



KPA NEWSLETTER.
SUMMER / AUTUMN
2017



This is the Beach at Sandbanks, Poole. This is a ten minute drive from the Poole flat.

Why not book your holiday NOW
The centre pull-out has all the information.
Visit our new website and facebook page @

Website: rlhkpa.org.uk

Fb: RLHKPA in groups.

Editorial.

We have gone through a period of reorganization within the KPA, one of the effects of which was that there was no Newsletter for a year. We had one in time for the spring this year and hopefully we are now on track to getting back to our four a year although this year we will not make the autumn edition because of timelines.

A lot has happened in the Royal London Hospital with some of our senior Consultants moving from the renal world to higher positions within the medical management of the Hospital. Two of the moves involve Dr Raj Thuraisingham who was briefly our Clinical Director, is currently interim Divisional Director. In addition to Dr Raj Thuraisingham's move, Dr Neil Ashman, who was the Divisional Director, is moving to the role of Deputy Chief Medical Officer.

At a recent Forum meeting, Dr Thuraisingham spoke about the pressures within the unit created by a combination of staff vacancies, which the unit is trying to fill, and the increased pressure on dialysis slots. This has resulted in a reduced choice for patients on dialysis, in terms of where they dialyse. This latter issue is being looked at but there is no immediate short term solution. Basically, we are having more patients coming into the system with Kidney Failure than the system can cope with. That is why the RLHKPA is, this year, continuing with the World Kidney Day theme of prevention of Kidney failure by looking after your Kidneys, Heart and your weight through adopting a healthy lifestyle to avoid getting high blood pressure or becoming Obese and therefore vulnerable to type 2 diabetes. We can only put the message out there and hope enough people take notice.

With the last edition of the Newsletter (Spring 2017) was a letter stating the hope of some recipients would be interested

receiving the editions by electronic means, i.e. email. Whilst there has been some response to this in that some recipients wish to do this, this does not mean the end of the printed version. Those wishing to receive a hardcopy will continue to receive it by mail. We are looking at other methods with recipients who are dialysing in the units. The postal costs are exorbitant and we are trying to cut unnecessary expenditure. Each edition means a print run of 800 copies and, although we are trying to increase our membership, this will result in ever more costs.

Please be assured, if you wish to have a hard copy, then you will get one.

Enjoy your newsletter, hopefully it is informative and will help to inform you of what is occurring in the kidney world.

Les Petchey.

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Dates for Your Diary



Transplant Week	TBC	https://www.organdonation.nhs.uk
Committee meeting (5)	13 th September 2017.	Dagenham and Redbridge Football Club.
Renal Remembrance Service	24 September 2017	Great Hall, St Bartholomew Hospital, 2pm. In remembrance of all those lost in the past year.
NKF Conference	13-15 October 2017	Leicester http://www.kidney.org.uk/home/news-2/annual-patients-conference-2017/
KPA AGM	11 October 2017	All Welcome. 7pm Dagenham and Redbridge Football club.
Quiz Night	4 th November 2017	For tickets email rlhkpa@gmail.com or contact 02082201756 Ann.
Committee Meeting (6)	15 th November 2017	Dagenham and Redbridge Football Club.
2018		
50 th Year Anniversary of Hanbury Ward		

*The RLHKPA moves into
the 21st Century.*

As mentioned in the editorial, there have been changes within the KPA and two of the changes are that a website has been created with a view to making information more readily available. This information includes links to a lot of the leaflets currently used within our renal world. These leaflets can be found under the 'Renal Online' tab. The current, and archived editions of the Newsletter, can be found under the 'Archives' tab.

The website address is **rlhkpa.org.uk**

Visit the site, try it out and let us know of any comments you may have where you think the site could be improved or changed.

We also have a facebook page which can be accessed within 'groups' under the title '**rlhkpa**'. The site is a closed group whereby you make a request to join the group. Once you have requested to join, an Administrator will grant access and you can join in the conversations

Please remember to moderate comments so as not to cause offence to other members

Use the site, get involved and try to improve our environment. Remember, we are all in this for life, and we all want that to be as long as possible. Let's enjoy it and make the most of it...

ON THE OTHER SIDE.

