



**LEICESTERSHIRE KIDNEY PATIENTS' ASSOCIATION  
NEWSLETTER – MARCH 2013**

**Leicester General Hospital, Gwendolen Road, Leicester LE5 4PW  
www.lkpa.org.uk Charity Number 505795**

# **HAPPY NEW YEAR!**

**FROM ALL OF US**

## **A MESSAGE FROM THE NEW EDITOR .....**



Welcome to the first newsletter of a brand New Year. We at the LKPA hope you all had a peaceful, healthy, Christmas and New Year break.

My name is Tony Monaghan and I am the new editor of the LKPA newsletter. I hope you enjoy the content and that the new format is to your satisfaction. If you have any ideas or wish to comment please feel free to contact me. After all this is **your** newsletter!

As always there is a busy year ahead and already our diary is beginning to fill with lots of exciting and interesting events hopefully for you all to participate in.

As you will see, there are some new features which we hope you will find of interest alongside some information for your reference. If you would like to see something in particular included, or you wish to submit copy to be included in future issues, then I would like to hear from you.

Remember, 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 the satellite Renal Units; and provides education and information on renal disease to the general public.

## A MESSAGE FROM THE CHAIR...



Margaret Ince

Best Wishes to all members for a happy, prosperous and healthy 2013 – albeit currently very wintery.

Welcome to Tony Monaghan as the 'new' Newsletter Editor and Nigel Allured at the 'new' Website Manager (see their separate remarks). Please support them by sending in your stories, news and suggestions.

The LKPA committee and supporters have been very busy over the first 4 months of the 2012/2013 LKPA year. This year, in addition to a full fund-raising and social events programme, we are widening our awareness-raising/education programme to include out-reach activities in communities outside as well as in the city. We are also planning to help members set up local groups to hold events in their own area. Of course to run our 'central' events we need your support at local and central. This could be helping prepare for or run events (e.g. making goods for sale, helping on a stand for 1 or 2 hours, selling raffle tickets etc.) but also attending events. We would also be happy to welcome more members to the committee. Please get in touch with your suggestions and offers or come along to a committee meeting to see how the LKPA works.

I am looking forward to hearing from you and also seeing some of you at our 2013 events.

## FUND RAISING EVENTS – NEWS UPDATE 2012!

As you know there have been several fund raising events since our last newsletter.

We have held several sales at the general hospital in both the main reception as well as the staff restaurant and all have been very lucrative. The addition of our jewellery range has proven to be a great asset to our portfolio. We are looking to expand in the New Year and hopefully will be holding sales at both the LRI and the Glenfield reception areas which of course will be in addition to our planned schedule at the general in 2013.

**Christmas party** – a great night was had by all! The party was a resounding success and was attended by approximately 130 people who all bought tickets and who were not disappointed. The feedback has been very positive with many asking when the next one is taking place! We would like to thank everyone who supported the event by either purchasing admission tickets or taking a chance on our raffle. Many thanks also to Carol, Manageress of the Willowbrook sports and social club who donated use of the venue free of charge. Entertainment was provided by Leicester based band Function Junction who stepped in at short notice and certainly added to the success of the event. Also to the delight of the children (and some adults) Santa dropped in on his way to Lapland and Mickey and Mini mouse also made a special appearance. Several people also very kindly

donated sums of money. A massive thank you – the money raised will certainly be put to good use and will certainly make a difference. We would also like to extend our thanks to all who donated raffle prizes however large or small. They were gratefully received.



Tony, Ann and Margaret in LGH reception



Christmas Party 2012



Ann and Jon trimming up



Bharat and Avril in LGH reception

## **A BIG THANK YOU... FROM SECRETARY - ANN CARTER**

To the First Nursery in Leicester for choosing the Leicester Kidney Patient's Association as their chosen charity for 2011. Over the year they held many events to raise funds, one of which was their summer fete. This was attended by Margaret and me, chairperson and secretary from the LKPA. We both had a wonderful day and were made really welcome by the nursery staff.



