



LEICESTERSHIRE KIDNEY PATIENTS' ASSOCIATION NEWSLETTER – NOVEMBER 2012

Leicester General Hospital, Gwendolen Road, Leicester LE5 4PW
www.lkpa.org.uk Charity No 505795

Chairperson's Remarks

As we have quite a full issue for the final Newsletter of 2012, I will keep my remarks short. Today it is clear that Autumn has definitely arrived and, according to the weather forecast, Winter is on the way sooner rather than later. That means that Diwali and Christmas preparations are also here. The LKPA is certainly planning for both of these with items for stands at LGH and elsewhere. We hope to see some of you at these and look forward to receiving further support in the future (see notes from the 2011-12 AGM). Please look at the reports of past and future events, especially the LKPA Christmas Party on December 14th - the Christmas raffle will be drawn at this event.

I hope that you are looking forward to celebrating the seasonal events and that we have a happy, prosperous and (typed with feeling in my case) healthy 2013!

Margaret Ince, November 2012

IMPORTANT INFORMATION ABOUT THE LKPA NEWSLETTER

In the AGM notes you will also see that balancing income with expenditure is an on-going issue. We are therefore following through with revising methods for Newsletter circulation – as detailed in the April 2012 issue. This means that this will be the **last** Newsletter that you receive by post unless you have either already opted for the email version or inform us in writing (c/o LGH) or by email (lkpa_mi@yahoo.co.uk) that you wish to keep receiving a paper copy by post. We will, however, continue to make paper copies available on wards, in dialysis units and at clinics (at LGH and Loughborough).



Some of the Skegness day-trippers



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REPORT ON THE LEICESTERSHIRE KIDNEY PATIENTS' ASSOCIATION 2012 AGM

Reports presented at the AGM included information on:

- **Events** that the LKPA ran/attended since the September 2011 AGM. These included the pantomime (not very well attended this time round), stalls a number of Leicester Parks, Great Central Railway events as well as at LGH and Loughborough and the KCA Walk. Notable events at LGH were World Kidney Day, Olympic Torch events with Carla Smith and her torch, and a Queen's Golden Jubilee Event at Markfield. These events raised ~£3000 to support LKPA grants and subsidise the September 2012 coach trip.
- **Members' grants** e.g. assistance with provision of storage facilities for home dialysis medication and attendance at the UK Transplant games.
- **Hospital grants** e.g. further assistance to LGH Ward 15 and the Kidney Care Appeal.
- **Newsletter** distribution in September 2011 and April and August 2012– stories, reports etc. from members always welcome (submit to the LKPA c/o LGH or by email to Bharat at kidneytrust24@yahoo.co.uk).
- **Financial** information (see separate financial summary). We spent more than our proposed budget due to increased activities and support to LGH. As our guaranteed income remains at £6000 (interest on a charitable bond) we do need members support to raise more income and also consider alternatives – such as 'regular giving'.
- **Future programme** there will be a programme of both fund-raising and social events (including a Christmas party and another coach trip). We now have an Events subcommittee to organise this programme).
- **Thanks** – to retiring committee members (Mohammad Anwar, Edie Dewing, Beverly King and Jayshree Pattni), to Carla Smith for her work on setting up the Website (new Website Manager) and Facebook communication (Carla will continue to run this), to supporting members and NHS staff and others in external organisations, family and friends of deceased members who have made donations to the LKPA.
- **Condolences** - to family and friends of members who have passed away during the year and especially the widow, family and friends of Wilf Patterson, our previous Chairperson, for his work with/for the LKPA.
- **LKPA Committee Elections** –The newly elected committee, which has 3 vacancies, is detailed on the back page. Please contact the Chair or Secretary if you are interested in possibly filling one of the vacancies.
- **Financial Summary**

Income		Expenditure	
Bonds Income	£6000	Events (goods+ equipment)/KCA activities	£11500
Sales/Events/donations	£3064	Hospital grants	£2660
		Welfare grants, subsidised outings, miscellaneous	£2560
Total	£9064	Total	£16720

With the treasurer's full support, the committee agreed to use £7650 from the reserve funds in this financial year to 'kick-start' new LKPA activities, which included subsidising some events and one-off purchases (display boards, tables, gazebo etc. for events and stands).

