Royal London Hospital Kidney Patients Association

KPA News
Winter 2015/2016

To make a donation

simply text 'TRLH12'

with an amount of money

e.g. £5.00 to 70070

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Renal Patients Forum

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The **R**oyal **L**ondon **H**ospital **K**idney **P**atients' **A**ssociation (**RLHKPA**)

Working for Kidney Patients …..within Barts Health NHS Trust

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Editorial,

Welcome to our Winter edition of KPA News. Winter - it doesn't sound too good, does it! Will we have snow and ice to contend with?

I've been thinking about the appalling conditions facing some of the people around the world, so a bit of cold weather seems nothing. I thank God that everyone reading this is blessed with a home which, at the end of the day, can be made cosy and welcoming.

I hope each of you finds something of interest. Those hoping for a transplant will be encouraged by an article in METRO 28th October which reads:

Organ Donor list soars to 22million

"MORE than 4million people have joined the organ donor register in the last five years. Numbers have grown from 17.8million in 2011 to 22million as of last week. London has more people registered than any other region, with close to 2.3million on the NHS list compared with 1.8million in 2011. There are 7,000 people on transplant waiting lists."

No one wants to learn of tragedies but, when something dreadful happens, it is good to know there may be life-giving outcomes for people struggling with disability. A heart-warming story of a live donation is recorded on page 8 of this issue.

Were you one of our lucky '97 Winners'? If you missed out, try not to miss out on our next fun event, a **Wild West** evening, with great entertainment and food.

Bon Yuletide or whatever festival you may choose to celebrate or not, Happy Holidays and a Healthy, Prosperous and Peaceful 2016 to you all.

Margaret Craddock

Dates for Your Diary

EVENT	DATE	PLACE
Holiday Home	Any week beginning Sunday or weekends/ mid-week breaks	Poole (see Pull-out section)
World Kidney Day	10th March 2016	RLH ?
Melanie's Variety Event	19th March 2016	Parkside Community Centre
British Transplant Games	28th to 31st July 2016 (Registration opens Feb.2016)	Liverpool
Renal Memorial Service	18th September 2016	Great Hall St. Bart's Hospital
Annual General Meeting	12th October 2016	Dagenham & Redbridge FC
World Transplant Games	25th June 2017	Malaga Spain

The RLHKPA is delighted to invite you to the opening of

DIAMOND LIL'S SALOON BAR

to meet the characters who work there, for an evening of song, dance, good food, good company and a few surprises too!

SATURDAY 19TH MARCH 2016

Parkside Community Centre

176 Goodmayes Lane, Ilford, IG3 9PP

EVENING INCLUDING

ENTERTAINMENT, SUPPER, PASTRIES & TEA/COFFEE

Tickets £15, Concession for KPA Members £12

DOORS OPEN 5.30 PM

SUPPER 6.30 PM

MENUE

Select from 1, 2 or 3

1. Fish & Chips including Roll & Butter
2. Frankfurter &Chips including Beans, Roll & Butter
3. Vegetarian Meal by arrangement

PLEASE CALL MELANIE ON 020 8551 7842

Please come dressed as Buffalo Bill or Calamity Jane, or just sporting a hat, for an amazing WILD WEST evening.

Trustees' Report 2014/2015

The past year's activity has fallen into 3 areas

- Fundraising
- Kidney Awareness
- Greater links with the Renal Patients Forum

Fundraising

We are lucky enough to continue to receive donations from our members and the general public through collecting tins, quiz nights, entertainment evenings and attendance at summer fayres. Thanks go to Ann Spicer, Melanie and Alan Rosenfeld, David Mansfield and their families and friends for their continuing efforts.

Kidney Awareness

The KPA supported an Awareness Day for all kidney patients at the RLH organised by Breeda McManus Senior Haemodialysis Nurse, who had a presence at the RLH Reception on World Kidney Day. We have funded educational DVDs for potential transplant patients. In addition, I would like to thank Les Petchey for his initiative in providing information for kidney patients at the various hospitals and satellite within the Trust, along with leaflet holders provided by the KPA. The value of this information has been commented on by patients and renal staff.

We have been lucky enough to have Adrian Capitan, from Queens Satellite Unit, engaged on building a website for the KPA. This will enable us to reach more patients and, in time, provide the KPA

newsletter on line thereby cutting costs, production time and effort. My thanks go to Adrian and we look forward to seeing the finished article!!!

Kidney awareness and education to patients and the general public is, I believe, key to what we are here for. I hope we can look at how to input further to this in the coming year.

Renal Patients Forum

Over the past year stronger links have been forged between the KPA and the Renal Patients Forum. There is a good understanding on 'who does what' and it has been a pleasure for me to get to know the Chairman, Brian Gracey, and some of the committee.

These links have been strengthened by both Les and David who both spend much of their personal time visiting the units across the trust and, where appropriate, influencing KPA business.

In addition, Les writes a Renal Forum Newsletter, part of which is reproduced in the KPA publication. These links – and, in particular, Les and David's participation in both committees, are bringing us closer to kidney patients by providing an understanding of the issues on the ground and allowing us to meet some of those needs. Long may this relationship continue and grow stronger.

New challenges

As I reflect over the past year, the KPA is changing. As the longer serving committee members continue to quietly carry out their responsibilities and provide stability and a wealth of knowledge and experience, newer members have provided welcome challenges to the

way we do things and are taking new ideas forward with enthusiasm and energy. As I look to the future, we have some challenges that are new to us, but I believe we must work on this in the coming year.

Some members of the committee have given a great number of years to the KPA. (You know who you are!) There would have been no KPA without them. However – we cannot rely on people to remain tied to the KPA because we need them. We need to respect the fact that people may want to move on or reduce their commitment and put plans in place accordingly. To that end we need to recruit new members on to the committee and this must be one of our key aims for 2015/2016.

