

# NKF In Touch with KPAs

Information from The National Kidney Federation – supporting kidney patients, their friends & family

Date: August 2014 Issue: Three

Welcome to the August edition of NKF In Touch with KPAs newsletter. Please forward any articles etc that you would like sharing via the next newsletter to Andrea Brown [andrea@kidney.org.uk](mailto:andrea@kidney.org.uk) by 8<sup>th</sup> September .



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## Who NKF seeks to influence:

NHS England  
NHSBT  
Department of Health  
Government Ministers  
Welsh Government  
Northern Ireland Assembly  
Scottish Executive  
All Party Parliamentary  
Kidney Group  
Trusts and Hospitals



## Action Point



### **URGENT NOTIFICATION – NKF reply paid envelopes**

*NKF have been notified by Royal Mail that existing reply paid envelopes will not be delivered to the NKF unless a “fine” of £1 per envelope is paid to Royal Mail. This change in Royal Mail “conditions” was unexpected and does mean that NKF only wants its new (issued in the Autumn 2014 edition of Kidney Life) reply paid envelopes used. PLEASE DESTROY ANY EXISTING NKF REPLY PAID ENVELOPES, and do not use them to send items to the NKF. Please convey this message to all potential users of NKF reply paid envelopes.*

# THE 2014 NKF ANNUAL PATIENTS' CONFERENCE BLACKPOOL

Taking Control – 10<sup>th</sup> – 12<sup>th</sup> October 2014

The NKF Conference is fast approaching, please book now if you haven't already to ensure you secure your place at this very popular event. There is a great line up of speakers in the conference programme and much information is to be gained by all that attend. On Friday evening there will be a Chairmans meeting followed by a quiz. Saturday sees Marc Clancy, Transplant Surgeon for Rare Diseases speaking in the morning. There will be a discussion on patient transport, transport providers will be in attendance to answer your questions at the ever popular question time. In the afternoon there will be a cookery demonstration from NKF Patron Lawrence Keogh, and four patients will be giving their personal journey story. Gala dinner will take place on the Saturday evening and after a three course meal you will be entertained by comedian, Bobby Dazzler followed by a disco. Sunday Morning sees the Council meeting followed by an open forum where speakers from Saturday and NKF staff will take any questions.

To book your place or for further information please call 01909 544999, or you can also book online at [www.kidney.org.uk](http://www.kidney.org.uk) . Bookings close on 26<sup>th</sup> September.

## Invitation to KPAs to participate in a survey

I am pleased to invite Chairman's of all KPAs to participate in a short survey on kidney research in this country. The survey consists of 10 questions and your responses will contribute to the development of a National Renal Research Strategy. A copy of the survey is attached. I would be grateful if you would send your completed survey to Andrea Brown at [andrea@kidney.org.uk](mailto:andrea@kidney.org.uk) by the end of September 2014. If you have any queries, please feel free to contact Kirit Modi at [kiritmodi1@hotmail.com](mailto:kiritmodi1@hotmail.com) . Many thanks.



## London Marathon 2014

We have a great opportunity for one person to represent the NKF in next year's London marathon, if you or someone you know could take on this task and not only run the 26.2 miles but raise a substantial amount of sponsorship money we would like to hear from you. Please email [pete.revell@kidneynkf.com](mailto:pete.revell@kidneynkf.com) with all your details and how much you would anticipate to raise by 1<sup>st</sup> September 2014.



## New NKF North West Advocacy Officer

The NKF are delighted to announce that Justina Oyekunle is the new Advocacy Officer for North West England.

Justina has a background as a Project Manager for the Sickle Society and most recently as a Senior Trainer/Programme Manager for the Expert Patients Programme in Greater Manchester. Importantly Justina brings her first hand experience from six years as a Haemodialysis patient and has recently started Home Haemodialysis. Justina's professional experience combined with her valuable personal insight will be of great benefit to the patient community she will serve in the North West and the NKF are proud to have her on board. Justina looks forward to meeting you at the NKF Conference in Blackpool in October.

## *NICE guideline for early identification and management of chronic kidney disease*

New NICE Guideline (CG 182) published July 2014 - ***Chronic kidney disease: early identification and management of chronic kidney disease in adults in primary and secondary care***

The guideline is applicable to adults (18 years or older) with or at risk of developing chronic kidney disease (people at risk include those with diabetes, high blood pressure or heart disease, and people recovering after a sudden loss of kidney function called acute kidney injury). Of particular note is the reference to the stages of CKD which refer to how well your kidneys are functioning, your G category, and how much protein they are leaking, your A category. The G category relates to the GFR (glomerular filtration rate) and runs from G1 to G5 where G1 relates to a kidney function greater than 90% and G5 less than 15%. The A category relates to ACR (Albumin Creatinine Ratio) and runs from A1 to A3 where A1 is the lowest amount of protein and A3 the most amount leakage.