Chair's Comments

Once again the AGM, whilst productive (ideas for events/activities). was **very poorly** attended.

Does this mean that:

- you are happy with the way we are operating?
- you are not interested in how the LKPA committee works?
- you are happy to attend events but are not willing/able to contribute to their planning and management? or
- you have no interest in and/or do not value what the LKPA is achieving?



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REPORT ON THE LEICESTERSHIRE KIDNEY PATIENTS' ASSOCIATION 2012 AGM (continued)

We ardently wish to see the LKPA continue with the magnificent progress it has made over the last 18 months and to meet its mission aims, therefore we would be **very pleased** to receive either negative or positive constructive feedback from members (that's **YOU**). After all, it is **YOUR ASSOCIATION** and operates to: promote and support the health and welfare of renal patients (and families); support Leicester General Hospital and its satellite Renal Units; and provide education/information on renal disease to the general public. We would value every contribution YOU can make, be it -

- time to help at an event or run one yourself;
- provide goods for sale on the LKPA stand;
- help with distribution of leaflets, newsletters etc. on wards and units (beneficial saving on postage);
- participating on trips – or helping to organise them before or on the day; or
- writing about your experiences for the Newsletter (e.g. dialysing away from home, travel insurance).

The LKPA is YOU and NOT the committee, which is only its management component, so we are looking forward to hearing from and seeing more of YOU.

Every hour or pound you contribute helps the LKPA not only to function as well as it now is but also to make investments in improvements - so it's really - support it or lose it.



The LKPA Gazebo and committee members – ready for customers at Knighton Park.

REPORTS OF PAST EVENTS AND FUNDS RAISED

2nd September: Knighton Park Community Fun Day, Leicester

LKPA had invested funds into purchasing a much needed gazebo which not only protected us from weather but was very impressive in that it allowed us to display lots more. It turned out to be a fine day and we had lots of people visit our stall on the day. Children's activities, especially the ball game, and the exclusive art of Mehndi (traditional Asian hand painting) were very popular.

16th September: Coach Trip to Skegness

The LKPA party of patients, family and friends met in the main car park accompanied by a number of volunteer nurses along with their families for the trip to Skegness on a slightly cool and overcast Sunday in September. We were to travel in one large and one small coach. After a few inevitable minor hiccups were sorted out, we set off as near to 8am as planned.

The journey to Skegness was straight-forward and uneventful and we reached there at about 10.30, two and a half hours later. We were dropped off outside the Embassy Centre, a very central and convenient location from where we were to be picked up at the end of the afternoon. Everyone went off in their family or friendship groups, some heading for the tea rooms while others went straight off to the sandy beaches, the amusement arcades or the attractions of the gift shops.

The cloudy, overcast sky was then replaced by a clear blue one for much of the afternoon and the sun shone warmly down on us lifting everyone's spirits. We walked by the Jolly Fisherman Fountain, then along the beach where Mr Yousaf and his family were playing on the sand, stopped for some food with Mr Lakhani and his party and then headed for a walk along the pier - first in a seaward direction and then heading inland to spend – or waste – some money on the games machines.

Many hours later, postcards bought and sent, photographs taken, sticks of rock purchased for those who weren't able to come, we gathered again for the return journey. Bottles of water were distributed to all who wanted them along with individual packs of biscuits and after a headcount to make sure all were present we set off back to Leicester. On the return journey people were asked to fill in a questionnaire on whether they felt the LKPA visit to Skegness had been a well organised and worthwhile activity. We were delighted to hear that the overwhelming feeling was that it had been a very successful event. The nurses who came with us were a reassuring presence but were not needed in any professional capacity; however, we thank them for joining us.