Humility and resilience in being a patient.

By Matthew Hopkins

During my 20s I was diagnosed with hereditary chronic kidney disease, which meant that last year I was placed on the kidney transplant waiting list. Two months ago I was fortunate enough to have a successful kidney transplant, which will change the way I live my life. As a former nurse and current Chief Executive of a hospital trust I thought I'd share my experience of being on the other side – of being a patient. The humility I've felt, the gratitude I feel and the resilience that I've needed, in the hope that it may help others in a similar position to me.

Last week, on the two month anniversary of my kidney transplant, I received a call from St George's, Tooting. The person on the phone explained that every quarter they hold a patient information session, for people who were in the same position as me two months earlier. People with chronic kidney disease who are facing transplant surgery or their friends and family who might be contemplating live organ donation, as almost a third of kidney donors come from live donors. The patient due to talk about their experience that evening had cancelled and they asked if I'd step in.

No stranger to public speaking, I would normally take this in my stride. As Chief Executive, I'm happy to talk to a room full of people. I have also been known to talk about successes and challenges in my career, including my personal reasons for deciding on a career in cancer nursing. But speaking to a room full of patients, as a patient, knowing that majority of them will be in my shoes in a short period of time was a different ball game. It was a humbling experience.

As I stood before my fellow patients, as a patient, without the protection of status or collar and tie, I felt uneasy knowing that I had been very lucky to have had a transplant while I was still fit and well, and despite very poor kidney function, my symptoms were well managed. Through strong personal resilience and the support of my family and team I'd been able to work hard, enjoy my cycling and my life. However, with deteriorating kidney function, soon I would need to consider dialysis.

With a trembling voice, I told my story of being called in as an emergency to receive a kidney from a deceased person on a Sunday morning in March. Whilst I'd been preparing for this day, I wasn't expecting it so soon due to the national shortage of donated organs. I was sharing my story knowing the vast of my peers, sat in the audience, would have to wait much, much longer. I was humble and filled with absolute gratitude knowing how lucky I had been in only waiting for seven months on the transplant list for a deceased donor to be available that was a good immunological match..

I explained how smooth the admission process felt, and how swiftly I was made ready for my operation. I told of my uncomplicated post-operative recovery, the attentive outpatient follow-up process on discharge, the side effects from the immunosuppressant medications and the care and compassion of the staff.

From the moment I awoke from my transplant operation I knew how lucky I was, and how important it would be to fully commit to the strict programme of kidney health, medications, diet and exercise. And so far I'm doing well. My thoughts are now turning to my return to work. I am active, building strength and stamina again and keen to get back to the helm. When I do return to work, my experience as a patient, and of sharing my experience as patient with other patients, will enhance how I do my job.

So what will I do differently? Three things...

1. The pastoral and coaching support that I provide to my team, will be enhanced as I seek to support them to develop their personal resilience to do a tough job, whilst balancing the challenges that life throws at us. The old adage of 'be kind you don't know what battles others are fighting' is important as a manager and leader.
2. More than ever I am convinced about the power of sharing stories to drive improvement towards outstanding healthcare. I will listen to our patients with a compassion that perhaps I hadn't felt so personally before, I will strive to further enhance our partnership with patients and ensure their voices are heard and their stories shared.
3. And of course, with over 5,000 people waiting for what could be two or three years for a donor, I will be an ambassador for organ donation. It takes two minutes to fill out the form to register to donate.

<https://www.organdonation.nhs.uk/register-to-donate/>

Reproduced with kind permission of:

Matthew Hopkins
Chief Executive Officer (CEO)
Barking, Havering and Redbridge University Trust Hospitals.

British Kidney Patient Association (BKPA)

Notification of Change of Name.

As of 12th June 2017. The British Kidney Patient Association (BKPA) will be known as **Kidney Care UK** the UK's leading kidney patient support charity. The name has changed but we are still the same charity that has supported kidney patients and their families for more than 40 years.

One in eight people in the UK will develop Chronic Kidney Disease but despite this number being so high, kidney health is not high on the agenda of politicians, healthcare professionals, benefit assessors, the media and help for the general public. We want to change that. We have bold ambitions to reach more of the people affected by kidney disease as well as raising awareness of kidney health across the UK.



