



## LEICESTERSHIRE KIDNEY PATIENTS' ASSOCIATION NEWSLETTER – APRIL 2012

Leicester General Hospital, Gwendolen Road, Leicester LE5 4PW  
[www.lkpa.org.uk](http://www.lkpa.org.uk) Charity No 505795

### FROM THE CHAIRPERSON

Welcome to the first Newsletter of 2012, which I hope finds you enjoying the early Spring (though probably not the summery conditions that we had earlier). Please accept our apologies for there being no Newsletter in February – a mixture of the Editor's ill health and our involvement in preparations for World Kidney Day (WKD) on March 8<sup>th</sup> – see inside on the 'Events' page for more details of WKD

We have changed the Newsletter format, putting contact details for the committee and details of the website etc. on the back page. . I hope that you enjoy reading this newsletter and we look forward to receiving your feedback on it and on possible events, such as a coach trip. We need YOUR feedback and comments so that we can better deliver what you wish the LKPA to provide.

Margaret Ince

April 11<sup>th</sup> 2012



**World Kidney Day at LGH, 8 March 2012**

### OLYMPIC TORCH – CONGRATULATIONS TO CARLA SMITH

Carla was successful in her bid so will be carrying the Olympic torch when it passes through Oadby in Leicestershire on July 2<sup>nd</sup>. If you live locally, go out on the 2<sup>nd</sup> and cheer her and the other torch bearers as they pass the flame from one to the other on its route to the Olympic Park.

Carla, who received a transplant from her sister in 2001, is a long standing, active member of LKPA. At present she manages the LKPA website and the growing Facebook network. Thank you to all who supported her bid.

The Leicestershire Kidney Patients' Association (LKPA) is a charity which promotes and supports the health and welfare of renal patients (and families); supports Leicester General Hospital and its satellite Renal Units; and provides education/information on renal disease to the general public.

LKPA: Charity No. 505795 Website: [www.lkpa.org.uk](http://www.lkpa.org.uk)



## LKPA - NEWSLETTER – April 2012

### EVENTS

#### WORLD KIDNEY DAY

To celebrate the many successful kidney transplants performed in Leicester, and highlight the importance for all of us to join the National Organ Donor Register, there was a balloon launch by over 200 transplant recipients, donors, people waiting for a transplant and staff from the John Walls Renal Unit and the Transplant Unit. Thanks to all of you who were able to come and support the launch – and also contribute to the nearly £600 raised on the day. Many others deserve 'Thanks' – the planning committee, the speakers, the backroom workers who blew up and netted (on a windy day) over 400 balloons, the band 'JETS' for the entertainment both outside at the balloon launch and later in the restaurant, and the many hands who set up, manned, and then dismantled the stands, NHS staff who took BPs etc. and others not specifically mentioned!

Two of the comments afterwards were:

"It was a very positive and uplifting event for everyone involved and it is certainly good for nurses and doctors to see people so well outside of the hospital environment. I am very sure that the kidney recipient speeches gave others a lot of encouragement; it was a credit to one and all."

"I was blown away by the number of people there, the speeches were moving and the band and balloons going off were wonderful."

One surprise announcement made on the day by Hon. Dr Peter Topham was the receipt of a letter from Buckingham Palace. The full text is too long to include but Her Majesty sent 'her congratulations to the Leicester Kidney Transplant Unit for its success in treating patients with kidney failure and for encouraging young people to become donors.'

#### EASTER FUND-RAISING

We have raised over £700 (to support coach/mini bus outings in summer/autumn) by selling Easter goods at LGH, Loughborough Hospital, the Hamilton unit and at the great Central Railway. Thanks to the LKPA team who knitted the chicks, bunnies etc and those manning the stalls.

#### FUTURE EVENTS

We have booked stands at the following events

June 2nd	Queen's Jubilee Street party, Markfield Community Centre
June 17 <sup>th</sup>	Kidney Care Appeal sponsored walk, Ratcliffe College Ratcliffe on the Wreake, Leicester, LE7 4SG
September 2nd	Knighton Park Community Fun Day

Suggestions for other events made by the committee include:

#### May/June/July/August

- Would you like to attend a renal questions and answers session?

