

NKF In Touch with KPAs

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

Date: **June 2014** Issue: **One**

Welcome to the first edition of NKF In Touch with KPAs newsletter.



Message from the Chairman: Kirit Modi



Elected NKF Officers

I am very pleased to report that the NKF will be sending this IN TOUCH newsletter to KPA officers and others to improve communication. This is as a result of discussions at our KPA DAY. We hope you find this newsletter helpful. We will, of course, be most grateful for your views on this initiative. IN TOUCH will be sent out by e-mail to all KPA officers (Chairman, Vice-Chairman, Secretary, Treasurer and NKF representative) for whom we have e-mail addresses. It will be sent out on or around the 15th of each month. It will include two types of items; those for ACTION and items for

INFORMATION. Contact names and e-mail addresses for further information on each item, as well as DEADLINES for action items will be provided. We would be grateful if you would circulate IN TOUCH to your committee members, other members of your KPA and anyone who may find it of interest. IN TOUCH will be available both in PDF and Word formats. We would also encourage all KPAs to use IN TOUCH to share appropriate information about your KPA with other KPAs. Please send details of your submission to Andrea Brown, Assistant Office Manager, at andrea@kidney.org.uk, by the 7th of each month.

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Who NKF seeks to influence:

- NHS England
- NHSBT
- Department of Health
- Government Ministers
- All Party Parliamentary Kidney Group
- Trusts and Hospitals



MEMBERSHIP LISTS

We are most grateful to all KPAs which provide regular updates of their membership. We would like to encourage all KPAs to do so to enable us to post KIDNEY LIFE to the correct addresses. Also, our aim is to increase the circulation of KIDNEY LIFE to 25,000 copies from the current 22,000 and we need your help! Membership Secretaries of KPAs will have received a list of your KPA members for checking and amending in May from Linda Fores. Could you please send your amended lists to linda@kidney.org.uk by 11th July 2014.

PART TIME ADVOCACY OFFICER VACANCY

The NKF is seeking a new part time (25 hrs per week) Advocacy Officer for the North West area, to replace Dennis Crane who is retiring. This is a paid position and applications to the NKF closes on 30th June – so you will have to be quick! For more information please contact Margaret Parkin nkf@kidney.org.uk



London Marathon 2015

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 with all your details and how much you would anticipate to raise by 1st September 2014.

Patient Participation in Chronic Kidney Disease (CKD) Programme



[Applications invited for CKD Programme Co-Chair Person](#)

NHS England and the UK Renal Registry are setting up an exciting national programme to look at the development of a patient care pathway for kidney disease.

The NHS Mandate includes an objective “to ensure the NHS becomes dramatically better at involving patients and their carers, and empowering them to manage and make decisions about their own care and treatment.” Shared Decision Making is embedded in the NHS Constitution and the NHS Mandate. The NHS Constitution states that “we have the right to full information about treatment options, and to participate in decisions”.

Over a period of two years the programme board will oversee several areas of work and be responsible for planning, developing, measuring and managing them according to the guidelines agreed. Your role as Co-Chair of the board will be to represent people affected by kidney disease and to influence the work programme accordingly. There will be support and mentorship available. This can be a challenging role and support and mentoring will be offered to develop you in this role.

This position is unpaid but an allowance is available for attendance at meetings, plus travelling costs. Any training needs for this role will be provided with on-going support to allow interested persons to take on these responsibilities.

If you are interested in leading in the development of a patient care pathway that is centred on patient needs working with NHS England, the UK Renal Registry and other partners including the Kidney Health Partnership Board (KHPB) then we would encourage you to register your interest.

Please contact Sue Shaw for further information, questions about this or an application pack.

By email: sue.shaw@renalregistry.nhs.uk or phone: 07432 518 589

Closing Date for applications: 30th June 2014

Information

The All Party Parliamentary Kidney Group



Madeline Moon MP
Co-Chairman

The All Party Parliamentary Kidney Group was pleased to welcome two new officers elected at its AGM on the 10th June – Yasmin Quereshi MP and Richard Benyon MP. That makes a strong team of 7 officers to take the group into the next General Election. Once again, all renal patients will be asked (through Kidney Life) to survey party candidates during the campaign period to ensure that they are “renal aware”. For Further Information please contact Timothy Statham tim.statham@btinternet.com

ATOS Assessments

It has been widely reported that ATOS will not have their contract renewed for either the work capability assessments or the benefit assessments and that they will finish before the end of 2015 – it remains to be seen who will be replacing them; we expect reports of problems with benefits to continue. For further information on advocacy issues please contact Nick Palmer Head of Advocacy nicholaspalmer.nkf@btinternet.com



The NKF Executive Committee has identified its key priorities for 2014 as:-

- Improve provision for Dialysis within the UK
- Improve provision for Transplantation within the UK
- Develop a plan for campaigning in readiness for the 2015 General Election
- Develop current NKF services to patients and others
- Review and monitor the financial position of the NKF
- Develop and strengthen partnership working with KPA's and others

For further information please contact Timothy Statham tim.statham@btinternet.com

KPA DAY



The feedback from our KPA DAY on 29 March 2014 has been excellent (and we will improve the quality of the food next time). Our next KPA DAY will be on 28 March 2015 and we will also have our AGM and Council meetings on that day. Please add the date to your diary; we will provide details of the venue in due course. The sharing of good practice on KPA DAYs by individual KPAs continues to be very popular. If you are interested in doing so at the 2015 KPA Day, please contact Kirit Modi kiritmodi1@hotmail.com.



National Transplant Week (7-13 July).

Marketing Materials

Transplant Week leaflets, posters, stickers, balloons and t shirts are expected next week. If you require any supplies, please email leaflets@nhsbt.nhs.uk with your requests. You'll also soon be able to download the materials (including electronic tools such as screensavers, web buttons etc) from the action pack section of our website: www.transplantweek.co.uk

NKF Website KPA Pages

NKF Website has a section listing KPA Pages <http://www.kidney.org.uk/kpa> - These pages contain details of the local contact and activities of each KPA.

We welcome updates to the pages, so if your KPA has any events coming up, please write or email Stephanie Allen with details Stephanie@kidney.org.uk . Please give your position within the KPA e.g. Chairman, Officer, Member.

Do you already have a KPA web site, and would you like the NKF page to link to your site? (If you want this link you must agree to put a link on your own KPA web site which points to www.kidney.org.uk)

Please send any relevant photographs you would like to appear on the NKF page – with caption.

Please inform Stephanie of any changes you wish to make to contact details displayed – no contact's details will be displayed without consent from the individual concerned.

- ❖ **Finally, thank you for the amazing work all of you do to improve the lives of kidney patients and have a good summer!**

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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Charity No 1106735 Company No 5272349 Reg. in England & Wales Give as you earn contributions No CAF.GY511