For further information the **Guidance** and **Information for the Public** can be viewed via the link <http://www.nice.org.uk/Guidance/cg182>



## **Royal Derby KPA**

Saturday July 19th saw the launch of a brand new KPA, The Royal Derby Kidney Patients Association took to the streets of picturesque Belper with the support of Spec Savers. The KPA committee were joined by Advocacy officer Sandy Lines and NKF Head of Fundraising Pete Revell. Throughout the day a collection and raffle took place, balloons and other goodies were handed out by Spec Savers.

The NKF would like to wish Simon Elmore and his committee from the Royal Derby KPA all the best for the future. You can contact the Chairman of Royal Derby KPA by emailing: [simon.elmore1975@gmail.com](mailto:simon.elmore1975@gmail.com)



### Christmas cards

I know we are still enjoying the summer but very soon in the next edition of our

Kidney Life magazine will be the 2014 Christmas brochure packed full of cards, gift wrapping and lots more, items can be ordered by post or via our web shop at <http://store.kidney.org.uk/>. Telephone orders are also welcome, please call 01909 544999.

By the end of this month you will have received the latest edition of Kidney Life magazine, you will find three books of draw tickets



– this is for the Christmas draw and the most prizes we have ever given away including an I Pad and 12 cash prizes. Don't forget as a KPA you can order special draw tickets that are a different colour with 60 % of sales going to your KPA, if you would like to order the special KPA tickets please email [linda@kidney.org.uk](mailto:linda@kidney.org.uk) or call 01909 544999.

### Draw tickets

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## David Kerr Memorial

David Kerr was one of the founding fathers of UK nephrology and particularly dialysis. He sadly passed away in April this year. His obituary is at <http://www.renal.org/news-item/2014/05/20/david-kerr's-obituary#sthash.fx0Ad8wi.dpbs>.

A memorial for David is being held at the Royal College of Physicians on Monday 1st September 2014. The event will start at 4.00 pm and last approximately one hour. During this time there will be several short presentations covering various aspects of David's life including the Newcastle years, the Hammersmith years and his contribution to UK/European/International nephrology. This will be followed by refreshments.

If anybody would like to attend they would be most welcome. Registration is at <http://www.kidneyresearchuk.org/david-kerr-memorial>.

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## Congratulations to Jim



At a recent meeting of NHSBT's Kidney Patients' Support Group for Organ Donation and Transplantation, Jim Higgins, Vice-Chairman of the NKF, was elected as the Co-Chair of this national group. He will work closely with Prof Chris Watson who will be the other Co-Chair. Many congratulations Jim. Please feel free to contact Jim at [Jimhiggins243@sky.com](mailto:Jimhiggins243@sky.com) if you would like any further information.



## **NKF @ British Transplant Games**

On Sunday 10<sup>th</sup> August 2014, I Mick Walker (Secretary, NKF), and colleagues Linda Pickering (Advocacy Officer, NKF) and Tracey Sinclair (Executive Member, NKF) went along to the British Transplant Games in Bolton. We arrived about 8.00am to setup the NKF information stand at the games, as we were setting up transplant patients and family members came and had a look at the stand and picked up information on things like diet, potassium, salt and skin care, we were also selling T Shirts (I gave a kidney, I received a kidney) NKF Badges, and young@nkf wristbands, and signing people up for Kidney Life. The NKF team was only there on the Sunday but we met many inspirational transplant patients and family members. What a fantastic atmosphere, loads of happy faces even when it was raining very hard outside. I would encourage any transplant patient to take part over the 4 days, in the many events available, such as running, long jump, high jump, walking, marathons, bowling, darts, shot put, badminton, tennis, football, tug of war etc. Next Year the British Transplant Games will be held in Newcastle

For more on the Games go to:

Twitter <https://twitter.com/WHBTG>

Facebook <https://www.facebook.com/BritishTransplantGames>



[www.kidney.org.uk](http://www.kidney.org.uk)

*The NKF - the largest Kidney Patient charity in the UK*  
*A federation of more than fifty patient charities, supporting kidney patients & carers*

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