The LKPA is organising this, probably in late May/early June. The panel will be made up of clinical staff and renal patients. Questions can be asked on the day or submitted in advance. If you are interested in attending please notify us so we can book an appropriate room. Questions are to be submitted before 12th May. The clinical staff give their time voluntarily so LKPA members need to ensure that the event is well attended. Once a date, location and time are finalised it will be advertised on our website, in the dialysis units and clinics and on ward notice boards.

To submit questions and notify interest to attend, please contact Mr Bharat Patel by email (kidneytrust24@yahoo.co.uk) or telephone (0116 2123710) or via the LGH postal address.

**EVENTS (CONTINUED)**

- Visits to a local park (e.g. Abbey or Victoria Park) where we could meet others and visit the café (tea/coffee/soft drink supplied through the LKPA) and maybe have a short walk in the park. Most people in the Leicester area should be able to reach either of these parks by public transport. For the less able we will look at alternative transport options.
- Coffee morning/afternoon tea socials in different locations in Leicestershire where patients in that area show an interest (e.g. Loughborough, Market Harborough). These could be arranged by the LKPA committee of a member living in the area. Please contact us if you would like to arrange an event in your area.

**September**

Excursion Coach Trip

At the request of members, the LKPA committee is planning a coach trip this autumn (probably a Sunday in September) but the location has yet to be decided as we need feedback from you on your preferences. Suggested destinations include countryside attractions (e.g. Trentham Gardens or Rutland Water) or the seaside (e.g. Skegness, Mablethorpe, or Cleethorpes). The cost of the trip inclusive of packed lunch will be a **maximum** of £20.00. Once the venue is decided you will need to pay a £5 deposit to secure a place. The date has yet to be decided. Interested members have to notify us so that we can decide on the destination and book suitable transport.

NB: The LKPA will be supporting NHS nursing staff to accompany us on the excursion to provide medical assistance if required. We will also book coaches with suitable disabled access and on-board toilet facilities. (Check our website for updates).

---

**EVENTS FORM**

Event	Interest (delete as appropriate)	Preference (date/day/venue)
Question and Answer session	I am/am not interested	
Visit to Abbey/Victoria Park	I am/am not interested	
Coach excursion (countryside)	I am/am not interested	
Coach excursion (seaside)	I am/am not interested	
Local event (outside Leicester)	I am/am not interested	

Name: (Print)

Address: \_\_\_\_\_  
 \_\_\_\_\_  
 \_\_\_\_\_  
 \_\_\_\_\_

Email/Telephone No.: \_\_\_\_\_

Please complete and return to LKPA c/o LGH or by email to a committee member

**LKPA MEMBERSHIP: WHO ARE OUR MEMBERS?**

- All kidney patients of University Hospitals of Leicester and its satellite units
- BUT** they have to supply us with their contact details (UHL cannot because of data protection)
- Interested NHS staff from UHL and satellite units
- Interested family and friends of renal patients
- Members of the general public with interest in supporting the LKPA and kidney patients

Currently we have about 1100 members but very few are actively involved with the LKPA and its events. We would like to change this so it is important that we hear from you what you would like in terms of social activities, information/education session, Newsletter articles, merchandise (e.g. alert wristbands, trolley tokens, pens, T-shirts/polo shirts etc.)

NB: The Kidney Donor/Kidney Recipient T-shirts were very popular on WKD and you will certainly notice committee members around the hospital and at events in their purple/white logo hoodies or white/purple logo polo shirts.

**NEWSLETTER “ ALERT”**

The escalating postage costs mean that the LKPA committee has reviewed distribution of the Newsletter. We are, therefore, notifying all members and interested persons that this is the last Newsletter that is being distributed to all members by post. In future it will be available at dialysis units, on wards and at outpatient clinics (at LGH and satellite units). It will only be sent by post to members who specifically request it by completing the slip below and returning it to us c/o LGH. Alternatively, if you wish to receive it by email please inform us by email (kidneytrust24@yahoo.co.uk) – ensuring that we have your correct email/postal address (if we don't already have it).

