Coventry and Warwickshire Kidney Patients' Association



The Kidney Kourier



June 2016

Coventry and Warwickshire Kidney Patients' Association (Charity Commission Registration Number 508587)

Committee

Grace Newman Chairman and website	01926 770924
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E-mail: info@cwkpa.org.uk

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Donations should be sent to:

Mr T Ivens 9 Fair Close Frankton Rugby CV23 9PL. Cheques should be made payable to **Coventry and Warwickshire KPA**

Articles etc for the *Kourier* should be sent to:

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E-mail: kbalfoursheep@gmail.com

CHAIRMAN'S MESSAGE

Welcome to our June edition of *The Kidney Kourier*.

Our Kate does a grand job of putting this newsletter together to keep local kidney patients informed of the latest news and events. We now have new postcards, designed by Michael Horton, around the local units giving an overview of our work, along with our contact details. If you know of a venue where these would be useful, please let us know and we will put them there!

I am looking forward to our CWKPA trip to Waddesdon Manor this July, somewhere I have not been before. I hope you will join us on this year's outing to a lovely National Trust house and gardens.

We also have some exciting speakers, as well as the Coventry Crocks transplant team competing in Liverpool,



and a fundraising stall at Asda, Walsgrave,.... details inside.

Grace x

DATES FOR YOUR DIARY 2016

Date and time	Event	Location/notes				
Sunday 3 July	Coach Trip to Waddesdon Manor	See website for details				
Sat 9 July 7.15pm	CWKPA meeting, talk by Dr. Gordon McGregor, about the Dialysis exercise machines and the results of the trial	Clifford Bridge Community Centre, Coombe Park Road, Coventry, CV3 2PD				
Mon 25 July	Deadline for September Kidney Kourier	n/a				
Thursday 28-Sun 31 July	British Transplant Games. Liverpool.	Transplant Sport website http://www.transplantsport.org.uk/				
Thur 8 Sept	CWKPA stall, part of Organ Donation Week	Asda, Walsgrave				
Sat 10 Sept 7.15pm	CWKPA meeting, details to follow	Clifford Bridge Community Centre, see above				
8-10 Oct	NKF Conference, entitled <i>Changes?</i> . Please let us know if you would like to attend on one or more days.	Hilton Hotel, Blackpool				
Mon 26 Oct	Deadline for December Kidney Kourier	n/a				
Sat 12 Nov 7.15pm	CWKPA meeting, details to follow	Clifford Bridge Community Centre, see above				

NEWS AND UPDATES

Organ Donation Week 2016 This is the new name for National Transplant Week, as announced by NHS Blood and Transplant recently. This year's Organ Donation Week will take place from Monday 5th-Sunday 11th September 2016. It is an opportunity for the organ donation and transplant community to promote organ donation, both locally and nationally, with the focus of encouraging people to discuss their organ donation decision with family and friends. The CWKPA will have a stall in the large ASDA store in Walsgrave on Thursday 8 September 2016, and as always, volunteers to do an hour or so on the stall would be very, very welcome. Please contact Grace if you can help out.

Stamps Vivienne sends a big thank-you to all who have given her stamps, including some anonymous bags of stamps passed on by Nick West and the nurses. Keep them coming - they bring in a good income!

Annual Dominoes Competition A big thank you to Shelagh Price, family and friends for their donation this year of £577.00, the proceeds from the annual dominoes league competition held at Trent Valley House WMC Bedworth. The total raised so far from these very generous people in memory of Shelagh's husband, Dick, amounts to tens of thousands of pounds over the years.

New TV in Renal Reception As the TV in Renal Reception had called it a day, a new 40" Panasonic with

Freeview was purchased and hopefully is now in place. The previous television, donated by the Reading family in memory of Molly Reading, would no longer work. This facility is very important, particularly to dialysis patients waiting for collection after HD etc. which can sometimes seem a long time.

New Members of CWKPA We welcome three new members to the Kidney Patients' Association this year. If there are any other patients who would like information about the KPA, you can find out more on our website:

www.cwkpa.org.uk

Kidney Quality Improvement Partnership (KQuIP)

This is a new initiative to improve quality of care and life for all renal patients by reducing variation in the quality of care around the UK, and by sharing good practice. Doctors, nurses and patients and carers are to be involved. There are six work streams which need patient/carer representation:

- 1 Projects
- 2 Networks
- 3 Education
- 4 Measurement and Understanding
- 5 Leadership
- 6 Communication and Engagement

There will be a **KQuIP Design Day** on 17 May 2016 If you would like to be involved, please email:

James.McCann@renalregistry.nhs.uk

MEETING BETWEEN MEMBERS OF THE UHCW PATIENT FORUM AND REPRESENTATIVES OF THE TRANSPORT SECTION OF THE LOCAL CLINICAL COMMISSIONING GROUP (CCG)

Nilesh Jogia (NJ) and Chris Smart (CS), both members of our Patients' Forum, met with Shaun Deasey (SD) (CCG transport lead) Donna Nolan Carver (CCG transport contractor) and Kate Montgomery (CCG communications lead) in the third week of March 2016. This is their report.