I would like to thank everyone for their time and energy over the past year. Our Secretary Mark O'Callaghan, our Membership Secretary and chief advisor/cake maker and all round contributor – Margaret Craddock, and our Treasurer Lesley McGarr. Thanks go to Ann, Janice, Melanie and Alan on the fundraising front, and Les, David, Marie and Deborah for their general contribution and support to kidney patients on the ground. Thanks go to Norbert for his dry sense of humour, and chauffeur duties. Finally, I would like to thank Clare Whittaker for her contribution and support as Vice Chairman as she steps down this year.

Jackie Fisher
Chair – The Royal London Hospital KPA
14th October 2015

PatientView

Over the past couple of years, an app has been under development nationally with the co-operation of NHS Trusts within the UK. This was initially launched as '*Renal Patient View' (RPV).*

After the initial release, 'PatientView2' (PV) was launched in 2015 and this is supported by, amongst many others, Barts Health NHS Trust. In 2014, other specialities began using the RPV system starting with IBS and Diabetes.

This means renal patients of Barts Health can, if they register with PatientView, view their blood test results; letters issued by the Trust after the date you register; your medications; plus keep check of the personal information held by the Trust relating to you.

Patients registered with PatientView can give the login details to your GP surgery allowing them to see your blood results, thus keeping them up to date without the need to have additional tests done. They can also download any letter sent by your Renal team so they are notified of any change to your medication.

PatientView is mobile friendly which means you can carry it about with you wherever your phone goes. Your records are available just by logging in to the App. Ideal in case of an unexpected visit to A & E or a doctor when away from home.

To find out more about PatientView, go to www.patientview.org and follow the instructions under the section 'For Patients' I Want to join. I can have my bloods taken on a Wednesday morning and they are ready to view on PatientView by Thursday evening. A very quick service.

Les Petchey

A total stranger gives Kidney to a stranger

I owe my life to a total stranger. Two women met for the first time at a party and within minutes, one had offered to donate her kidney to the other

It was a chat with a stranger at a party that saved Manoly Viravong's life. The mother of two, who had been waiting for a kidney transplant for five years, struck up a conversation with Veronica Buttigieg, a friend of a friend she had never spoken to before.

The talk turned to health and Mrs. Viravong's disappointment that her brother had decided against donating one of his kidneys to her.

But Mrs. Buttigieg, 53, did more than just politely sympathise:over the clink of glasses and chatter of the other guests, she made an amazing offer. 'Why not have one of my kidneys?' she asked.

Friends for life: Manoly Viravong (left) and Veronica Buttigieg.

Two months later, the operation took place and Mrs. Viravong, 45, is well on the way to recovery. Mrs. Buttigieg, who lives with her husband Mario, 54, a painter and decorator, said she would happily donate again if she could.

A total stranger gives Kidney to a stranger

'I barely knew Manoly but after talking to her and hearing of how desperate she was, I felt it was the right thing to do,' she said.

Mrs. Viravong, who has suffered from kidney problems for 18 years, is still astonished at her good fortune.

'I did not know Veronica very well at all. We have a mutual friend and I had seen her at social gatherings a hand full of times but we had never really talked', she recalled.

'Shortly after arriving at the party, which was a friend's 40th wedding anniversary, she offered me her kidney; just in a really casual way.

'I thought that she was joking, so I just said thank you. But then I realised that she was serious.

'I asked her if she was really sure, and she said she was positive. Two days later she had gone to the hospital to be tested to see if we were compatible.

'When I found out we were a match I was stunned. I just couldn't believe it.'

'For two years I had endured eight hours of dialysis a night and my kidneys were deteriorating. My life expectancy was very short – it would have killed me ultimately.

'I had been feeling very low because my brother had changed his mind about giving me his kidney, yet here was a virtual stranger offering to do an amazing, wonderful, selfless thing for me.

Veronica's husband and sons Richard, 20, and Robert, 22, supported her decision, although they became increasingly anxious as the operation neared. 'Mario is used to me,' Mrs. Buttigieg said. 'When I offered Manoly my kidney, I turned to him and asked if it was all right.' He simply said, 'If that is what you would like to do.'

As the operation loomed, the family became more concerned, aware that any type of surgery involving a general anaesthetic always carries a risk. 'We all knew there was a chance I could die,' Mrs. Buttigieg said matter-of-factly. ' But I wasn't worried at all. I am a Christian and I felt that God said it was right. I had a real peace about it because I knew it was what God wanted me to do. I felt completely calm.'

A total stranger gives Kidney to a stranger

*As they waited at **The Royal London Hospital** before surgery, Mrs. Viravong kept asking her new friend if she was definitely sure.*

She said she was positive but she just wanted them to get on with it. After that it was a few days before we could talk to each other again.

When I saw her, I just cried and cried. We held each other and I told her how grateful I was.

The women both live in Leigh-on-Sea, Essex, and the operations took place in July, on the first day of the school summer holidays, so Mrs. Buttigieg, who teaches sick children at Basildon Hospital, could be back at work in time for classes to resume.

By the time of the transplant, Mrs Viravong's kidneys were functioning at just 10 per cent of their capacity. They remain inside her body, along with the transplanted organ.

'I can't really thank her enough. We are very close now, like sisters. I'm really grateful to her and I count my blessings every day.'

Since the operation in July, the women have become the closest of friends.

Mrs. Viravong, who is originally from Laos, is well enough to consider reopening the Thai restaurant she used to run with husband Sene, but closed

due to her ill health. Manoly has two teenage children, Viumee, 18, and Sam, 16, and is relishing every moment with her family. 'It has been wonderful. I have got my life back,' she said.

