, we have been able to complete training for all of our specialist nurses and implement the new law across the country. It is still early days, but we have been really encouraged by the levels of support shown for organ donation and the new law over the last six months. While it is important to remember that many of these families may have agreed to organ donation even if the law hadn't changed, for others, it has provided them with the confidence to allow organ donation to go ahead."*

Of all the families approached about organ donation between 20 May and 31 October, when the criteria for deemed consent applied, the consent rate (percentage of families giving their agreement for organ donation to go ahead) was 71%. In comparison, the consent rate was 91% for patients who had expressed their decision to donate and 52% for patients who had not expressed a decision and were in one of the excluded groups.

Since April 2016, more than 2000 people across the UK have died while waiting for an organ transplant. The hope is that the new law will eventually enable more people to donate and/or receive the transplants they need. Prior to the law change, around 80% of people in England said that they supported organ donation in principle, but only 38% had actually recorded their decision to donate. When asked, the majority said they just hadn't got around to it.

Courtesy of Kidney Care UK

Kidneys for Life: Morecambe Bay Walk –13 July 2019

On a lovely sunny day on Saturday 13 July my wife, I and friends (along with the authorised guides and about another 200 people) completed the 7 mile walk across the iconic Morecambe Bay sands to help raise funds for the Kidneys for Life.

The event started about 1pm with a crammed (full of bay walkers) ten minute train ride from Kent's Bank railway station, close to Grange-over-Sands to Arnside. We left the car there. This journey takes you over the River Kent which flows from the hills above Kendal and eventually passes Arnside into Morecambe Bay.

To cross the river the train travels over the Arnside viaduct. The railway line opened in 1857, and the viaduct was rebuilt in 1915. There are a total of 50 piers, and the viaduct is 522 yards long. It's amazing with spectacular views across to the Lake District hills in the far distance.

Arnside is a modest sized unspoiled, holiday resort on the estuary of the river Kent. This former fishing port has retained many of the features from its past. The beautiful pier and port areas of the town offer stunning views across Morecambe Bay as well as providing an enduring reminder of Arnside's illustrious history.

As the walk didn't start until about 3pm because the walk can only be completed at low tide we stocked with lunch, pork pies and sausage rolls were the order of the day. Thankfully as the weather was so nice we were able to wear shorts as part of the walk wades through the channel caused by the river Kent flowing into the bay.

Starting by the river side we walked along the river bank for about 2 miles, through a holiday camp finally reaching the shore further west of Arnside. This is where we started to walk across the sands. At first the sand is quite dry soft sand but as you walk further into the bay the sand becomes a lot firmer and the ridges caused by the movement of the tide feel hard under foot. The views to our right were of Grange-over-Sands then in the far distance stretched out outlines of the Lake District Mountains. Behind us you could see Arnside Knott a grassy hillside rising to about 159 metres.

To our left you could see Silverdale, which forms part of the Arnside and Silverdale Area of Outstanding Natural Beauty. The RSPB's Leighton Moss nature reserve is close to the village. The National Trust owns several pieces of land in the area. Further round the coast you could see the promenade Morecambe and then Heysham with its power station, a lovely

promenade Morecambe and then Heysham with its power station, a lovely sight! Still further in the distance you could just make out the shape of Blackpool tower. The walk through the channel was quite an experience. The water was up to my thighs and we were told as the warm water of the river meets the cold water of the Irish Sea it can cause an undercurrent which on very high tides and strong currents can be very dangerous. Thankfully for us the current was very slow which made the crossing easy. The water was surprisingly warm; my wife said it was like being abroad.

We finished the walk about 6.30pm at Kent's bank railway station where we had started the walk. The 7 mile walk took about 3.5 hours and was really enjoyable. Except I decided to wear sandals. It's advised not to wear good shoes because of the salt water. Well the rubbing of the salt water and sand left lovely cut marks across the top of my feet!

It's a fantastic experience so if you fancy doing it when things get back to normal look out for the advert on the Kidneys for Life website

Mike Kewley



How to avoid excess potassium: for renal transplant patients

Potatoes are high in potassium but some may be removed:

- Peeling and soaking the uncooked potatoes for several hours or overnight before cooking.
- Boiling in a large volume of water
- Throw this water away

Do not use to make gravy or sauces

Do not eat potatoes more than once a day (bread, boiled rice and pasta are low potassium alternatives)

Do not eat more than 2 pieces of fruit or 2 portions of vegetables per day

Foods to avoid: Bananas, grapes, melon, mango, apricots, pure fruit juice (including tomato juice) dried fruit e.g. raisins, sultanas, figs, dates

Suitable alternatives: Apples, pears, pineapples, clementine's, mandarins, tangerines (within allowance)

Foods to avoid: All bran, bran flakes, muesli, and any cereals containing fruit or nuts

Suitable alternatives: Puffed wheat, sugar puffs, Weetabix, shredded wheat, porridge, frosted wheat's

Foods to avoid: Baked beans, beetroot, mushrooms, spinach, plantain, yam, avocado

Suitable alternatives: Runner beans, cabbage, carrots, peas, onions, swede, turnip

Foods to avoid: Coffee, chocolate (bars and drinks) evaporated milk, Horlicks, Ovaltine, Complan, Ribena, high juice squashes, beers, lager, stout, cider

Suitable alternatives: Tea, lemonade, orange squash (not high juice), spirits, white wine

Foods to avoid: Peanut butter, all varieties of nuts, potato snacks e.g. crisps, fudge

Suitable alternatives: Corn or wheat snacks, boiled sweets, marshmallows, Turkish delight (not chocolate)

Foods to avoid: Salt, salt substitutes e.g. ruthmol

Suitable alternatives: Pepper, vinegar, herbs, spices

***Speak to the renal dietitians on 0161 276 6521
Information provided by NHS Foundation Trust***

The belated Christmas Quiz

1) In the Dr Who Christmas special in 2017, which actress made her first official appearance as the 13th Doctor?