We hope to organise another such visit in 2013; so, if you didn't go in 2012, make sure you put your name down next time!



Some of the Skegness trippers. Who's trying to hide behind the lamp post?

Leicester Parks and GCR Quorn

In addition to Knighton Park (see report above), we also had stands/stalls at Aylestone, Evington and Western Parks and at a steam event at the Great Central Railway's Quorn Station. At most of our events the children's games and bran tub plus a raffle prove to be the most profitable – though, when we have cakes to sell, they both attract customers and help to part them from some of their cash! Thanks to all who have kindly and freely provided us with their baking and to the committee members who have manned stalls for several hours at each of the events.

In addition to raising money, these events provide an opportunity to publicise the LKPA and provide information and advice to the general public. Whilst many queries are about holiday insurance and diet, we were surprised by the number of discussions we had this year about children born with only 1 functioning kidney. We were able to tell them that, barring the effects of other conditions, people can live long and happy lives with only one kidney - one of my friends age 70+ is evidence of this as are most transplant patients and living donors.

8th October: Ulverscroft Manor, The Shuttlewood-Clarke Foundation (www.shuttlewood-clarke.org)

A group of 20 patients, carers and NHS staff visited Ulverscroft for the day (morning and afternoon refreshments and lunch included). Although a dull day, with some early rain, people enjoyed the gardens, walks (some kitted out with pedometers by the 'exercise research team') and those who were less mobile (and some of the mobile ones too) took advantage of 'golf-buggy' rides in the grounds. Everyone enjoyed the facilities and time and space to socialise in such a welcoming environment. It was a very successful day and we plan to arrange other events here next year. Watch the events calendar!



**October 8th: Chatting at Ulverscroft Manor
Wrapped up ready for a buggy ride?**



**November 5th 2012: Tony, Ann and Margaret at the
LKPA stand in the Main Reception area at LGH**

DIWALI – 2012

**THE LKPA WISHES ALL MEMBERS CELEBRATING DIWALI (FALLING ON 13TH NOVEMBER 2012)
“ A VERY HAPPY DIWALI AND A PROSPEROUS NEW YEAR”.**

FUTURE EVENTS – DATES FOR YOUR DIARY

LKPA Events are advertised at various locations in Leicester General Hospital Wards, Outpatients' clinics, Dialysis units at LGH, Hamilton and Loughborough as well as in the Newsletters and on our website (when reconstructed!).

Fund-raising events:

Stands at LGH and Loughborough Hospital - currently booked for 13th and 26th November at LGH. Others are yet to be confirmed).

There will be our Christmas trolley 'runs' at the hospitals and units.

This year there is a Christmas Social event – see below – and a Christmas raffle (to be drawn at the party)

LKPA members' fund-raising events

If you wish to have an event in your area, e.g. a coffee morning, to raise funds for the LKPA please get in touch and we can help and/or advise you.



IT'S PARTY TIME

Friday the 14th December

7.30pm - Midnight

Cabaret and Buffet

(English and Asian Food)

Come and join in the fun at:

Willowbrook Sports and Social Club,

Thurncourt Road,

Leicester LE5 2NG

ADMISSION BY TICKET ONLY - £5.50 includes buffet and cabaret (Under 5's are Free)

Tickets Available from: **Ann** 07702703882 or **Tony** 07902101995

Buy your tickets as soon as possible to avoid disappointments as numbers are limited.

An innovative way to deliver information and encourage self care activities that can help improve health outcomes in people with Chronic Kidney Disease.

Chronic Kidney Disease or 'CKD' is a condition where there is a gradual and irreversible decline in kidney function over a period of many months or – more usually - years. CKD is a major public health problem and known to affect around 8-10% of the adult population in the UK. People with CKD are at an increased risk of heart disease and strokes, and in a small minority of people the kidney disease deteriorates to the point that the person needs to undergo dialysis or a transplant.