As you can see, with our new name comes a new logo and website which together will help us to reach more people and raise more funds to allow us to support more kidney patients, than ever before. We will continue to offer all the support services we have provided, as well as developing new ways of helping, continuing health and care services and campaigning for change.



Paddy Tabor MVO, adds: “We’re thrilled to share our new look with you, and excited to work with everyone in the community to help kidney patients take control of their lives, now and in the future. We want to be the charity to turn to; giving kidney patients and their families the support they need, when they need it. Visit our website at www.kidneycareuk.org

Royal London Hospital Kidney Patients' Association
Registered Charity No. 266660

Support us online

with



You can make a donation online by going to:

www.justgiving.com/rlhkpa/donate

All major credit/debit cards are accepted.
25% is automatically added in Gift Aid if you're a UK taxpayer.

Can you enter a Sponsored Event?

- ❖ You can simply create your own page with details and a photo
- ❖ Email your friends and they can donate online
- ❖ The money goes direct to the Royal London Hospital Kidney Patients' Association.

To do this, go to:

www.justgiving.com/rlhkpa/raisemoney

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World Transplant Games 2017.

The 21st World Transplant Games were held in The Malaga in June of this year. More than one thousand athletes and donor families from fifty-two countries converged on the Spanish City for a seven day bonanza of sport. The World Games take place every two years and offer an opportunity for organ recipients from all over the world to celebrate the gift of life they have received and to spread the word about organ donation across the globe.

The lovely city of Malaga proved a stunning location for the games. The opening ceremony took place at the Plaza de Toros (the bull ring) and its majestic new port development provided a glamorous backdrop to the road race at the beginning of the week. The weather was less welcoming however with temperatures reaching upwards of eighty-five degrees. Plenty of sun tan lotion and bottled water were the order of the day as the 175 athletes from the British Games fought to retain their title as the foremost nation in the world of transplant sport.

Great Britain and Northern Ireland managed to top the medals table again with a healthy 152 Gold, 80 Silver and 100 Bronze. A grand total of 332 medals. Tack Booth and myself (Joan Bell) – sole representatives from London Barts – managed to claim our share of the glory with respective successes. Jack winning bronze in the badminton (men’s doubles) and myself winning Gold in field and track (5K, 1500m, 800m and 400m). My own achievements was made no less satisfying for being entered as ‘John rather than Joan Bell’ in the 5K Road Race. Imagine my surprise to find not only that I had been the fastest female runner of my age group but that I had been placed third in the men’s too. Most importantly the Games are a marvelous chance to say hello to old friends as well as new. My thanks go as always to all those who made the event possible and to the support of my friends and family without whose encouragement none of this would have been possible, The World Transplant Games re-camp in two years to Newcastle where we’ll no doubt be seeing some new faces and old. Don’t forget that if you’ve had a

transplant, keeping fit is a great way to staying healthy. Who knows, you might get to represent your country and win a medal! I warn you though, I won't be giving up my titles easily!!!

This is an article by Joan Bell.

July 2017.

Medal Table

Position	Country	Gold	Silver	Bronze	Total	
1	Great Britain and Northern Ireland	152	80	100	332	
2	United States	31	45	35	111	
3	Spain	26	15	12	53	
4	Australia	25	24	18	67	
5	Germany	24	20	20	64	
6	South Africa	22	19	10	51	
7	France	19	11	27	57	
8	Hungary	18	22	30	70	
9	Iran, Islamic Republic of.	17	13	9	39	
10	Argentina	16	19	22	57	



MEMBERSHIP ADDRESS LIST

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. Should you wish to receive KPA News by email, please complete the **form** and send your email address to the Membership Secretary.