Veronica with Hannah Perry, an organ donor nurse.

Mrs Buttigieg is back at work, going to the gym and coping perfectly well with one kidney.

Although her safety net is gone if ever she develops kidney problems of her own, she is adamant that she has done the right thing.

She said, 'I have no regrets and I would do it again tomorrow.'

Via **Peter Spray**

97 Winners

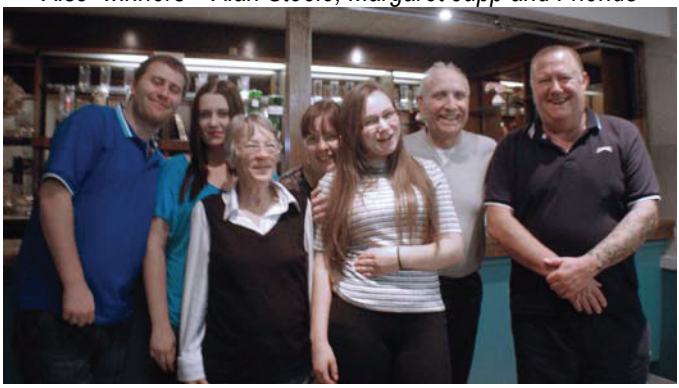
On 17th October, the day which Melanie Rosenfeld said was a favourite date on her calendar because it was **Anne Spicer's** Quiz Night, 97 expectant participants came to Dagenham & Redbridge Football Club's hall to pit their wits and hope to win.
And win they did!

Our Quiz Master, **Justin**, clearly and patiently read the questions which he had compiled. **Margaret** marked and **Norbert** kept score, updating the scoreboard after each of the 10 rounds.

A delicious meal of fish or chicken with chips was enjoyed while the Marathon round was completed and raffle tickets were purchased.
The raffle raised £265 and the winners were pleased with their raffle prizes.

The winning quizzers – Mr Canton and Friends

Also winners – Alan Steele, Margaret Jupp and Friends



And then…we were thrilled to have a very special bike unexpectedly donated by **Paul Eastall** and **Andy Turner** of **SPECIALIZED CYCLES UK** and **SECOND CHANCE CYCLES**. When two young gentlemen, **Laurence Barber** and **David Ford**, offered to bid for the bike, Committee member, Melanie, rose to the challenge of holding an auction. We all waited, with bated breath, as the auction progressed to the final bid of £300 by David. Loud was the cheer from the happy crowd who had enjoyed this extra spectacle following a really fun evening, where new friends were made and the company of old friends enjoyed. We felt we were all winners!

Mark, David and Melanie

Ticket sales, less food etc., brought in £345, raising the total profit to £910!

Margaret Craddock photos by **Elliott Rosenfeld**

A Welcome Break

My wife and our son and his wife accompanied us to holiday in the R.L.H.K.PA.'s flat in Poole in Dorset in August.

The flat was very comfortable and no stone has been left unturned to make it a very pleasant place to stay with everything to make it a home from home.

The surrounding garden, which is through the back gate of the garden, was a very good place to be: it had coy carp in the pond and was a very pleasant place to relax.

The weather wasn't too kind to us, but that didn't stop us from enjoying some of the very pleasant and interesting places in the area.

We visited the "Tank Museum" which is in Boddington and we found it very interesting and we were treated to a demonstration on the field outside. We also enjoyed a very pleasant lunch there.

I was diagnosed with kidney failure 9 months ago and didn't think we could ever take a holiday again!! The flat provided a wonderful break for us all.

The dialysis unit which I attended was superb. A taxi picked me up sharp at 9:00AM. I was given toast and tea on arrival and another cup of tea before I left. The husband and his wife who run the unit are very kind and caring people. I was transported promptly back to the flat at 1:00PM, where I had my lunch and a rest before going out together to some very pleasant beaches and very interesting places to eat.

We ate out every evening at some lovely restaurants in the area.

We thank the charity for providing such an oasis for dialysis patients and their families to have a welcome break.

Thanks again
John, Iris, Gary & Deborah Carter
Upminster

John Carter is currently having dialysis in Queens' Renal Unit.

Editor's note
We are indeed most fortunate that our members are welcomed for dialysis at this excellent facility, the **KC Holiday Dialysis Centre** (Bournemouth), and that Barts Health NHS Trust pay for the sessions!

Fund Raising Day @ Queens Renal Unit.

On Friday 25th September 2015, Gayle Tyrer, a Haemodialysis patient at Queens Renal Unit, held a fundraising day in aid of Macmillan Nurses.

Gayle provided a large quantity of homebaked cakes, including Cup Cakes, Victoria Sponge and Chocolate Masroeni Cake.

After tasting quite a few of the cakes I can verify they were very tasty and by the end of the day, Gayle had raised £100 for her charity.

Thank you very much Gayle for your hard work involved in the day and thanks to all who supported her.

RLHKPA HOLIDAYS

Poole Flat

There are holidays for all members: Pre-dialysis, CAPD, Home and Unit based Haemodialysis and Transplant patients and non-patient members.

How to book a holiday

1. Check with your Unit that you are well enough to go on holiday.
2. Choose the date(s) you wish to go – giving second and third choices.
3. You may also request a second holiday, perhaps to follow on giving you two consecutive weeks, if bookings allow. Second holidays are allocated from March.
4. Complete the Booking Request Form, sign the declaration then send to Margaret Craddock (address on form). Send no money at this stage.

Please book early to avoid disappointment!

Confirmation of your holiday will be sent to you together with payment slips, details of the home and a map of how to get there.

APD/CAPD patients

Your dialysis supplies can be delivered direct to your holiday home provided you give the Home Dialysis Manager at least three weeks' notice.