It is therefore important that people with kidney disease understand their condition and the things they can do to improve their own health outcomes. For example, high blood pressure is an important factor as it can cause the kidney function to deteriorate more quickly and it also increases the risk of heart disease. There are other important factors such as obesity, not taking exercise and smoking which can all speed up the deterioration in kidney function.

People often find it difficult to control their blood pressure and may not understand the importance of this and other factors because they are not involved enough in their own care. Improving peoples' knowledge and understanding of their condition can help them to make important lifestyle changes and improve the way they take their medication.

Education that involves and empowers patients has been successful in people with other diseases, such as diabetes. We wanted to develop a new and interactive way to get important information about self-care activities to people attending kidney outpatient clinics. To achieve this we have developed and installed a Kidney Information Kiosk in Out Patient Clinic 3 at Leicester General Hospital. It can be used by any person wishing to get information about chronic kidney disease. It has information aimed at encouraging people with kidney disease to self-care aspects of their disease, such as blood pressure monitoring. It lets people:

1. access the information leaflets
2. e-mail leaflets to their home e-mail address
3. request postal copies of the leaflets
4. access important information links
5. watch and request a DVD 'Living with Kidney Disease'.
6. request access to 'Renal Patient View'
7. give feedback to us about their visit and care received



If patients have access to a computer and the internet they can register for '**Renal Patient View**'. Once connected they can see their latest blood test results, read clinic letters and view a range of other information about different aspects of kidney disease which allows people to feel more 'in control' of their health.

The kiosk has only been in use for a few weeks but feedback so far has been encouraging. One patient (female, 41 years) who has used the kiosk said 'This is really useful and a great idea..... I watched the video and requested leaflets, it's definitely a good way to get the information that you need'.

We have also developed a simple questionnaire that is given to each patient whilst they are waiting to see the doctor in the out-patient department. This highlights the important self care activities that are recommended for people with CKD, and encourages patients to use the kiosk to obtain relevant information and advice.

We hope that the Kidney Information Kiosk project will:

- improve knowledge and understanding of kidney disease with our patients
- improve their ability to self care
- promote shared decision making
- improve health outcomes
- reduce the risk of their disease progressing

For further information please contact Prof Sue Carr or a Renal Research Nurse.



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LKPA Committee

Resigning and appointment of new members

The LKPA wishes to say a big thank you to all the work and contributions members who resigned at the AGM have made over the years namely Beverley King, who acted as our secretary, Mohammed Anwar, who helped with our finances, Jayshree Pattni and Edie Dewing. We also thank Carla Smith who, though not a committee member, ran our website until July and for bringing the Olympic torch to our events at LGH.

We welcome Mr Tony Monaghan, a Radio Gwendolen DJ, to the committee.

All Committee members are volunteers, mostly renal patients themselves. We are always happy to welcome members who are interested in supporting and/or joining the committee.

Chairperson	Margaret Ince	lkpa_mi@yahoo.co.uk	Members without port folio David Farnsworth, Naresh Lakhani, John Lancaster, Tony Monaghan, Helen Noon, Avril Patel, Bharat Patel Pravin Patel AND - 3 Vacancies
Secretary	Ann Carter	lkpasecretary@yahoo.co.uk	
Treasurer	Madhu Madhani	lkpatreasurer@yahoo.co.uk	
Newsletter	TBC		
Events	Alan Carter		

LKPA Website (www.lkpa.org.uk)

Please note that the new website manager, Nigel Allured, is currently reconstructing the site – apologies for the time this is taking as he is awaiting input from the newly-elected committee. It will have information about the LKPA, our events etc. and will still have links to other sites where you can find a wealth of useful information and advice will be maintained.

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

FaceBook - managed by Carla Smith

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

LKPA Postal Contact address

c/o Leicester General Hospital,
Gwendolen Road,
LEICESTER,
LE5 4PW