<p style="text-align: center;">? ? ?</p> <p style="text-align: center;">PLEASE TELL US</p>	<p><input type="checkbox"/> I wish to join the KPA (FREE)</p> <p><input type="checkbox"/> I am moving home</p> <p><input type="checkbox"/> I have changed my name</p> <p><input type="checkbox"/> I have changed my 'phone no.</p> <p><input type="checkbox"/> I no longer want the Newsletter</p> <p><input type="checkbox"/> Email address</p> <p><input type="checkbox"/> I have changed my email address</p>
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<p>Previous</p> <p>Name: _____</p> <p>Address: _____</p> <p>_____</p> <p>_____</p> <p>Post Code: _____</p> <p>Telephone: _____</p> <p>Email: _____</p>	<p>New</p> <p>Name: _____</p> <p>Address: _____</p> <p>_____</p> <p>_____</p> <p>Post Code: _____</p> <p>Telephone: _____</p> <p>Email: _____</p>
<p>Please send completed form to the Membership Secretary: 90 Station Road, West Horndon, BRENTWOOD CM13 3LZ</p>	

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 2017 (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
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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/integral DVD;
- 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

PLEASE NOTE: THE FLAT IS A NO SMOKING PROPERTY.

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

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

Signed: _____ Date: ____ / ____ / ____

Kiran's Story.

My Name is Kiran Mistry, My Mum has been a patient of the Royal London Hospital Kidney unit since the early 80's. She was on CAPD then had a kidney transplant in 1995 which unfortunately failed in 2012. I've seen first-hand the amazing support from all the staff on the kidney wards and dialysis unit. Earlier this year when mum had another stay of 2 months in hospital, I decided that I needed to do something in order to give something back in support too.

As a result I've chosen to raise money for the Royal London Kidney Patients Association. They are essentially a self-help group, have no paid officials and membership is free. One of their main objectives is to relieve and assist persons suffering from kidney disease who are patients of the Royal London and St Bartholomews Hospital and associated renal units.

Kiran ran in the Great Newham run and, as a result, raised **£2,199.00** for the RLHKPA.

The GREAT NEWHAM LONDON RUN took place by taking the runners through the Queen Elizabeth Olympic Park, starting near the iconic ArcelorMittal Orbit, making its way past the Aquatics Centre before looping back round behind the Stadium towards the Cooper Box Arena. At the 7k mark runners cross the River Lea towards Lea Valley Velopark before eventually heading back to the Stadium. This is a course of 10k metres, no mean feat.

Many thanks to you Kiran for you generosity and marvelous effort. It is greatly appreciated.

Kiran Mistry

Quick Fact: More than 50,000 people in the UK are alive today because of organ donation, new data suggests.

NHS Blood and Transplant said the figure included 36,300 kidney, 9,800 Livers, 1,900 pancreas and 1,000 intestine transplants.

It marks the first time the 50,000 barrier has been broken, the NHS added.

The registered Donors reached a record 23.6 million, up 4.9 million over 5 years.....Source BBC.

GIFT AID

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’**.

<p>THE ROYAL LONDON HOSPITAL KIDNEY PATIENTS’ ASSOCIATION Registered Charity No. 266660</p> <p>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.</p> <p>Surname & Initial.....</p> <p>Address.....</p> <p>.....</p> <p>.....</p>

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.

Summer Fayre at the Chase.

Sunday 18th June 2017 was a blisteringly hot day, in the 30's, and a fine day for the Eastbrookend Fayre run by London Borough of Barking and Dagenham.

The RLHKPA had a stall at the event to raise awareness of kidney disease and to promote a healthy lifestyle in order to reduce risks of Chronic Kidney Disease through high blood pressure and obesity. We had booked two tables but the charity next to us failed to show, so we luckily had three tables. One was used for the raffle, 1st prize a bottle of Champagne very kindly donated by Glen Maloney, and the other two tables used for literature and the sale of Bric-a-brac.



The team consisted of Marie Niven, Glen Maloney and Mel, a friend of Marie's with Mel's dog guarding the monies and Prize. The show consisted of Dog training with the Essex Dog Club display team putting

on a dog show, Lamb National sheep racing, face painting, wall climbing. There was also a falconry display with the birds of prey, pony rides, stables, live music, Archery, bouncy castle, crafts, Go-Karts and local arts and crafts sales. There was also hot food stalls and ice cream vans.

It was a good day for all, finishing at 4pm, and we managed to raise £112 for the KPA funds. May thanks to the team for their time and effort.



Marie Niven



Wings and Wheels Event Damyns Hall, Upminster.