Haemodialysis patients – Unit/Satellite based and Home patients

Arrangements may be made for haemodialysis patients staying at the Poole flat to dialyse at the KC Holiday Dialysis Centre at Bournemouth. The arrangement of dialysis treatment is subject to availability at the time of booking. The RLHKPA pays, where necessary, for transport to and from the dialysis centre.

Important:

Unit/Satellite based patients must ask their Unit's advice before booking.

Haemodialysis patients must be **stable on treatment for six months** prior to their holiday.

HOLIDAY HOME	CONTRIBUTION* Inclusive for up to six persons	DATES FOR 2015/2016 (w/b = week beginning)
Poole Flat	£200 per week £75 (except during £125 school hols.)	w/b Sundays weekend (12 noon Fri – 12 noon Sun) Mon-Fri (12 noon Mon – 12 noon Fri)

*Requests for financial assistance towards contributions are considered on an individual basis. The KPA is unable to fund alternative holidays.

Accommodation for up to 6 persons

Bedroom 1 two single beds	Bedroom 1 (partitioned) Two child bunk beds	Bedroom 2 one double bed

The Association runs a self-catering holiday flat at Poole (Bournemouth) in Dorset. Administration and maintenance are carried out voluntarily and no profit is made. The home is available to ALL members.

The flat is on the ground floor of a block of six residential flats and, being centrally heated, is available for holidays throughout the year. Bournemouth town centre is a short bus ride from the bus stop outside the flat and, for those more energetic, a gate at the rear of the property opens onto the Central Gardens and affords a pleasant walk to the main beach, pier and shops. The flat is ideally situated for enjoying the south coast with its picturesque villages and the New Forest. (Haemodialysis treatment may be arranged, subject to availability at time of booking.)

The home is well appointed and provides:

- accommodation for up to six persons;
- lounge with colour television;
- well-equipped kitchen with fridge, electric cooker, microwave and a washing machine;
- central-heating / hot water;
- shower;
- facilities for safe CAPD exchanges and APD; and
- garage parking .

NB It is advised that Members on Haemodialysis book early.

BOOKING REQUEST FORM – POOLE FLAT

Name _____

Please Tick:

Pre-dialysis☐ Haemodialysis ☐ CAPD ☐ Transplant ☐ Other ☐

Address _____

_____

_____

Post Code_____ **Tel. No**. _____

Holiday request – Week beginning Sunday:

1st choice 2nd choice 3rd choice

Sunday _____ _____ _____

For Weekend or Midweek break, phone 01277 810326

Please arrange Haemodialysis treatment for me at the KC Holiday Dialysis Centre. (Please tick if required: ☐)

Date of birth _____ Dialysis unit _____

Usual dialysis days _____ _____ _____

Please list the names of ALL your holiday party

	Title (e.g. Mr)	First Name	Last Name	Age (if under 18)
1.		(patient/member)		
2.				
3.				
4.				
5.				
6.				

Send to: **Margaret Craddock, 90 Station Road, West Horndon, BRENTWOOD CM13 3LZ**

RLHKPA Poole Holiday Home ~ Terms and Conditions

1. Bookings are only taken from members of the RLHKPA.
2. A member must be **in residence** throughout the holiday period.
3. A **non-returnable** deposit must be paid **on receipt of booking confirmation** and the **balance** paid a minimum of **four weeks** before the holiday.
4. In the event of a cancellation, please inform the RLHKPA promptly so the holiday facility may be offered to other members.
5. Guests must adhere to the stated times of arrival and departure.
6. No pets (except guide dogs) are allowed at the Poole flat.
7. Cars must be parked in the garage (No 4) and not left on the drive.
8. Please leave the garage **UNLOCKED** at all times as Dialysis supplies are delivered directly into the garage throughout the year.
9. Report any problems or breakages so they may be quickly rectified.
10. **Remove** spare dialysis supplies and all food from cupboards and fridge before you leave.
11. Domestic waste must be put in black sacks and placed in the wheelie bin/recycle bins in the front garden. CAPD clinical waste should be put in yellow sacks (provided) and put in the garage.
12. Cleaners are not employed so please leave the flat in a **clean state** for the next guest.
13. For security and safety **Please note the Check List** on the notice board before you leave.
14. Turn off electric sockets (except kitchen appliances) and lights, lock windows and doors, turn down central heating.
15. Please return the key immediately you return home.
16. The RLHKPA reserves the right to refuse future bookings from guests who contravene these terms and conditions.

.

Declaration: I agree to abide by the booking Terms and Conditions

Signed: _____ Date: _____

NKF Roadshow.

In case you didn't know the National Kidney Federation (NKF) is the National Federation of Kidney Patients Associations from around the country and the RLHKPA is a founder member. This year your KPA sent Deborah Emery, David Mansfield and Marie Given, all kidney patients and committee members and me, KPA Secretary.

David and Marie have been to the Roadshow in recent year but Deborah and I have not been for a few years. I think sometimes you take thinks for granted and think perhaps you won't learn anything new going this year, but now I feel I got it wrong. As many of the speakers are truly inspiring and there is so much to learn.

This year the Roadshow was held in Reading only a two-hour drive away, so I felt there was no excuse for not going and a rewarding experience it was. So what were my highlights?

Dr Jyoti Baharani, Consultant Physician and Nephrologist from North Bristol NHS Trust, explained how she got in to Renal Care by accident, having missed the cut off time for her first choice. Interestingly she highlighted the different attitudes patients had with regard to making decision on their dialysis. Some patients clearly had no interest in making decisions about their treatment and preferred leaving it to the professional, whilst others wanted to take charge. Other patients decide they want treatment not necessarily in line with the professional advice and some prefer to travel to a dialysis centre rather than dialysing at home. After all this we were left with the impression of a doctor who clearly had a great deal of compassion for her patients.