In June the same year the LKPA fun-day was held, which featured a sponsored walk, many stalls, amusements, face painting and refreshments, which the nursery attended with parents and children.

Over the year the grand total of one thousand four hundred and five pounds was raised.

I was then invited to the nursery to receive the cheque on behalf of the LKPA from the Company Director Cathy Griffin and the nursery manager Angela Cox.

### **CHECK OUT OUR NEW WEBSITE- [www.lkpa.org.uk](http://www.lkpa.org.uk)**

Hi my name is Nigel Allured. I am the LKPA Website Manager. I have suffered from renal disease for over 20 years which eventually led to renal failure. I was lucky to be able to receive a living donor transplant from my partner (Amanda) in 2010. I am hoping to help make the new LKPA website a great resource and information portal for renal patients and their families. I look forward to hearing your comments on the site and receiving, in due course, your news, stories and messages.



**HELPERS REQUIRED AT ALL OF OUR EVENTS, IF YOU HAVE SPARE TIME ON YOUR HANDS AND ENJOY MEETING PEOPLE PLEASE CONTACT US USING ANY OF THE ADDRESSES ON THE BACK PAGE OF THIS PUBLICATION.**

# EVENTS DIARY 2013



## FUN DAY -

We are planning yet another fun day which is due to be held on Sunday June 30<sup>th</sup> at Markfield Sports and Community Centre. This will include a sponsored walk around the grounds, various stalls, face painting, hook a duck, bouncy castle and much more! For more details contact Ann 07702 703882 or Tony 07902 101995.

Alan Carter- Events Chair

## Seaside Daytrip -

After the success of the trip last year, here as promised is yet another invite for a day at the seaside. Why not pack up your best bucket and spade, and join us for a day to remember in Skegness. This trip is planned to take place on Sunday September 8<sup>th</sup>, Departing from LGH at 8am and leaving Skegness at 5.30pm. Due to the success of the trip last year, we have been asked for a repeat performance! For more details contact Ann 07702 703882 or Tony 07902 101995 Remember - book early to avoid disappointment! Unfortunately we are not able to supply care services throughout the day on this trip. However qualified help and advice will be available.

## World Kidney Day (WKD) -

World Kidney Day is on Thursday 14<sup>th</sup> march. There will be lots happening on this day so keep your eyes peeled. We will have a presence at Beaumont Leys with an information and education stand. We will also be in main reception at the LGH with a variety of items for sale and also information for those who would like it. The theme for this year's event is **Go purple and Acute Renal Failure**.

## OTHER DATES FOR YOUR DIARY-

Saturday 6<sup>th</sup> July Western Park

Sunday 1<sup>ST</sup> September Knighton Park

Other dates still to be confirmed.



[www.kidneyresearchuk.org](http://www.kidneyresearchuk.org)

## CASH GENERATION BREAKDOWN

### FUNDS RAISED TO DATE –

|                                      |   |         |
|--------------------------------------|---|---------|
| Christmas party and raffle           | £ | 552.00  |
| Donations received –                 |   |         |
| Sales in reception/restaurant at LGH | £ | 346.00  |
| Wakefield acoustics                  | £ | 150.00  |
| C.A.F                                | £ | 24.00   |
| Ghelani superstore                   | £ | 10.00   |
| Anonymous donations                  | £ | 5362.00 |
| Grand total so far                   | £ | 6441.00 |



Madhu Madhani-Treasurer

We would like to thank everyone who donated money to us. Donations are always welcomed and gratefully received. A special thank you also to the committee and non- committee members who gave their time on several occasions for the purpose of ensuring funds were raised. Thanks also to those who helped behind the scenes. Let us hope 2013 continues to be yet another very lucrative year. This allows us to continue to offer the help and support to kidney patients, their families, and carers. Should you need our help in the future, please feel free to contact either myself or any of the committee members whose details are on the last page of this newsletter.