16th July 2017 saw the annual Wings and Wheels event organised by Havering Mind and held at Damyns Aerodrome, Damyns Hall, Upminster. The RLHKPA had a stall at this event where the agenda was to continue the theme of World Kidney Day 2017. This was to promote a healthy lifestyle with a view to prevention of renal disease. A raffle was also



promoted to raise funds for the KPA and the prize was a meal for two at the Holiday Inn, Brook Street, Brentwood, Essex, donated by James Barkhouse, the General Manager at this site. Our sincere thanks to

James Barkhouse and the Holiday Inn organisation for supporting the RLHKPA on the occasion.

The KPA was represented by David Mansfield, Glen Maloney, Les Petchey, Catherine, who used to be a staff member at Queens Dialysis unit and Adrian Capitan. The weather was good in that it did not rain and it was very sunny but, oh, the wind, nearly blew my wig off. The event was very well attended by old military vehicles and classic cars and motorhomes. The London Fire Brigade



was there with an Aerial Ladder which was very busy lifting children high in the air, including quite a few older children, I mean dads.

The day was from 10am – 4pm and we had quite some interest in our literature. We managed to raise £78.00 for the raffle



40th British Transplant Game – North Lanarkshire.

Congratulations and well done to all the Barts London Team who have just returned from the British Transplant Games in North Lanarkshire. As always this year's hosts went out of their way to provide great facilities and could not have been more warm and friendly towards the 850 athletes and over 1,500 spectators.

Transplant Sport who run the games encourages members to participate in activity throughout the year. The annual highlight is the British Transplant Games which brings together hospital teams from across Great Britain and Northern Ireland to join in over 20 different sports events. Participants range from those seeking to set new world transplant records to those for whom just joining in is reward enough.

Transplant Sport Says 'As active transplant recipients, you are the best advert for the success of donation. All our events



strive to increase the numbers of registered donors and emphasise the importance of letting loved ones know about the decision to be a registered donor. After each British Transplant Games, there is a significant increase in the



number of registrations on the Organ Donor Register'

This year the team brought home 17 medals, and whilst the whole team, together with Team Manager Conrad Ryan deserve a big pat on the back, we would like to give a special mention to those++ that received medals. Well Done!!

MEDAL LISTINGS.

Ladies Golf	Sarah Viner	Gold
Mens Golf	Norbert McGarr	Bronze
Cycling 10km Road Race	Jack Booth	Bronze
Cycling 10km Road Race	Tony Capon	Silver
Cycling 5km Time Trial	Jack Booth	Bronze
Cycling 5km Time Trial	Tony Capon	Silver
Tennis	Warren Harris	Silver
Badminton Doubles	Arlene Foster	Bronze
Badminton Doubles	Norbert McGarr	Gold
Swimming Backstroke 50m	Sarah Viner	Bronze
Swimming Butterfly 50m	Sarah Viner	Bronze
Swimming Freestyle 50m	Sarah Viner	Bronze
Mini Marathon 3k	Joan Bell	Gold
Track 1500m	Joan Bell	Gold
Track 400m	Joan Bell	Gold
Ball Throw	Warren Harris	Bronze

If you are interested in knowing more about the Transplant Games, please contact Kelly in the Transplant Office on 0203 594 1754



Joan Bell being awarded a special award for outstanding achievement. Joan won Gold at Malaga in field and track (5K, 1500m, 800m and 400m) and, at the British Transplant Games she won Gold (mini marathon 3K) Gold (1500m) and Gold (400m).

Well done Joan, an outstanding achievement indeed.

Barts Health Renal Patients Forum.

Thursday 29th June 2017 saw the latest of the regular meetings at the RLH. Awareness of the Patient Forum is spreading and it is hoped word of what we are doing will continue to spread. All patients are most welcome to attend these meetings but if anyone has an issue of concern they wish to raise through a different channel, please feel free to drop Brian Gracey a line via his e-mail (briangracey15@gmail.com).

Dr Thuraisingham referred to a new scheme being introduced in the unit to monitor the entitlement of patients to receive NHS care. This is an NHS Improvement initiative, and we are participating in the pilot. All patients will be advised in advance of the changes being implemented but it is likely to involve patients being requested at their appointments to bring some form of I.D. with them. Further details will be announced in due course.