Zandria Richards, a patient, spoke with enthusiasm about her simple but practical steps for managing fluid intake. She has also produced a practical guide. I particular liked her phrase "No one gets it right all the time, but the people who get it right a lot of the time are those who are trying most of the time".

Zandra continued, "Her e are a few of my favourites tips:- Large ice cubes have less surface area than smaller ones, so ultimately contain

less fluid; when out, I ask for a glass of water and the ice separately, just to avoid the strange looks I get when I ask for just for ice; have a drink after a meal and not during; try to avoid foods high in sugar if you can, as they make you very thirsty; try never to finish a drink and even leaving just a couple of inches can make all the difference to how much you become overloaded; whenever possible don't leave drinks in arms reach; sip a small amount and leave the drink in the fridge or another room; use the smallest cups you can find; if out and I want a drink I share whenever possible in order to drink less or just leave the rest or throw it away; try to stay away from places where drink is the main activity.

For more hints from Zandria check out this link:-

http://www.kidney.org.uk/assets/Uploads/Patients-Conference/Zandria-Richards.pdf

Andy Eddy, Chairman, Transplant Sport and a qualified barrister confessed to sleeping in his car during trial breaks and being diagnosed as suffering renal failure. Following his transplant he took part in the transplant games with a good deal of success. Interestingly, before his transplant Andy was a stranger to exercise but he was able to win medals and tells us he is now fitter than he ever was. He now enjoys taking part in sport with fellow transplantees and expressed his gratitude to the family who had agreed to donate their loved ones organs.

Rachel Gair, Patient Centred Care Coordinator, UK Renal Registry, spoke about the difference young people experience when suffering kidney failure and their attitude to treatment.

Adolescence and Chronic Health Problems - Picture the world as an adolescent – peer pressure, development of identity, pre-occupation with appearance, and the joy of the moment, aspirations and dreams for the future. Add to this a serious medical condition. There may be poor self-image and self-esteem, self-confidence, depression and anger displaced onto the disease or treatment.

WHY are they so special? - Non-compliance in adolescents with renal

transplants is four times greater than in adults. The ability to take on the decision making varies greatly in this age group. There is a need to support these young adults beyond the transfer to the adult service

Challenges of working with adolescents - Poorly developed abstract thinking and ability to plan. Difficulty in imagining the future, self-concept. Rejection of medical professionals as part of separation from parents. Exploratory risk- taking behaviours.

Angelo Joseph talked about living life to the full on dialysis and not letting it stop him from enjoying his life including getting married and travelling overseas, including Turkey. Even the language wasn't a problem thanks to Google Translate. Angelo has not sat back to feel sorry for himself. He make the most of his situation and is taking part in sport and raising funds for Kidney related issues and has built his own website. Find out more about Angelo's exploits on the following website.

http://randomactsofkidney.co.uk

In addition to the speakers there were a variety of exhibitors including:
- Class Health brought along a number of publications to help patients understand and learn how to live with Kidney Failure. Including; "Living Well with Kidney Failure" and "Help I've got Kidney Failure". Other publications can be seen at www.classhealth.co.uk.

Baxter's gave away copies of CAPD and APD Travel Booklets.

Oversea Dialysis Centres were represented by **IMED Hospitals** in, Benidorm, Spain www.dialysisinspain.co.uk and **Mesogeois Dialysis Centers** with 7 locations in Greece www.mesogeois.gr

To find out more about the NKF Roadshow in full check this link out.

http://www.kidney.org.uk/about-us/conference/nkf-annual-patients-conference-2015-presentations/

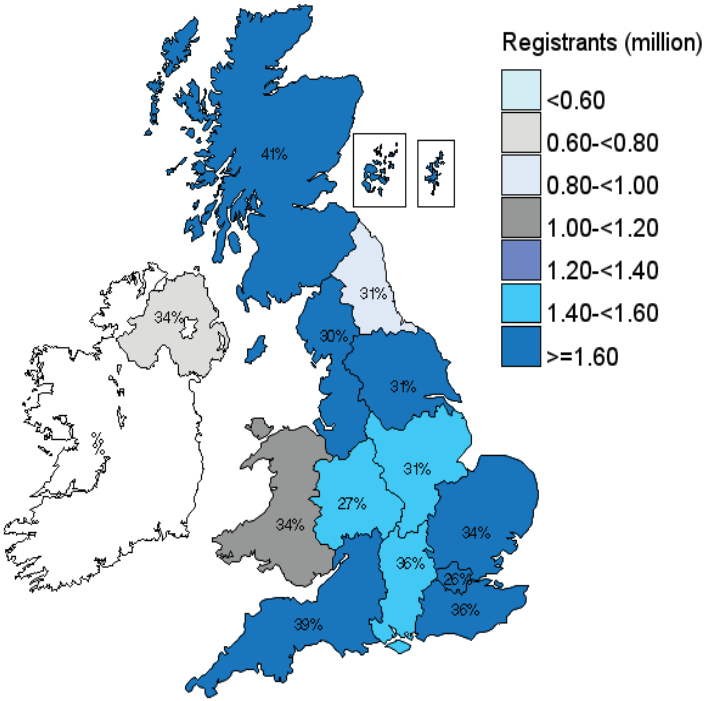
Some patients and carers may have thought about visiting the NKF Roadshow: I urge you to do so if you can!