The two main areas discussed were:

1. Eligibility criteria

- We were informed that the eligibility criteria for Patient Transport Services (PTS) are not unique to Coventry and Warwickshire, but have been rolled out since 2007 across most PTS services.
- There are no separate criteria for renal patients as the PTS criteria have to be seen to be equitable across all patient groups.
- To ensure vulnerable renal patients are not missed out in the 3-monthly review process, West Midlands Ambulance Service (WMAS) and renal services should be communicating lists of these patients, to ensure that bookings are ongoing.
- The CCG assured us that patients who have a medical need for transport will receive it. This was stressed by the CCG. The eligibility criteria are there to ensure

that these patients receive it and those who do not qualify will have to make their own arrangements. At any time the medical need changes for a patient, the situation will be reviewed.

- There is no "history" of eligibility each booking is assessed independently at the time of booking.
- There is an appeals process in place and the CCG is working on communications for patients, to show how this would work.
- It was noted that there are renal patients who are mobile, and those that receive motability allowance are already being provided a resource for travel to and from dialysis. Those who are mobile would be expected to make their own way.
- Transport post-dialysis would be available to those needing it if their medical condition changes postdialysis.
- The CCG also stated that patients meeting the eligibility criteria for travel to dialysis should be also eligible tor transport to hospital appointments. The booking would have to be made by the individual with WMAS before the appointment.

2. Key Performance Indicators (KPIs)

 CS highlighted the clause where a new booking onthe-day is subject to a potential 4-hour delay. Why was this when there was a renal-specific fleet? The CCG outlined that this was a standard condition of onthe-day bookings and that the renal-specific fleet may already be running at maximum efficiency.

- NJ asked whether these KPIs were in line with NICE guidelines. SD responded that the guidelines were for guidance.
- Both CS and NJ commented that since the implementation of the new contract there were improvements in transport waiting times. And that the drivers were very good and helpful.
- They also reported that communication with the Leamington Call Centre was much better than with the old Stafford Centre. But this could be worse in the evenings when the Call Centre switched back to Stafford.

We would like to thank Shaun, Donna and Kate for listening to our concerns. Hopefully we will have created a channel of communication for the future.

I would also like to thank Chris for his time and enthusiasm.

Regards, Nilesh

Many thanks to Nilesh and Chris for taking the time to meet with the CCG staff, and for letting us know the outcome. Discussions of this kind are invaluable in promoting a good transport service for patients, and preventing misunderstandings. Kate (ed)

COACH TRIP TO WADDESDON MANOR, IN MEMORY OF CHRIS AND VIVIAN MEYRICK

The annual Coventry and Warwickshire Kidney Patients' Association charabanc tour will this year be going to Waddesdon Manor, near Aylesbury, on Sunday 3 July. This National Trust estate was created by Baron Ferdinand de Rothschild in the 19th Century. It was farmland when he bought it, and he had the house built in the style of a French chateau, as a country retreat.

As you may remember, Chris Meyrick, who was very active in the CWKPA, passed away some years ago. When her husband Vivian passed away more recently, he left a small legacy to the CWKPA and the committee decided that an appropriate use of this money would be to fund the cost of the coach for this year's trip, for patients and carers. Vivian himself was a coach driver, and was always very supportive of our coach trips, and we on the committee felt it was a nice way to honour their memory.

If you are a member of the National Trust, you will not have to pay for entry to Waddesdon Manor - but don't forget to bring your card! Otherwise, you will need to pay £14.00 entry fee, the group entry fee (normally £20.00).