**NEWSLETTER FEEDBACK FORM**

Question	Your feedback
I am happy to receive the Newsletter when at the dialysis unit	Yes/No
I wish to continue receiving the Newsletter by post.	Yes/No
I wish to receive the Newsletter by email	Yes/No
I no longer wish to receive the Newsletter	Yes/No
What type of articles would you like to see in the Newsletter?	
Any other comments?	

Name: (Print) \_\_\_\_\_

Address: \_\_\_\_\_  
 \_\_\_\_\_  
 \_\_\_\_\_  
 \_\_\_\_\_

Email/Telephone No.: \_\_\_\_\_

Please complete and return to LKPA c/o LGH or by email to a committee member.



### **PATIENTS' STORIES**

This year the focus of World Kidney Day was Transplantation. Every single day one person in this country dies whilst waiting for a kidney transplant and there are over 400 people waiting for a kidney transplant in Leicestershire and the surrounding area. Leicester General Hospital now performs about 90 kidney transplants each year. More than half come from living donors. Whilst a 35 year-old patient on dialysis has the same life expectancy as a 75 year old adult with healthy kidneys, he/she could benefit from transplantation, not least from avoiding their time-consuming dialysis treatment. This Newsletter has, therefore, two stories from LGH transplant patients (both cadaveric).

#### **A KIDNEY PATIENT'S TRANSPLANT STORY-1**

I was diagnosed with kidney disease in the early 90's and placed on various medications. Clinic staff were preparing me for dialysis and adjusting my lifestyle when, out of the blue, I had a call from Ward 17 to say that there was a kidney available for transplant. I rushed to the Ward and, after positive test results, the transplant went ahead the following day.

When I was discharged from the ward, I was advised to follow a diet regime and, at best of times, I did - helped by my wife and daughters who gave up food/drink items which I could not eat. I sincerely believe that this sacrifice greatly helped me to avoid the temptation.

During my recovery stage and ultimate return to work, my wife, daughters, friends and work colleagues have been extremely supportive, without which I believe I would not have recovered so well or quickly. My work colleagues and management team provided me the best of support and even now they ensure that my workload is relatively stress-free. I wish to say a huge 'Thank you' to one and all from the bottom of my heart.

Of course, this could not have happened without the surgeons, the supporting medical staff and the whole Ward 17 nursing team, not forgetting the domestic team and the pharmacy team. Their efforts in ensuring all patients recover quickly and are looked after is, in my opinion, of the very best and deserves appropriate recognition.

I would like to emphasise to all transplant patients that the pain is worth going through. The best way for a quick recovery is to follow the medical guidance and, most importantly, ensure you take all your medications without fail. I would encourage one and all to carry a donor card and I can tell all of you that, without me having a kidney transplant, my whole life would have been completely different.

#### **A KIDNEY PATIENT'S TRANSPLANT STORY-2**

I was on the transplant list for five years and had overnight Peritoneal Dialysis during this time. My cadaver transplant was in April last year (2011) and six days after the operation I was home and feeling really well. A week later the kidney rejected and I also had an infection. It was back to hospital for three weeks while these issues were resolved.

During the next three months, I was unlucky to keep getting urine infections that were resistant to a lot of antibiotics. This resulted in spending a few days in hospital each time but the problem was dealt with quickly and efficiently by Ward 17 staff. The freedom from dialysis and feeling of well-being far outweigh the setbacks. I cannot thank all on Ward 17 enough for all they have done. Their expertise, kindness and support was, and still is, second to none.

**PHOTOGRAPHS FROM LKPA EVENTS**



The LKPA stand at GCR's Loughborough Station – new hoodies needed on a cold Easter Sunday!



Members around the LKPA stand at LGH on World Kidney Day, March 8<sup>th</sup> 2012



Pictures of the KCA-LKPA balloon launch on World Kidney Day, March 8<sup>th</sup> 2012



### MEMBERS' PAGE

This page is where we would like to see news, notices, stories etc. from YOU. Please send them in to Bharat Patel by June 30<sup>th</sup>, ready for the next Newsletter.

