

News-letter

Summer 2011

The Voice of Lincolnshire Kidney Patients

Lincolnshire
Kidney
Patients
Association



www.lincs-kpa.org

Registered Charity No 1096552

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A independent Association Run by Patients and Carers

LINCOLNSHIRE KIDNEY PATIENTS ASSOCIATION

The LINC-S-KPA committee have recently reviewed the allowances made to patients who are members of the Association and is effective from May 2011.

Anyone seeking assistance from the Association must be registered members of the Lincolnshire Kidney Patients Association.

Membership is free and joining forms can be obtained from the secretary.

Allowances

Car parking for visitors for patients in Hospital for five days or more, A "10 day parking voucher for £15" available at the hospital reception will be refunded when the voucher is submitted with a claim form.

Travel allowance for investigations relating to the kidneys or related matters at Leicester or other hospitals other than Lincoln.

The allowance will be based on mileage or a one off payment.

Holiday grant annually plus 25% of insurance costs.

Patients who drive themselves to the dialysis unit for treatment can claim an annual payment of £25.

Medical Alert Wristbands worn on the wrist advising that there is a fistula and on which wrist.

Also for transplant patients.

Illustrated on the enclosed form.

Anyone wishing to claim for any of the above please contact the secretary, Mick Walker on 01427 880125.

Claims for additional assistance can be made to:-
Grants and Charity Services, Kidney Research UK
Nene Hall, Lynch Wood Park, Peterborough, PE2 6FK
Tel 08450 707601

British Kidney Patients Association,
3 The Windmills, Turk Street, Alton GU34 1EF
Tel 01420 541424.

Medical



Wristbands

We can get wristbands specially made up for Haemodialysis and Transplant patients, in large and small sizes,
Wear one to protect yourself in a Emergency.

Please contact the Secretary of the Lincs-KPA if you require a wristband and say the size,

Fistula Right Arm Large__ Small__

Fistula Left Arm Large__ Small__

No BP Testing/ Needles Large__ Small__

Transplant Large__ Small__

Or if you want to send for them yourself.

They are available from Tyneside-KPA, by post at £1.50 each, this includes post and packaging

The Address is, if you make the cheque out to NKPA

TKPA, Mike Hayhoe, 67 Melness Road, Hazerigg, Newcastle Upon Tyne, NE13 7BJ.

Thankyou

Thank you to the following for their generous donations

Donations and stalls	
Gainsborough Riverside Festival	£115
Cranwell Shop	£13.41
South Park Newsagent	£34
Hundleby Ladies Dinner (The Royal Wedding)	£355
Angela Murphy (Lincoln 10k Run)	£248
Cranwell Post Office and Shop	£14.53
Stafford Motor Cycle Show	£16

Counselling Feedback

LKPA Counselling Client Feedback 1

"I had been waiting on the kidney transplant list for 5 ½ years when I received the call to say that a kidney was now available for me. Sadly, I was not able to accept this offer. My concern was not going through the hospital procedures, but I was overly worried about leaving my house empty whilst I was away and how much I could rely on the close contact being responsible for its upkeep in my absence.

I spent the next 3 weeks coming to terms with my decision and my loss of a potentially significant improvement in my health and quality of life.

Fortunately for me, the Lincoln Kidney Patient Association had just invested in the appointment of a counsellor who was available to help with issues of patients related to their kidney treatment. I contacted the LKPA and was accepted to meet up with the counsellor. I outlined my difficulties and over 4 sessions at my home, we considered my problem at length and then I learned some practical skills and did some homework to enable me to put a practical plan in place which gave me the confidence to feel that I could cope with going into Leicester for a transplant of another kidney, if offered to me. That call came again a few weeks ago, and I now have a fully functioning transplanted cadaveric kidney. At present, I am attending the Transplant Follow-up Clinic at Leicester General Hospital. Without my contact with the LKPA counsellor, I would still be spending several hours each day on CAPD and feeling quite tired for parts of each day. The counsellor listened to my problems and helped me put them into perspective. He taught me some behavioural skills and gradually I began to learn to deal with my difficult situations. Together we worked out some practical solutions to difficulties. As a result, my confidence improved considerably. When things were especially difficult, he was just a telephone call away. Without his help, I would not be feeling the benefit of my new kidney.

I would seriously recommend anyone who feels he/she might benefit from a counsellor's skilled help to contact the LKPA for a referral. There is nothing to lose and everything to gain."

The above is an unsolicited transcript.

Counselling feedback 2

Counselling helped me to realise I'm not a freak, idiot or a weak person, it gave me a better understanding of myself enabling me to challenge my way of thinking/feeling. People will and do want to help, it is me that has to let them. To be more positive about my feelings and to act on them. The use of skills has proved invaluable. Given me control back in my life, to confront issues rather than bury them.

Thoughts and behaviour relate to the way I feel, I don't like my illness but have a better acceptance of it.

You didn't judge me, you are approachable, and you listened and were constructive in your method of working.

"Life can be a bitch, But it's how the bitch fights back".

Thank you Paul for your invaluable help.

S.Mundin 30/05/2011

The people who has written these has asked us to put the articles in the Lincs-kpa newsletter.

Any one wanting to know more about the Counselling Service please contact the Lincs-KPA Secretary (see back cover for

Dear Members, Having had members contact me over the last few weeks about difficulty in getting Renagel, please see below.