Waddesdon is a super property which I thoroughly recommend. To book, please contact Grace (01926 770924). **Kate**

FINANCES - thanks to Terry Ivens

Income and Expenditure for January-April 2016:

Income

IMO Ray Bird	£415.00
IMO Jim Croasdell	£25.00
Donations	£32.00
Firebird Singers	£100.00
Mrs G Hillyard - cakemaking	£100.00
Just Giving	£401.25
Legacy - Vivian Metric	£1251.92
Price family - Trent Valley WMC	£577.00
Raffles	£28.00
Sale of books	£8.00
Tachbrook Fish Shop	£90.00

Expenditure

Christmas meal	£60.00
Just Giving fees	£91.07
Parking	£71.60
Postage	£176.08
Printing	£199.20
TV for renal reception	£269.00

DON'T BE AFRAID TO GO ON HOLIDAY

In late 2012, when my 36 year transplanted kidney failed, my first thought was "Oh no, no more holidays". That was until my Consultant, Dr. Simon Fletcher put me right and introduced me to CAPD and APD.

In 2013 we decided to give it a go with some accommodation we had stayed at before. I contacted them to see if they would be prepared to take delivery of the boxes of fluid, to which their reply was that they would be very happy to do so. Not only did they take delivery, but they put it into our accommodation so it was there when we arrived. Everything ran like clockwork. I have spoken to them and they are quite happy for me to recommend them as dialysis-friendly accommodation for anyone who is a little dubious of doing it for the first time.

The accommodation is Cardsmill Farm near Charmouth in Dorset. They have bed and breakfast at the farmhouse and also self catering cottages, some dog friendly. The web site is farmhousedorset.com and the owner is Mrs. Johnson. Another new kidney patient who I know from Walsgrave actually went there on my recommendation and was pleasantly pleased.

This year we decided to venture further afield and have just come back from a week on the Costa Del Sol staying with friends and again everything ran like clockwork – Baxter need to be applauded.

We then decided to be a bit more adventurous and book a holiday in Crete. We visited Thomas Cook and explained the situation and that I needed someone to telephone the accommodation before booking to check they would accept my fluid. The travel agent was most unhelpful and said she had never heard of that before and we didn't get very far.

After a bit of research I found an independent travel agent in Syston, Leicestershire, who arrange accommodation for Freedom Holidays who do the haemodialysis holidays. After a telephone call they sent me a list of accommodation they thought we would like and after choosing one, the agent phoned the hotel to ask the question of the delivery of fluid. No problem, they would be more than happy to help, and I got a confirmatory email to this effect. I then contacted the hotel direct to ask if I could contact them to make sure the delivery had arrived, and they were most obliging and said anything more they could do for me I just had to ask. I would thoroughly recommend anyone thinking of travelling abroad contact Millington Travel, 1238 Melton Road, Syston, LE7 2HB. Telephone 0116 4218888. If anyone would like any more information I would be very happy to help. **Susan Morris** 02476 543311

Thank you, Susan - your experiences are tremendously helpful for anyone worried about going away while on dialysis. I was on CAPD and got the call for my transplant while camping at a folk festival in Lincolnshire. So go for it, if you can!

KOURIER KROSSWORD

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Across	Down
1 Honey insect (3)	1 Heavy footwear (5)
4 Trainee (5)	2 Santa's helpers (5)
9 Stuffing for pillows (5)	3 Paradises (5)
14 Not so young (3)	4 Dishonourable men (4)

45 71	
15 Thin mountain ridge (5)	5 Profit on investment (3)
16 Maternally related (5)	6 Scottish river (3)
17 Dress too formally (9)	7 Aliens, abbr, (3)
19 Beat back (5)	8 Exam taker (6)
20 Camping homes (5)	9 Actress Deborah (4)
21 US comedy film (2011) (5)	10 An epoch (2,3)
23 Hissing sound (4)	11 Wart or corn (9)
24 City on the Ruhr(5)	12 On-target earnings (abbr) (3)
27 Northern Norwegian city (4)	13Mitchell, US comic (3)
30 Many (6)	18 Royal Television Society, (abbr) (3)
32 Dawson, comic (3)	22 Compass direction (3)
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33 Tom Sawyer was one (8)	24 Thompson, UK actress (4)
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33 Tom Sawyer was one (8) 37 College town, Maine, US (5) 39 High-spirited horse (7)	24 Thompson, UK actress (4) 25 Bridge width (4) 26 Railway stop (abbr) (3)
33 Tom Sawyer was one (8) 37 College town, Maine, US (5) 39 High-spirited horse (7) 40 Asphalt (7)	24 Thompson, UK actress (4) 25 Bridge width (4) 26 Railway stop (abbr) (3) 28 Belief (5)
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33 Tom Sawyer was one (8) 37 College town, Maine, US (5) 39 High-spirited horse (7) 40 Asphalt (7) 42 Bed (5) 43 Very close (8) 44 Bear in Barcelona (3) 45 Eg Nadia Comaneci (7) 48 Geek (4)	24 Thompson, UK actress (4) 25 Bridge width (4) 26 Railway stop (abbr) (3) 28 Belief (5) 29 Together (2,3) 30 Putting to work (5) 31 Something else (3,2) 33 Hazardous gas (5) 34 Get up (5)

