

NKF In Touch

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

Date: **January 2016** Issue: **Twenty**

Welcome to the first edition of NKF In Touch newsletter for 2016. NKF would like to wish one and all a very **Happy New Year!**

Please forward any articles etc that you would like sharing via the next newsletter to Stephanie Scott stephanie@kidney.org.uk by 10th February.



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Who NKF seeks to influence:

NHS England

NHSBT

Department of Health

Government Ministers

Welsh Government

Northern Ireland

Assembly

Scottish Government

All Party Parliamentary

Kidney Group



Advocacy Service Announcement jointly issued by Paddy Tabor (BKPA CEO) and Timothy Statham (NKF CEO) concerning the **ADVOCACY** service

The Kidney Patient Advocacy Service started by the National Kidney Federation (NKF) fourteen years ago and run as a partnership between the British Kidney Patient Association and the National Kidney Federation since 2012, is being brought under the sole management of the British Kidney Patient Association. This is part of a significant move designed to maintain the service, secure its long term future and as part of a planned approach to expand and extend the service it provides for patients and their families.

In the immediate future, kidney patients, their families and all the other individuals and organisations that engage with the service, will not see any change to the service, as both charities stress the importance for a smooth transition that ensures there is minimal disruption to the quality of service offered to patients across the UK.

The service will be wholly delivered by the British Kidney Patient Association from the 1st January 2016 with exactly the same Advocacy Officers who currently provide the service, covering the same catchment areas they have supported over the last 4 years.

Paddy Tabor MVO, CEO BKPA said

“The Advocacy Service is a major source of help and support for thousands of kidney patients and their families’ right across the UK. We are delighted that it will now form a stronger part of the range of patient support services provided by the British Kidney Patient Association. Patients will in the short term see no change to a service which will continue to operate as it has for the last four years, empowering and supporting patients to make a real difference in their lives. However, BKPA have firm plans to both extend and improve the service in the future and we very much look forward to working with patients and the Advocacy Officers to develop an even better service”.

Nicholas Palmer, Head of Patient Support Services, BKPA said

“Together with my fellow advocacy colleagues I am tremendously privileged to be continuing my role leading this highly respected service on behalf of the BKPA for patients and carers across the UK. The service developed by the foresight and dedication of the NKF will now have the opportunity sustain its unique patient facing offer, improve further, and embed with the well-established grants and counselling resource provided by the BKPA, whilst maintaining the continuity of current working arrangements with the NKF Helpline. Advice, assistance, representation and empowerment will continue to run at the heart of the service to improve the care and quality of life for all patients no matter what stage of Chronic Kidney Disease.”

Timothy Statham OBE, CEO NKF said

The National Kidney Federation (NKF) is extremely pleased to have reached this agreement with the British Kidney Patient Association as apart from securing the future of the Advocacy service for patients, it releases resource to the NKF that will enable the Federation to further expand and develop its other vital services to kidney patients, namely the NKF National Kidney Patient Helpline, the NKF range of 200 medical information leaflets, the NKF patient magazine “Kidney Life”, the NKF annual patient conference, and the NKF programme of campaigning at national, local and parliamentary levels.

To contact the two Charities:

British Kidney Patient Association - 01420 541424
www.britishkidney-pa.co.uk

National Kidney Federation Helpline - 0845 6010209
www.kidney.org.uk



Would you like to help the NKF and/or take part in this?

The NKF has been given one of the 90 minute sessions to organise at the BRS Conference which is to be held at the ICC Birmingham between Tuesday 7th June and Friday 10th June 2016. This is a wonderful opportunity for the NKF to advance the case of patients to the entire renal community – this is a very large conference.

The proposal made by the NKF, and now agreed, is that the session will consider the many issues surrounding **Dialysis Away From Base (DAFB)** (sometimes referred to as Holiday Dialysis) as we know from the NKF Helpline that this issue is a continuing cause of anxiety, stress and disappointment to Dialysis patients, often preventing a much needed holiday, or preventing a patient being involved in a family celebration such as a wedding or a grandchild's birthday. It even jeopardises the employment of some kidney patients trying to hold down a job. The issues affect both haemodialysis patients and Peritoneal Dialysis patients.

The NKF wish to identify five people to form a panel and who would be prepared to speak to part of the BRS conference (a specific breakout group of about 50 to a 100 people) and who would fill one of the following criteria :-

1. A patient on HD who has experienced difficulty organising a holiday because no renal unit could be identified or organised to receive them.
2. A patient on PD who has experienced stress and worry trying to ensure their PD equipment and solutions were where they had to be during a trip away.
3. A renal nurse or other unit DAFB organiser who can explain the hurdles to accommodating a patients break from a units perspective
4. A holiday Dialysis provider (private company) who can explain the issues affecting their business (PD or HD)
5. Anyone else with a particular slant on this issue that needs airing

If you can take part in this, or know someone who can, then please contact Tim Statham (NKF CEO) on tim.statham@btinternet.com or contact the NKF helpline or HQ in Worksop.