Helen Rainey, Clinical Nurse Specialist (CKD) spoke about a project, the Community Kidney Service that she has been running, in conjunction with Tower Hamlets, Newham and Waltham Forest local authorities.

The project has been running for about 18 months and enables the renal unit to monitor remotely the blood results of patients through their GPs. Any patients whose results are a cause for concern can then be reviewed and appropriate advice provided by the unit, either for the GPs themselves to pass onto the patients, or, where a more serious condition exists, from the renal department itself. The project is likely to identify patients at risk of early kidney damage before they might otherwise have been picked up. It has also reduced the number of patients needing to visit the unit and has allowed patients with more acute problems to be addressed earlier in their disease and, finally, many more patients at risk will receive good advice about how to live a healthy lifestyle.

The Forum has also, in line with the KPA, been going through some

changes in the way it operates.

It has been divided into sub-groups chaired by a patient member of the forum and including other patients and members of staff. These groups have been defined as:

Transport, Home Haemo Dialysis, Well Run Ward, Information sub group and Black, Asian and Minority Ethnic (BAME) subgroup.

Transport. Chaired by Brian Gracey and Ronnie Moodley, this has been responsible for ensuring the transport was improved following the disastrous takeover by ERS three years ago. As a result of the discussions with Trust representatives over the period of time, Nathan Webber, Trust updated the forum on the new Transport contract which will be run In-House, rather than given to an external provider. There was some robust discussion about the risk and benefits of this policy, but the key issue came through that, following the disaster three years ago every effort would be made to ensure there was no repetition this time. ERS, who were represented at the meeting, gave an assurance that the process should be ‘seamless’ to the patient. It was agreed that patients would be involved in the transition process, towards mobilization, which is scheduled for to talk to 1st October.

Home Haemo Dialysis. This sub group is chaired by Richard Endicott, a home Haemo Dialysis Patient. Richard discussed progress made in this area, particularly the formation of a bespoke unit on the 9th floor, which is dedicated to the training of patients who would like to dialyse at home. There are currently three patients training, with a waiting list of thirteen, which is very encouraging. He also spoke of a need to encourage an element of self-care amongst appropriate patients and to this end, the Renal Unit is organizing a number of Road Shows, which visit each of the satellite units to talk about the merits of self-care and the possibility of taking more control over patients’ lives. There will be further announcements about this in due course.

Well Run Ward. This sub group is chaired by Ronnie Moodley and

has recently met where the objectives of the group were discussed and how he would concentrate on specific issues. One of the current issues is the air conditioning, which is leaving too many patients at the RLH too cold while they dialyse. An approach has been made to Skanska (again) and we are waiting for them to respond to suggest improvements.

Information Sub Group. This is chaired by Les Petchey and he is joined by Helen Rainey. The purpose of this group is to look at what information is provided, and to ensure that it is available to patients at an appropriate time in their pathway. There is a great deal of information available but assuring it is accessible electronically is also one of the objectives of the group. The group is also looking at updating both the internal and external websites.

Black, Asian and Minority Ethnic (BAME) Sub Group.

Chaired by Shaila Hussain. This group has not met since the last forum meeting. Its objective is to promote organ donation amongst the Bangladeshi population of East London. To do this requires the support of the local Imams, which it is actively seeking. It is also recruiting peer educators to help spread the word about organ donation. The intention is to run a series of outreach events in the local mosques and provide a forum for discussion about this topic.

Shaila updated the group on her attendance at a workshop in Birmingham on Transplantation within the framework of Sharia, the Muslim code of law. The overall conclusion is that, within Sharia, it is permissible to donate an organ, both as a cadaver and as a live donor, but for this to be accepted more widely, it is necessary to work with key Islamic scholars. This the NHSBT is doing.

Les Petchey.

Important Information Regarding Queens Dialysis Unit.