Examples of what you may wish to send in include:

- Stories from pre-dialysis and dialysis patients
- Questions/queries that other patients may be able to help with.
- Adverts for LKPA events that you are holding in your own area.
- Comments on 'holiday' dialysis units that you have visited (good and not so good).
- Well wishes and congratulations

Best wishes to Dave for a speedy recovery following his recent illness.

From Ann and Margaret

Congratulations to Margaret and Frank Ince on the first transplant anniversary on May 5<sup>th</sup>.

From the rest of the LKPA committee

### STOP PRESS

In the Easter raffle, the giant Easter egg was won by Tammy Bevin from Corby. Thank you to all who supported us.

### RENAL FRIENDS' SUPPORT NETWORK

We have had a suggestion from a member that we set up a support network for patients who rarely go out or are frail and have no close family or friends nearby to visit them. To do this we would need to know who would like to be visited and who is willing to volunteer to visit someone living in their area. Please let us know if:

EITHER:

You are housebound or, apart from going to dialysis sessions, rarely go out.

OR:

You could give an hour or so once a week/fortnight/month to visit a housebound renal patient?



## LKPA - NEWSLETTER – April 2012

### LKPA GRANT and FUNDING EXPENDITURE

<b>Patient grants</b> Two patients received a grant for a garden shed for storing dialysis materials	£500
<b>Research projects at LGH</b> 1. Patient Involvement in cardiovascular risk control (pilot in outpatient's clinic) managed by Dr Reem Al Jayyousi. LKPA funding will provide BP and weighing machines.	£700
2. Equipment for haemodialysis bay on Ward 15A. LKPA funding will provide: - a wall mounted Television for patients to watch. - Medstrom Interlocking Drip Stands	£182 £1560
<b>World Kidney Day and Kidney Care Appeal Walk</b> Advertisement in Leicester Mercury's MORE Magazine urging people to become donors. Part funding for the World Kidney Day balloon launch and this year's Kidney Care Appeal Sponsored Walk (June 17 <sup>th</sup> )	£600 £1500
<b>Total</b>	<b>£5042</b>

### LKPA Website ([www.lkpa.org.uk](http://www.lkpa.org.uk))

The website provides information about the LKPA and also links to sites where you can find a wealth of useful information and advice.

It is **YOUR** website so please send in articles, information and queries to share with other members.

### FACEBOOK

LKPA Members have the opportunity to join and make friends via Facebook. To join type LKPA and then click on the kidney bear.

### LKPA COMMITTEE

All Committee members are volunteers, mostly renal patients themselves. The Association relies solely on charitable means to fund its activities. We are always happy to welcome members who are interested in either joining the committee or supporting the LKPA at its events. We welcome ideas from the membership, any of whom are welcome to attend our bi-monthly meetings, normally the last Sunday in alternate months. The next meeting is, however, on Sunday May 20th at 10.30 in the Small Committee Room at LGH. The table below provides names and contact details for the committee. For additional information and any additions/changes please look at the website or ward, clinic, and dialysis unit notice boards.

<b>Chairperson</b>	Margaret Ince	lkpa_mi@yahoo.co.uk	<b>Other Committee Members</b> Beverly King; Helen Noon John Lancaster; Avril Patel Naresh Lakhani
<b>Secretary</b>	Ann Carter	lkpasecretary@yahoo.co.uk	
<b>Treasurer</b>	Madhu Madhani	lkpatreasurer@yahoo.co.uk	
<b>Newsletter</b>	Bharat Patel	kidneytrust24@yahoo.co.uk	
<b>Contact address:</b> Leicester General Hospital, Gwendolen Road, LEICESTER, LE5 4PW			

The Leicestershire Kidney Patients' Association (LKPA) is a charity which promotes and supports the health and welfare of renal patients (and families); supports Leicester General Hospital and its satellite Renal Units; and provides education/information on renal disease to the general public.

LKPA: Charity No. 505795 Website: [www.lkpa.org.uk](http://www.lkpa.org.uk)