Many thanks for considering this



KPA Officers

If your KPA has a change of officer(s) please remember to inform HQ so we can update our database and ensure information goes to the appointed officer. Full name and address details are needed along with an email address if applicable, as our preferred method of contact is by email. You can email your updates to Stephanie@kidney.org.uk or telephone the office on 01909 544999

Concerned by ESA or Pip?

Concerned by ESA or PiP? Visit <http://www.kidney.org.uk/home/news-2/concerned-by-esa-or-pip/>



Essential guides to Employment and Support Allowance (ESA) and also to Personal Independence Payments (PiP) are now available from c-App – *C-App is designed to help people with disabilities or long term physical or mental health conditions to apply for two benefits, Personal Independence Payment (PIP) and Employment and Support Allowance (ESA).*

The sites contain essential guides to ESA and PIP, in long and short versions, and a video covering the same ground as the short version. Most importantly, they contain a tool which allows users to test out the sort of questions they might be asked in the assessment, and to save a list of their key answers in advance of the assessment.

Alternatively call our Helpline on 0845 601 0209

Would you like to have the voice of your KPA heard?



NKF KPA DAY/AGM – on 2nd April 2016 at the Arden Hotel Birmingham our 4th KPA Day will be taking place, the same venue as last year. Attendance is open to anyone interested (an attendance form **must** be completed) we are hoping at least one representative from each KPA will be in attendance. The AGM will be taking place and nominations for new executive members will be considered. **This is your opportunity to let us hear your voice! It is your chance to be heard and have your say! Be the voice for your KPA!** Further details about our AGM and the Council meeting along with nomination forms for joining the executive will be emailed to KPA Officers on 18th January and posted to officers without email addresses. For further information about the role of an exec member please contact Andrea Brown – andrea@kidney.org.uk or call 01909 544999



Make a difference join the executive!



World Kidney Day is a joint initiative of:  

Help us unite with one powerful voice for **World Kidney Day 2016** by organising an activity or event in your KPA to draw public attention to the importance of kidney health, what can be done to protect kidneys before disease strikes, and to assist patients who already have chronic kidney disease. This year there is also a particular focus on kidney disease in children.

APPLY NOW FOR YOUR SUPPORT PACK via info@worldkidneyday.co.uk

To help with your event, the **Kidney Charities Together** team have produced a Support Pack containing:

- 2 A4 kidney health awareness **posters**
- A number of double-sided A5 kidney health awareness **flyers** (please confirm how many you need)
- World Kidney Day logo **stickers** (in sheets of 48 per A4 page – please confirm how many sheets)
- A poster to help **advertise your event** (an electronic version is available on the website to customise and print out yourself)
- 2 **'How to Guides'** – *A guide to working with the media* and *'A guide to using social media'*
- A sample **press release** (an electronic version on the website which you can customise and use)

Further details on getting involved are available on the UK website www.worldkidneyday.co.uk along with more hints, tips and ideas for activities and additional downloadable resources.

World Kidney Day in the UK is led by the Kidney Charities Together Group



Contact us

info@worldkidneyday.co.uk • www.worldkidneyday.co.uk



[@kidneydayUK](https://twitter.com/kidneydayUK) and use #worldkidneyday



www.facebook.com/worldkidneydayuk

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On December 14th Addenbrookes hospital opened its new kidney dialysis unit Cambridge - with a better service and more room for patients. The Cambridge Dialysis Centre can be found in Unit E, Beadle Industrial Estate, off Newmarket Road.

It is able to accommodate more dialysis patients with 36 chairs -11 more than the unit currently has - including four side rooms with en-suite facilities, which will mean Addenbrookes is able to provide a better service for patients.



Transforming Participation in Chronic Kidney Disease (CKD)

A unique NHS programme to help people with CKD live their best life.

To go to the NHS 'Think Kidneys' program; a national programme led by NHS England in partnership with the UK Renal Registry. Copy and paste <https://www.thinkkidneys.nhs.uk/ckd/> in to your search engine



NKF Helpline 0845 601 02 09

Local Kidney Patient Associations are in an excellent position to help new patients in their area, welcoming them into their group offering their experience and support. Thankfully, there are many local groups who can do this. However, there are lots of patients throughout the UK who don't have access to such a friendly, local group of people who understand their anxieties and can help them through it.

The National Kidney Federation Helpline is here to help **ALL** kidney patients to find these local support groups but if there isn't one, then the NKF can offer the help, support and information needed.

It is important that the Helpline number is widely distributed so that "new" patients can easily find the help they need.