Mark O'Callaghan, Secretary

Organ Donor Register

Proportion of population registered on the NHS Organ Donor Register by 31 March 2015, by Strategic Health Authority

by 31 March 2015, by Strategic Health Authority



In the financial year to 31 March 2015, compared with the previous year

• There was a 3% fall in the number of deceased donors to 1,282

• The number of donors after brain death fell by 1% to 772, while the number of donors after circulatory death fell by 6% to 510

Organ Donor Register

• The number of living donors fell by 5% to 1,092, accounting for approximately half of the total number of organ donors

• The number of patients whose lives were saved or improved by an organ transplant fell by 5%
to 4,431

• 3,575 patients had their sight restored through a cornea transplant, representing a fall of 3%

The total number of patients registered for a transplant has fallen slightly, so that::

There were 6,943 patients waiting for a transplant at the end of March 2015, with a further 3,375 temporarily suspended from transplant lists
429 patients died while on the active waiting list for their transplant and a further 807 were removed from the transplant list. The removals were mostly as a result of deteriorating health and ineligibility for transplant and many of these patients would have died shortly afterwards.

Some of the other key messages from this report are that, compared with last year, there has been:

• A fall of 7% in the number of pancreas transplants

• A fall of 3% in the total number of liver transplants

• A fall of 12% in the total number of cardiothoracic organ transplants

• A fall of 4% in the total number of kidney transplants

• An increase in the overall referral rate of potential donors from 76% to 80% and the proportion of approaches involving a Specialist Nurse – Organ Donation from 76% to 78%

• A fall in the overall consent/authorisation rate for organ donation from 59% to 58%

NKF In Touch Extra

22nd October 2015

The NKF has had two major successes regarding issues recently reported on at The NKF Annual Conference, in Kidney Life and In Touch.

Commissioning Dialysis Services

The threat of Dialysis Services being commissioned by CCGs instead of centrally by NHS England has receded. Following a long and hard-fought battle waged by the NKF for over a year and involving KPAs we are pleased to report that NHS England has now published *"Improving Value for patients from Specialised Care" – Commissioning intentions 2016/2017 for prescribed Specialised Services.*

NKF is relieved to see there are no wholesale plans to remove Kidney Dialysis from the Specialised Commissioning stable – so from that point of view this is an NKF victory. Even Co-commissioning is not proposed, although there is some experimentation with Collaborative commissioning where Dialysis remains centrally commissioned but in co-operation with CCGs. It should be noted that NHS England (the central commissioners) now splits its work into National, Regional and Sub-regional levels.

Changes that will go ahead are as follows:-

1. Renal in London will be Collaborotively Commissioned across the whole care pathway
2. Data is being collected to highlight service variations in Renal dialysis by Public Health England
3. Some Renal Services will be commissioned via evaluation schemes
4. Renal Transplant is to have a national Tariff
5. Collaborative Commissioning will be proposed where there are links to Obesity and Diabetes in an attempt to increase prevention across the CKD pathway

NKF is very pleased with this, as we seem to have prevented the downgrading of Dialysis from level one commissioning to level three commissioning. The changes that are being proposed make a lot of sense, and as London is a region in its own right (Under the NHS England new tier structure) what is now propose is logical.

Cuts to the Dialysis Tariff

At a meeting with MONITOR on 21st October 2015 the threat to make swinging cuts to the Dialysis Tariff also recede – instead it was understood that the existing Tariff will be "rolled over" to next year – this also followed extensive campaigning by the NKF. The meeting further agreed to ensure that the Tariff was fit for purpose in future years, the following work would be undertaken:-

- Identifying a reference costbaseline
- Involving a 'working group' of stakeholders which can reflect the holistic patient pathwaynand the inherent patient support services of the MDT
- Incentivising Home Dialysis
- And assessing the BPT

The NKF believes this to be a sesible approach and is very pleased at this outcome. NKF thanks the All Party Parliamentary Kidney Group who supported the NKF in both campaigns.

SMILING ☺

Smiling is infectious
You catch it like the 'flu:
When someone smiled at me today
I started smiling too.
I walked around the corner
And someone saw me grin;
When he smiled, I realised
I had passed it on to him.
I thought about the smile
Then realised its worth –
A single smile like mine
Could travel round the Earth
So if you feel a smile begin
Don't leave it undetected;
Start an epidemic quick
And get the world infected.

Sandra Alexander

MEMBERSHIP DETAILS

It is our continued policy to keep our mailing list up to date and avoid any undue distress to relatives who may recently have suffered bereavement.
Please help us by advising any deletions, or other changes, by using the form below.

PLEASE TELL US

□I wish to join the KPA (FREE)

□I am moving home
□I have changed my name
□I have changed my 'phone no.
□I no longer want the Newsletter

Previous	New
Name:_____	Title: Mr/Mrs/Miss/Ms_____
Address:_____	Name:_____
_____	Address:_____
_____	_____
Post Code:_____	_____
	Post Code:_____
	Telephone:_____
	Partner/Friend: Mr/Mrs/Miss/Ms_____
	Name:_____

Please send completed form to the Membership Secretary:
90 Station Road, West Horndon, BRENTWOOD CM13 3LZ

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Help us through Gift Aid to help others – and increase every pound you donate.

If you pay UK income tax and you make a gift aid declaration we can claim back this tax (at basic rate) on your donation so your donation is worth 25% more. Please complete the declaration below and send it, with your donation, to the Treasurer (see back cover).

Please make **cheques/POs payable to: 'RLHKPA'**.

THE ROYAL LONDON HOSPITAL KIDNEY PATIENTS' ASSOCIATION
Registered Charity No. 266660
I
I/We would like the Association, as a Registered Charity, to treat this donation as a Gift Aid donation on which it may reclaim tax. The person below is a UK Tax Payer.

Surname & Initial…….

Address…….

……..

……..

GIVING THROUGH THE SELF ASSESSMENT RETURN (INLAND REVENUE)

RLHKPA is participating in a scheme that will allow any individual to nominate a charity to receive their tax payments as a donation. Our charity's name and code number are listed on the IR website.