FUN DAY 2012



EVINGTON VILLAGE FETE

# THIS MONTHS FOCUS – HOME DIALYSIS

Did you know that you are now able to dialyse in the comfort of your own home? No more living your life around a hospital slot! Sue Sharman of the Renal Community Team reports .....

## **Home Dialysis**

Home dialysis offers greater flexibility and gives you more control over the management of your kidney problems. You can decide when to dialyse with a variety of treatment plans. You are able to dialyse in the privacy of your own home with support from the hospital staff. Specialist nurses are only a phone call away to offer advice, encouragement and guidance. There are two types of dialysis and both can be carried out at home.

### **Peritoneal dialysis (PD)**

PD involves having a soft plastic catheter inserted into the peritoneal cavity in the abdomen. Dialysis fluid is then used to remove the toxins from the body and regulate fluid balance. PD can be done in 3 different ways:

1. Continuous Ambulatory Peritoneal Dialysis (CAPD) - 4 bags of fluid exchanged each day.
2. Automated Peritoneal Dialysis (APD) – Fluid exchanged using a machine overnight.
3. Assisted Automated Peritoneal Dialysis (aApd) - APD but with some extra assistance from nursing staff.

### **Home Haemodialysis (HHD)**

This type of treatment uses a dialysis machine. Blood is circulated from the body and passes through a special filter. There are choices available as to how often you would have HHD.

- 1) Alternate days,
- 2) Five times per week,
- 3) Three times per week,
- 4) Nocturnal dialysis.

Home dialysis provides undoubted clinical benefits as it allows for longer and slower dialysis, improving kidney function and life expectancy. It will improve your quality of life and increase your independence. Home patients tend to have better fluid balance control, better blood pressure control and better blood test results. The fluid and diet restrictions are often less for home patients.

If you opt for home dialysis you will receive training delivered at your own pace, you will not be expected to dialyse at home if you do not feel confident. The renal community nurses come to your home to offer help and advice as required. Help is only a phone call away. Home dialysis offers greater flexibility and has many advantages but very few patients currently do it.

At present we support approximately 60 patients on peritoneal dialysis and 24 patients on home haemodialysis in Leicestershire but we would like to look after more. Not every patient will be suitable for Home Dialysis; however if you wish to discuss your circumstances and you think Home Dialysis might be beneficial (HHD or PD) then ask to discuss these options with your renal doctor or nurse. You can contact the Renal Community Team on (0116) 2584120 if

you get the answer phone please leave a message and we'll phone you back. We look forward to hearing from you.

Sue Sharman- *Renal Community Sister*



### **Information for all kidney transplant patients of UHL Renal units who take Prograf®**

The hospital is planning a phased switch of tacrolimus brands for all kidney transplant patients taking Prograf® starting with those on home delivery.

The new brand of tacrolimus called Adoport® has been used successfully for 2 years in all new kidney transplant patients (about 200). It is very important that you keep taking the same brand of tacrolimus until you get different advice, which is why the switch will be made under the close supervision of the transplant pharmacist. The hospital will be in touch very shortly to start the process. In the meantime please feel free to contact them if you need any more information.

NB: It is important that patients getting Prograf® from their GPs should continue to do so. Switching this group of patients to Adoport® will be managed through hospital clinics in the next phase.

### **FROM THE HEART –**

There were a series of programme aired recently on ITV. One of which was hosted by Dermot O'Leary (of X factor fame) and very positively raised awareness of organ donation. The programme was supported by many celebrities including Rowan Atkinson, Jools Holland, Alexandra Burke, (whose mother has kidney failure) and many more. The point of the programme was to highlight how important it is to register for organ donation. Many people may want to donate organs but rarely let their loved ones know about their wishes and more often than

**Just Think About It**



[www.facebook.com/WantedKidneyDonor](http://www.facebook.com/WantedKidneyDonor)



not, delay in releasing details to the organ donor register. It is very simple to register and only takes a matter of minutes. You can do it through your driving license application, apply for a donor card, at your GP surgery and on line. Go on – make a difference! Well done ITV on an excellent information broadcast.