Just by informing your local GP surgery and local pharmacist about the NKF Helpline you are helping **ALL** the kidney patients in the UK to find the help they need to face their journey into the kidney world.

And if the NKF Helpline can be of help to your group then give us a call.

The **NKF Helpline** is here to help **YOU**
0845 601 02 09

Date: Thursday, 14th January

UHNM battles Chronic Kidney Disease with Research Study

Research is now underway at University Hospitals of North Midlands NHS Trust on a new treatment that could help some patients with Chronic Kidney Disease avoid the need for life-saving dialysis or a transplant.

It is now looking for local residents who have been diagnosed with the kidney disease Autosomal Dominant Polycystic Kidney Disease, known as ADPKD.

ADPKD is a genetic condition where cysts grow in the kidneys. Whilst not all patients are affected by these cysts, in some cases there can be so many, and so large, that they cause severe backache and even a male patient may appear to be pregnant. Patients may have difficulties eating as the stomach is pushed out of the way. There is no cure for the condition, which may also cause a range of other symptoms including high blood pressure and kidney stones and severe abdominal pain.

There are also further complications with this condition as the cysts may burst or become infected. As the cysts grow they cause permanent damage to the kidneys leaving patients needing life-saving dialysis or a kidney transplant.

Already the Trust has recruited the most patients in England for the study looking at a new treatment, but it is now looking for any more patients who would like to take part before recruitment closes at the end of January 2016.

The Trust is now looking at how a drug, which has already been found to stop the growth of the cysts, can be used practically by patients so they can check things such as the best time to take it and what dose works best.

Consultant Dr Dominic de Takats, who is the local Principal Investigator, is heading up the study at the Trust.

He said: "There is no cure for ADPKD and this is the first time we have had a licensed drug that slows down the progress of this chronic kidney disease to help patients avoid the need for dialysis or a transplant.

"As ADPKD is a genetic condition, I find I can be treating several generations of a family.

Patients can present at any age, though many are not troubled until after their 20s. Family members who want to be declared clear of the disease currently need to wait until they get a negative scan at the age of 40. In the future, as costs come down, genetic testing is likely to be more widely used to tell apart affected from unaffected family members. Here at UHNM, we treat around 500 patients with the condition from around Staffordshire and South Cheshire.

“This study is very much a practical test for our patients to see how the drug fits in with patients’ lifestyles so we can work out when is the best time to take the tablets and how much works best for a patient to stop the cysts growing.

Volunteers, aged between 18-65, are needed to take part in the study and must have been diagnosed with the chronic kidney disease ADPKD.

For more information and an informal chat call the Renal Research Team on 01782 675397 or e-mail Carol.Edwards@uhns.nhs.uk



NKF Fundraising

What are your plans for 2016?



After Christmas we all seem to look to the New Year for inspiration and here at the NKF we hope you can help us support kidney patients throughout the UK by taking part in some kind of fundraising?

We would love to hear from you or anyone you know that is interested in taking part in an event in 2016, that could be one of the NKF events or one you are taking part in like the Great North Run, but you don't have to be a runner or a harden walker to support the NKF, why not organise a fundraising disco or maybe your place of work could support the charity?

The NKF relies totally on donations and sponsorship so it can continue its vital work with kidney patients. Please join us in 2016 to give kidney patients a brighter future.

NKF events please visit www.kidney.org.uk/fundraising

Fundraising office - 01263 722287 or email pete.revell@kidneynkf.com

Working together in 2016

In the past the NKF has teamed up with Kidney Patients Associations and successfully organised joint fundraising activities, already we have plans for a couple of large events.

If your KPA would be interested in working with the NKF please contact Pete Revell our head of fundraising who is full time and has a wealth of experience to offer you.

If you are interested in working with the NKF this year please call Pete on 01263 722287 or email pete.revell@kidneynkf.com he is more than happy to come and see you and have a chat about how we can all work together ?



NKF armchair fundraising - no training required! Ever heard of it? We at the NKF realise for

many jumping out of planes, running marathons or having your head shaved is pretty daunting or nigh on impossible! Armchair fundraising **is for all** from recycling clothes, being a regular donor, buying draw tickets or simply 'liking' us on face book - we value your support, we are grateful for all donations whatever the amount!





Well Done to Mrs G Baines of Lancashire who is a lucky winner in the first NKF/Unity Lottery draw of 2016! Sign up to Unity Lottery and you too could join the list of NKF Unity Lottery winners! You could win £25000! For every £1 entry you have NKF receive 50p! If you play £1 per week for 1 year you will have raised £26 for NKF and had 52 chances to win! You could win £25000 (you must be over 18 years of age to play)



Interested? Visit <http://www.unitylottery.co.uk/charity/display/national-kidney-federation> or call 01263 722287 for an entry form



Join us on facebook and keep up to date with NKF news
<https://www.facebook.com/nkfukfundraising>

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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