Renagel Supply

Many of you on Renagel have reported difficulty in getting supplies of this product in the past few months. The manufacturers, Genzyme, assure us that there is not a manufacturing problem with the tablets. It would appear that the wholesalers are operating a quota system which means that each pharmacy is only allocated a certain number of packs of Renagel each month. This appears not to reflect the actual need of some pharmacies for their patients, leading to supply problems for some of you.

In order to minimise this, I have a few suggestions:

1. Try to keep at least 2 weeks' supply in hand by ordering your next supply as early as your surgery will allow
2. Contact your local pharmacy/ dispensary to let them know you have a prescription for Renagel, tell them how many tablets are on the prescription and ask if they have sufficient stock to dispense. This may save you a wasted journey.
3. If your pharmacy/dispensary tells you they cannot obtain them, suggest they ring the manufacturer (Genzyme) direct to request delivery of a supply direct to your pharmacy. The number is 01865 405200.
4. If you still cannot obtain any Renagel, it may be possible to request a similar product (Renvela, sevelamer carbonate) to be prescribed by your GP. These tablets are the same strength as Renagel and may be used in the same dose as your Renagel tablets. However, I have heard that there are some supply problems with this product too, so it would be worth checking with your pharmacy that they can obtain these before you follow this route.

If you still have problems, please do contact me :

Caroline Taylor Renal Pharmacist County Hospital, Lincoln

Telephone 01522 573598 or bleep 01522 512512 bleep 4019

Secretary Page

Lincs – KPA committee meeting dates:

8th August 2011

10th October 2011

Meetings to be held at the Carholme, Golf Club, Lincoln

Lincs – Kpa are always wanting members to join the Committee to help with the Lincolnshire Kidney Patients Association.

Change of information

If you have changed your address or e-mail address, could you please let me know so I can keep up to date with the right information,

Please send in articles for the Newsletter such as pre-dialysis about starting into dialysis, APD/CAPD, Haemodialysis, I would like to hear from Transplant patients,

Future Events

Lincolnshire Kidney Patients Association Golf Day 10th September 2011

For more information on the day contact the Lincs-kpa Chairman (Tony Perry), if anything would like to donate a raffle prize contact the (Chairman or the Secretary),

Gainsborough Christmas Charity Market Sunday 27th November 2011.

Skegness New Dialysis Unit, a new unit was officially opened on the 23rd June 2011 a full report in next newsletter.

Anyone wanting to learn on computers,

The bbc has set up a course at Birchwood Access Centre, the course helps you learn how to start using a computer,

E-mail www.birchwoodaccess.org.uk

Tele No 01522 697587

Computers in Libraries, with lots of people wanting to go on line, Lincolnshire Libraries all have computers in them so you can go and join the library and get on line and start e-mailing friends, there`s lots going of in libraries these days,

National Kidney Federation



NKF ROADSHOW 2011



Hilton Hotel Blackpool Friday 7TH – Sunday 9th October

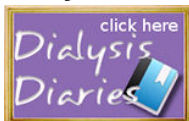
The **Programme includes**,

**STEM CELL RESEARCH, GENETICS, HOME DIALYSIS
TRANSPLANT, LIVING WELL. INTEGRATIVE HEALTH
“STRICTLY” – NKF**

Booking form is on the back of the Latest Kidney life or online
www.kidney.org.uk

You can also book online **by Credit card**

Dialysis Diaries



The NKF has been working with Baxter on a new website ***Dialysis Diaries***. “A blogging community where people share their experiences of kidney failure”

The Site was launched on 15th June 2011 and is now live for kidney patients and others to visit, www.dialysidiaries.com.

NHS Kidney Care Launches new resources to support the Carers of people with Chronic Kidney Failure.

NHS Kidney Care, the quality improvement organisation, has launched a new online video and a report aimed at addressing some of the issues and problems that face the carers of people with chronic kidney disease and in particular those on Dialysis. There's a video and a report has been launched as part of carers week, which took place 13 – 19 June 2011,

The Film about

<http://www.kidneycare.nhs.uk/whatworks-shortfilms.aspx>

http://www.kidneycare.nhs.uk/_Ourworkprogrammes-PublicHealth-HealthInequalitiesandChronicKidneyDiseaseinAdults.as

Anyone want a hard copy of the report contact the Lincs-kpa Secretary

Officers of the Lincs-kpa

Chairman – Tony Perry (01522 803763 chairman@lincs-kpa.org)

Secretary – Mick Walker (01427 880125 secretary@lincs-kpa.org)

Contact address – Hideaway, Fingle Street, N.Leverton, Retford, Notts, DN22 0AE

Treasurer – Steve Emsley (treasurer@lincs-kpa.org)

Website of the Lincolnshire Kidney Patients Association is

www.lincs-kpa.org

For information and advice 01427 880125

The National Kidney Federation

For information and advice

08456010209

www.kidney.org.uk

E-mail helpline@kidney.org.uk

**Address:- The Point, Coach Road, Shireoaks,
Worksop, S81 8BW**

Websites:-

www.emrn.org.uk

www.nhsdirect.nhs.uk

www.nhs.uk/

www.renalpatientview.org

www.mykidney.org.uk

www.pkdcharity.co.uk

www.kidneypatientguide.org.uk

East Midlands Renal Network

NHS Direct

NHS Choices

see your results on line

polycystic kidney disease