### **MY RENAL JOURNEY BY STEWART RUSHTON**

The very first time I came into contact with nephrology was in outpatient 3 at LGH I was referred by urology consultant Mr Osborne to see the late Prof Walls, I actually saw the now Professor Feehally who told me that my kidneys had been damaged due to childhood urinary problems and eventually they would fail, which eventually they did in 1992. Once I had been admitted it was soon clear I had kidney failure and soon found myself having a catheter inserted into my shoulder and put onto a dialysis machine which would happen several times during my 5 week stay in hospital. During this time the doctors and nursing staff explained about CAP which I decided was my treatment of choice thus had a PD catheter fitted into my stomach. Upon discharge it was arranged for me to attend daily training on how to perform CAPD at home. I did this for 2 years very successfully occasionally needing admission to occasionally correct different issues. Then I went on holiday to the Isle of Wight. However, at the end of the holiday I got an infection which the local GP thought maybe peritonitis and arranged my transportation to Portsmouth Renal Unit, who later discharged me with antibiotics so I could travel home. That was a long journey! On returning home I was admitted to Ward 15 where the infection was treated. Then in summer 1994 the call I had been waiting for came. A kidney was available for transplant and I might be a suitable match. Which, indeed I was. Professor Nicholson went on to perform the operation. My new kidney continued work for 16 years with only a few problems along the way which were easily treated. When I attended transplant clinic one Monday it was discovered that I had begun to lose protein in my urine. This however was resolved. But then as the months went on, it was arranged for me to have an ultrasound and later a biopsy which showed that the kidney had indeed begun to fail. The doctors gave me medication to slow the loss of function down, but the inevitable was that I would need at some point to dialyse again. So after a lot of thought I decided haemodialysis was my preference. So two operations were arranged to create a Bronchial Fistula. I attended a pre-dialysis educational course which was very helpful. Then at the start of 2012 my health clearly began to deteriorate and after many meetings in transplant clinic with Dr Topham, we decided the point had come to start haemodialysis. A slot was offered at Corby. But have since secured a slot at Hamilton. During this time I have been reviewed by the transplant team and they are happy for me to be transplanted again. When that will be, no-one can say. We all hope the call comes soon!

### **MEET THE MEDICAL TEAM - Coral Wimbury**

My name is Coral Wimbury, I am the senior sister on the Haemodialysis unit at LGH. I have been in this post for just over 2 years now and have thoroughly enjoyed the challenge. After originally training in London I worked on a busy medical ward with 5 renal beds I was then "hooked" on renal nursing. I met my husband Kim while attempting to become a parachutist at Sibson (near Peterborough) and moved here to be with him. I started working on ward 15 in 1984 and apart from a short 6 month break in 1986, have been working both on the wards and on the dialysis unit ever since. One of my proudest



moments in nursing, was passing the nurse prescribing course recently.

I have 2 sons of whom I am very proud. Our eldest (David) is at university in Bristol and his younger brother (Michael) is at Loughborough. I am still attempting to play field hockey at the weekends. This amuses some of the patients when they see me limping around the unit on a Monday morning aching and bruised.

I have never lost my enthusiasm for working here; I have a great team of nurses and hope that I still have a few more years to continue to strive towards excellent care and a forward thinking progressive unit, which will provide the care that our patients deserve.

LKPA - Contact Details ;

|                        |               |  |
|------------------------|---------------|--|
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By Post: The Secretary, LKPA, Leicester General Hospital, Gwendolen Road, Leicester. LE5 4PW

**A MASSIVE** thank you -

To everyone who submitted articles for print in this issue. May I also take this opportunity to say a special thank you to Keri Brighty for her help in the production of this publication.

Next issue is expected to be circulated in June 2013. Copy deadline by end of May 2013 please!