Following on from the original notification from Barking, Havering and Redbride University Hospital Trust (BHRUT) to Barts Health (BH) that the renal dialysis unit located at Queens Hospital would have to close and re-locate to another location in order to allow BHRUT to implement the planned closure of Accident and Emergency and Maternity Services at King Georges Hospital and to relocate them to an enlarged and improved

location at Queens Hospital. In order to do this modernization at Queens, it was envisaged that the A&E footprint would spread over some of the dialysis unit.

Ever since this notification, the Barts Health Renal Patients Forum has led a programme of meetings with the Senior Management of BHRUT, including the CEO. We have met with the Design Management responsible for the envisaged layout planning and walked some of these people through the dialysis unit.

Once they had an idea of the layout they could understand some of our arguments. They were also told of some of the patients that are at the unit and the need for at least part of the unit to be located within a hospital environment.

It was explained to BHRUT that all the renal patients were in fact BHRUT patients. Whilst we dialyse, we are under the care of Barts Health. Once we return back into the outside world, we then return back to being BHR patients. Should one of us be taken ill and require hospitalisation, then we would invariably go to either Queens or King George hospital. It could invariably be that the renal patient

has to have a limb amputation or other serious operation, but would still have the requirement to dialyse every other day. What is the intention, to drive us around the east end of London to get to a dialysis unit. That would not be a viable answer. No, we would dialyse at Queens.

We also dialyse patients on behalf of BHR so there has to be more consideration given to the requested closure of the unit. There will be more talks in the coming months BUT, during a meeting on July 26th between the Forum, Barts Health and Sarah Tedford, Chief Operating Officer BHRUT, the subject of the A&E alteration was raised.

At this point, Sarah Tedford notified us that BHRUT had won a bid for a large sum of money to allow Queens A&E to have an interim alteration which would include utilising space to be vacated by re-locating the Out Patient Sexual Health and the other therapy units situated around the A&E area. This plan would not affect the dialysis unit.

This is good news but it must be remembered that this is only an interim plan. We must continue with the meetings to ensure our unit at Queens is secure.

Les Petchey

We would like to thank the following people for their kind gifts, which were most gratefully received between 13th March – 4th July, 2017

Donations

£10.00	Monthly donation J & P White
£ 5.00	Monthly donation D Dasandi
£15.00	Monthly donation Mr C Turner, Brentwood.
£100.00	Val Manzi celebrating 13th anniv of new kidney.
£18.00	Norbert McGarr, Billericay.
£20.00	Mrs Beackon, Bow, in memory of Cliff Jenkins.
£300.00	Sale of raffle tickets at 2 quizzes by Iain Burns.
£5.00	Dave Rowland (Transplant Games)
£25.00	Sarah Viner (Transplant Games)
£50.00	Conrad Ryan, proceeds of talk to student doctors
£25.0	June Moors
£100.00	Mr VK Patel & Mrs BV Patel in memory of their son Mayur.
£50.00	Anonymous
£30.00`	Elisabeth Niklaus. In memory of husband Franz.
£30.00	Holiday Appreciation, Ronald Adams.
£910.00	Family and friends in memory of Clifford Jenkins.
£25.00	Miss Green, Ilford, in memory of Mr Moore.

£25.00 Helen Gray, Wickford, in lieu of Christmas Cards to celebrate husband's 10th transplant anniversary. (Just Giving)
£40.00 Natashja King "crochet for kidney patients" (Just Giving.)
£639.00 Kiran Mistry – Great Newham Run (Just Giving).
£50.00 David Daniels, holiday appreciation.
£243.00 Eileen Hand charity shop Stratford
£945.00 Barclays £4£ matching quiz night
£47.00 In memory Michael Pascal
£25.00 in memory Margaret Jupp (After purchase of flowers Renal Unit).
£530.00 Family and friends in memory of Margaret Jupp.

Collection Boxes.

£41.51 Maria Petchey

Foreign/Old Coins/Scrap Metal/Stamps

Fund Raising

£361.00 Quiz night (Mark) profit.
£112.00 Easbrookend Fayre stall. Marie Niven and Gang
£78.00 Wings & Wheels stall, Damyns Hall.

Grants Pending

Ladies Day at the Royal London

Memorial Service Refreshments

Grants Paid Out

£5,000.00 bequest from Joy Keat for Research

YOUR KPA COMMITTEE

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Vice Chair	Vacant
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