For the purpose of this scheme the RLHKPA unique code is **QAE95LG.**
This method of giving is only available on Self-Assessment returns.

Newsletter

Barts Health Renal Patients Forum

The Royal London, Whipps Cross, Newham, Queens and Redbridge Renal Units

EDITORIAL

Well, that's another year's quarter gone by and here we are again. Where does the time go? What happened to summer and autumn?

Transport is still a major topic for discussion at the Forum and Barts Health and the subject is mentioned in this newsletter later.

Whilst Barts Health responds to our approaches when we raise issues on your behalf, I find it disappointing that representation at our meetings by hospital staff is not always met. Whilst I understand that Breeda, Renal Nurse Consultant, is not always available, it would be nice for other representatives to attend more often and be involved in the initial, face to face discussion where the matter may well be resolved.

PatientView seems to have settled down since its rename and relaunch from RenalPatientView and is a good source of information for patients.

We are still looking for patients who are interested in being representatives on the forum to put forward issues, good and bad, for discussion at the meetings.

I personally find that being involved with the Forum is a way of giving something back for the care and treatment I have received over the last 10 years since I started dialysis. Also, whilst the hospital will look at what they consider best for the patient, sometimes this can be misguided. The Forum is the platform where issues affecting the majority can be aired and resolved.

If you think you would like to be involved in this process, please contact Breeda McManus or Brian Gracey from the listing at the end of this newsletter.

As established, there is the round-up of news from around the units. If you have an issue with something at your unit or when visiting Barts or The Royal London, please let us know so we can take it up on your behalf.

Remember, if it affects you, it probably affects someone else as well.

Les Petchey

Transport

As you will all be aware, the provision of transport for patients at Barts Health Trust has been far from trouble free over the last seventeen months or so. ERS, our Transport provider, have experienced a whole range of difficulties trying to deliver an adequate service and have failed the needs of patients time and time again. Dialysis patients, particularly, have missed sessions or been very late as a result of not being picked up or delivered to hospital on time.

As a result, staff have had to change the timings of appointments and alter some patients' sessions, at the last minute. We have also suffered with out-patient appointments and various other one-off hospital sessions.
Over the last six months, with the active involvement of patients, the Trust has been heavily involved in getting ERS to improve their service. ERS has introduced a new computer system and the Trust has introduced a more robust system for monitoring failures by the company when picking up and delivering patients. The new computer system, Cleric, went live this month, October, and it has enabled the Trust to monitor for the first time how successful ERS have been in picking up patients. It has also enabled the Trust to ensure the terms of the contract are being met and, if they are not being met, that appropriate measures can be taken against ERS. The Trust has also introduced a more robust way of recording incidents and it is now possible for each of the dialysis units to record, via a system called Datix, every instance where a patient is picked up or delivered late, to and from their appointments. It is important for us, as patients, to let someone in the unit know whenever an incident occurs and it will then be the responsibility of the unit to record the incident. This is the best way we have of holding ERS to account and for us to be able to accurately assess how well they are performing.
Given all the hard work that has been put into making this contract work, let us hope that, finally, we are going to see ERS's performance improve. It is really helpful, though, to know when things do go wrong, so please don't forget to let the unit know when things don't work as they should.
Let's hope that,in the next update, we can record a distinct improvement.

Brian Gracey (Chair RPF)

Leaflet Holders

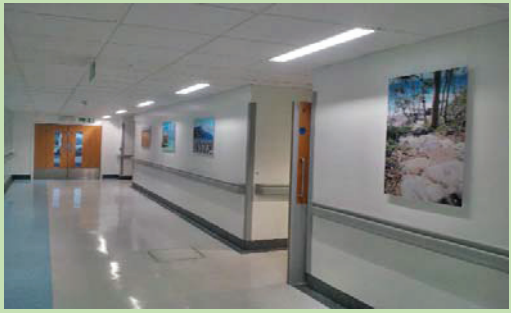
The KPA have now authorised the purchase of leaflet holders for use at Newham and the Whipps Cross dialysis units so we should be seeing some movement in the patient information at these sites. A new printer is also being ordered to replace the old laser that has seen better days.

Unit Round-up

Queens Unit

The outer doors leading to the dialysis unit have now been de-activated and are unlocked between the times of 0700 hours to 1900 hours (7am to 7pm). We are still waiting to hear about the Wi-Fi that is being installed within Queens and as soon as we know anything it will be advertised on our notice board in the waiting area.

The BHR Business Plan is apparently nearing completion so we will be chasing BHR in order that we can start to know our future at Queens.
The entrance corridor has been cleaned, a new handle fitted to the outside of the fire exit doors where we enter and the latest addition has been the installation of pictures along the corridor walls. New signs have also been fitted above the external entrance doors. This makes our environment so much more attractive. Thank you to BHR for listening to us and responding appropriately.



Redbridge Renal Unit.

Holders have been fixed to the wall of the waiting room and stocked with information leaflets and booklets for the patients use. Please use them as they are for your benefit.

Patient car parking is by using the main barrier controlled car park. An A4 size laminated document is given to the patient so when they arrive to exit the park, they press the buzzer on the barrier. The call is answered and they show the document to the camera and the barrier is raised. As King George is part of the BHR group, it is being muted that a concessionary ticket be issued for three months to allow automatic exit from the park.

We have also suggested a dedicated Renal Dialysis car park close by the unit but this would involve money being spent.

Whipps Cross (Renal, Patience and Lister) Renal Unit.