55 International insurance company (5)	38 Cap'n Jack would drink this (3)
57 Celebratory smoke (5)	40 Brith, international Jewish Organisation (4)
58 To reinforce concrete (5)	41 Otis (anagram) (4)
60 What a matelot does (9)	43 King of Wessex (3)
64 of the ball (5)	46 Japanese cash (3)
65 Lions' locks (5)	47 Noxious air (6)
66 Romanian coin (3)	49 Agreements (5)
67 my case! (1,4)	51 Space station (3)
68 A useful thing (5)	52 Light on one's feet (5)
69 Summer in Paris (3)	53 French artist (5)
	54 Bicker (5)
	56 Waste allowance (4)
	57 Price tag (4)
	58 Baseball stat (3)
	59 Literary, 'ever' (3)
	61 Small batteries (3)
	62 Not outs (3)
	63 Shelter (3)

DOCTOR, DOCTOR . . .

Nurse: Doctor, Doctor, there's an invisible man in the waiting room.

Doctor: Well, go in there and tell him I can't see him!!

Question: How does a crazy person travel through the woods?

Answer: They take the psychopath.

Now, where I come from, when you get a prescription for antibiotics, you don't say, "Will it work? Will there be any side effects?" No, it's "Will I be able to drink with these?"

A man went to visit his doctor. "Doc, my arm hurts really badly. Can you check it out please?", the man pleads. The doctor rolls up the man's sleeve and suddenly hears the arm talk. "Hello, Doctor," says the arm. "Could you lend me twenty pounds please? I'm desperate!" "Aha!" says the doctor. "I see the problem. Your arm is broke!"

Sorry about these - maybe you can send something a bit funnier! Kate

SUDOKU

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Medium

KOURIER KWIZ - What happened in 2015?

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1	Who was the last president to meet the leader of Cuba before Barack Obama?
2	\$1.2 was paid for the original lyrics for which 1971 song by Don McLean?
3	Which horse won the Epsom Derby in 2015?
4	Which ride at Alton Towers failed catastrophically?
5	Christian is the lead character in the 2015 film of which best-selling book?
6	To what did Japan lower its voting age in 2015?
7	Who stepped down as chief of 21st Century Fox?
8	Which car company launched the Avensis?
9	Evidence of water was found on which planet?
10	Which historical feature did Fiji remove from its national flag?
11	Who, aged 21, won the US Masters and the US Open Golf Championships?
12	Which footballer scored the most goals for the England team?
13	Who won the French Open Tennis Championship?
14	Which company launched the S6 Edge smartphone?
15	"Dismaland" was the temporary theme park/exhibition of which famous anonymous artist?
16	Which anniversary did the game of Monopoly celebrate?
17	Name the royal princess born in 2015.
-	

THE KOURIER KROSSWORD SOLUTION

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SUDOKU SOLUTION

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Easy

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4	3	7	5	6	2	1	8	9
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Medium

ANSWERS TO THE KOURIER KWIZ

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1	President Eisenhower
2	American Pie
3	Horn
4	The Smiler
5	Fifty Shades of Grey
6	To 18 years of age (from 20)
7	Rupert Murdoch
8	Toyota
9	Mars
10	The Union Jack
11	Jordan Speith
12	Wayne Rooney
13	Stan Warwinka
14	Samsung
15	Banksy
16	80th anniversary
17	Princess Charlotte - 4th in line to the throne

COVENTRY AND WARWICKSHIRE KIDNEY PATIENTS' ASSOCIATION

Free to Join!

Membership of the Coventry and Warwickshire Kidney Patients' Association is open to all kidney patients, relatives and friends plus anyone who is interested in the welfare of kidney patients. Why not have a look at our website:

www.cwkpa.org.uk

If you would like to join, please complete the form below, or send the information to the Secretary by email.

Mr/Mrs/Ms/Miss (please delete as appropriate)
First name:

Surname:		
Address:		
Postcode:		
Tel:		

E mail:

- If you have any comments, suggestions, ideas etc, please let the Chairperson know.
- Please send the completed form to:

Secretary - Vivienne Dodds
51 Magyar Crescent
Nuneaton
CV11 4SQ
Telephone - 02476 384061
Email - pvdodds@googlemail.com