2) Alphabetically, which of Santa's reindeer comes first?

3) Who is generally recognised as writing the poem "A Visit from St. Nicholas" (also known as "'Twas the Night Before Christmas")?

4) Snowflakes are often portrayed as being 6 sided but studies suggest that less than what percentage of snowflakes exhibit the ideal six-fold symmetric shape?

a) 0.1% b) 1% c) 10%

5) A Bellini is flavoured with which fruit?

6) From the Morecambe and Wise Christmas Special of 1971 can you complete this quote - 'I'm playing all the right notes but ...'?

7) In 'The Gingerbread Man' fairytale, who or what devours the gingerbread man in the end?

8) What stick would you put into a mulled wine?

9) In the 1947 version of Miracle on 34th Street, who plays the little girl Susan Walker?

10) Who wrote the Band Aid song 'Do They Know It's Christmas'?

Renal recipe

I was going through some of my mother's (Mary Kewley) old dialysis papers and found the renal recipe book entitled "No more hardboard and cardboard" compiled by Carol Halliwell a renal patient at Withington Hospital. I think this was published in the late 1980's so its a long time ago.

I thought I would share one of the recipes.

Liver Pate

1 oz salt free butter
1 medium chopped onion (boiled)
4 ozs pigs liver
8 ozs chicken liver
1 clove of garlic peeled and crushed
½ pint water
2 tablespoons sherry
Lemon juice

Fry the onions in the butter and add all the ingredients.

Simmer for 1 hour.

Allow to cook, then liquidise the mixture until smooth and turn out. Add two tablespoons of sherry and a few drops of lemon juice to the mixture and seasoning as requires (no salt). Place in ovenproof dish and cook for 1 hour gas mark 4. (350F or 160 C).

Answers

1) In the Dr Who Christmas special in 2017, which actress made her first official appearance as the 13th Doctor?

Jodie Whittaker

2) Alphabetically, which of Santa's reindeer comes first?

Blitzen (Blitzer)

3) Who is generally recognised as writing the poem "A Visit from St. Nicholas" (also known as "'Twas the Night Before Christmas")?

Clement C. Moore

4) Snowflakes are often portrayed as being 6 sided but studies suggest that less than what percentage of snowflakes exhibit the ideal six-fold symmetric shape?

a) 0.1%

5) A Bellini is flavoured with which fruit?

Peach

6) From the Morecambe and Wise Christmas Special of 1971 can you complete this quote - 'No. I'm playing all the *right* notes. But' ...?

'not *necessarily* in the right order.'

7) In 'The Gingerbread Man' fairytale, who or what devours the gingerbread man in the end?

A fox

8) What stick would you put into a mulled wine?

Cinnamon

9) In the 1947 version of Miracle on 34th Street, who plays the little girl Susan Walker?

Natalie Wood

10) Who wrote the Band Aid song 'Do They Know It's Christmas'?

Bob Geldof and Midge Ure

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

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

Telephone/Mobile

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

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

Important - Data Protection Information:

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

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

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

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.

- Mrs. E. Jenkins & Dr .D. Joseph in memory of Linda Maskell-Glynn £50.00 22.3.19
- Paypal Giving Fund £218.50 12.4.19
- In memory of John Elliott £300.00 30.5.19
- Mrs. L. Myers in memory of David James Myers £50.00 13.6.19
- Paypal Giving Fund £22.00 17.6.19
- Mr. & Mrs. Spooner in memory of Eileen Needle £10.00 19.7.19
- Mrs. J. Grzesiak in memory of Eileen Needle £25.00 19.7.19
- B & C Jacques in memory of Eileen Needle £40.00 19.7.19
- Miss J. Farmer in memory of Eileen Needle £20.00 24.7.19
- Paypal Giving Fund £81.00 9.8.19
- In memory of Zoe Knight nee Chapman £200.00 15.8.19
- S. Bowman in memory of Eileen Needle £10.00 27.8.19
- In memory of Eileen Needle £190.00 27.8.19
- Stella Carrington & family in memory of Zoe Knight £20.00 27.8.19
- In memory of Harold Roy Porter £500.00 5.9.19
- St. Johns Dukinfield in memory of Zoe Knight £424.50 5.9.19
- Miss S. Lailey in memory of Zoe Knight £50.00 18.9.19
- Paypal Giving Fund £107.00 11.10.19
- Mr. & Mrs. L. Shaw £100.00 6.12.19
- Chorlton Sports and Social Club £320.85 6.12.19
- Paypal Giving Fund £179.75 11.12.19
- Alan Proctor in memory of Lynn Proctor Bradshaw £100.00 30.12.19
- Paypal Giving Fund £31.00 17.2.19



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.

Helpful 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 1.30 pm)

Transplant office (appointments) 0161 276 4492/3646

Blood results 0161 276 8721 (1.30-3.30 pm)

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 Pharmacy 07817 136791

Renal Vascular Access nurse 0161 276 7985

British Transplant Games

Zoe Dixon - Manchester Adult Transplant Games team Manager
07780858558

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

Sources of advice

Kidney Care UK
www.kidneycareuk.org

National Kidney Federation
www.kidney.org.uk

GMKIN
gmkin.org.uk

Kidney Research UK
kidneyresearchuk.org

Polycystic Kidney Disease Charity
pkdcharity.org.uk

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 publish and issue newsletters free of charge each year to members.

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