It was noticed that the dedicated renal patients' car park has been taken over by Hospital Staff, probably in view of the building work currently going on next to the unit. Patients are now to park in the parking area where the maintenance area was, displaying the Unit-issued A4 permit in the windscreen. It is felt that this exposes patients to an unnecessary risk as they have to walk around the roadway, past the building site to the far end of the Renal unit and sometimes in the dark. This could be a health and safety risk. As parking is difficult at this location, a dedicated park should be found for the patients. Opposite the unit is an old unmade park holding about 20 vehicles. It has been suggested to Barts Health Renal that part of that park be roped off for the sole use of Renal patients. The building works should be completed soon but we will keep this matter ongoing.

There is a security camera located in the ceiling of the unit and it was felt that this should be covered during unit operating hours as it could be a privacy issue for the patients.

The entrance doors currently being used require fixings to be fitted to enable the doors to be held open whilst wheelchair bound patients are being brought into and out of the unit. There has been no reported outcome on this and follow-up enquiries will be made.

Newham.

It is envisaged that Leaflet holders will be supplied to this unit in the near future. Pat Froyze raised the issue of individual biscuits being given to patients with their tea instead of the small pre-packed biscuits as previously which the Forum found was unreasonable. The Renal General Manager Helen has agreed to look at sourcing refreshments for regular Dialysis patients through NHS Supplies, rather than an external contract.

Royal London Hospital.

As a result of a complaint made by a KPA member attending the 9th Floor, RLH, representation was made to the Renal Team over the lack of hand sanitising fixtures in the Main Reception area. After using public transport to get there, opening doors and using the lift, it was felt there should be hand sanitizers available for hygiene.

The complaint was taken up and initially the response was that the sanitizers had been removed owing to theft. Following consultation between departments, it has been agreed that units will be fitted in the reception area and Infection Control are currently looking for suitable non-alcoholic sanitizers for this area. What a sad world we live in. Thanks to Breeda for following this one through.

The problem of wheelchair entry into the 9th floor of the RLH has been raised as they have to be opened manually. Trust representatives are pursuing the viability of adapting certain selected doors and seeking a quotation from the Small Works section of the Trust. Initial enquiries indicate each selected door could cost approximately £2,000.

The issue of free TVs at the point of view for renal patients at RLH is still being discussed although some agreement has been reached on this matter. This is still being chased as is the matter of Wi-Fi access.

The Bed/Chair repair topic is being followed up with some movement.

Barts Hospital.

A complaint has been received that there are no refreshments available in the Departure Lounge either by vending machine or from the staff. Refreshments such as a cup of tea or coffee with a biscuit were always available whilst patients were waiting for their driver to pick them up, bearing in mind this can be a very long wait followed by a long drive round the East End of London after a long day, often without refreshment (Nil by Mouth) since leaving home in the morning. Whilst some can cope with this, thought has to be given to those with conditions that require dietary controls such as diabetics. Wheelchair bound patients may not have the opportunity of popping off to the local 'Costa'. Enquiries have also indicated this is the same at the RLH although the Stepney Road area appears to have tea refreshment facilities. Representations have been made and this is being looked at by the Trust Admin team.

New Issues – All Units.

Pat raised the issue regarding patient confidentiality around the demise of a Renal patient. It was discussed that Renal patients, through the very nature of the regular close contact with the same people three times a week, for many years, close relationships are formed. When a patient does not appear, it is sometimes assumed that maybe they are an in-patient in a hospital.

Owing to the confidentiality surrounding patient information, it is not always readily available that the friend may have passed away, thus denying their Renal friends the opportunity to pay their respects. This is being pursued by Brian, Chair of the Forum.
Les raised an issue of the desirability of dialysis patients attending hospital on out-patient clinics or day case surgical procedures within Barts Health being prioritised over non-emergency patients. As dialysis patients, they already attend hospital three days a week, sometimes for life, and therefore have just two working days free of the hospital environment. Most Clinics fall on those 'Days Off' and it would make a better experience if they did not have to spend those days again in a hospital environment. Although it is understood such appointments are for the patients' wellbeing, it can affect the psychological wellbeing to seem to be on constant hospital appointments.

Renal Patients Forum Members.

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Meetings are also attended by Breeda McManus, Renal Nurse Consultant, Barts Health NHS Trust.

Donations received 22nd August – 30th October, 2015

We would like to thank the following people for their kind gifts, which were most gratefully received:

£	10.00	Monthly donation J & P White
£	10.00	Monthly donation Mrs J Keat, Billericay
£	5.00	Monthly donation D Dasandi
£	15.00	Monthly donation Mr C Turner, Brentwood
£	10.00	Alex and Matt Richards
£	50.00	Anonymous
£	805.72	Breeda McManus, to date (700 + GA less JG fees)
£	103.00	Raffle proceeds at Aroma Restaurant Quiz
£	150.00	N McGarr, Billericay
£	30.00	G L Ong, E1
£	30.00	Shirley Hodge, Chadwell St.Mary, in memory of her husband Bill
£	2000.00	Bequest from Annette Hewlette
£	500.00	Karen Burwood (sister of Annette)
£	10.00	Mrs B Burrell, Hornchurch
£	171.00	Fundraising by Helen Hunt (Glyn Hopkins Motors)
£	230.00	Raffle money raised at the Aroma Restaurant by Iain Burns
£	100.00	Jo Stevens, Cambridge, in memory of Bruce
£	100.00	Mr & Mrs John Carter, Upminster-holiday appreciation

Fund Raising

£	910.00	Quiz Night profit

Grants paid out

£	840.00	British Transplant Games kit funding
£	1620.00	British Transplant Games accommodation/travel for approx. 10 athletes

Grants pending

Reprinting of DVD – new quote for £740
Request from Breeda for Kidney Patient Awareness event (refreshments)
Refreshments for Memorial Service

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