

# NKF In Touch

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

Date: February 2016 Issue: Twenty One

Welcome to the NKF In Touch newsletter for February 2016.  
Please forward any articles etc that you would like sharing via the next newsletter to Stephanie Scott [stephanie@kidney.org.uk](mailto:stephanie@kidney.org.uk) by 10<sup>th</sup> March



## Contents:

Action Point

NKF KPA Day AGM - Page 1

Information

Annual patients' Conference– Page 2

Priority Setting Partnership – Page 3

[www.kidney.org](http://www.kidney.org) – Page 3- 4

Fundraising – Page 5 -6

## 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  
Trusts and Hospitals



Action Point

## Please book your place NOW!

NKF KPA Day (including AGM and Council meetings) – 2<sup>nd</sup> April – Arden Hotel Birmingham.



Places are filling fast for this free to attend KPA Day. Please book your place as soon as possible to avoid disappointment.

Please also remember that the NKF Executive Committee election is held during the AGM. As many of the executive committee are coming to the end of their service we need you! Let us hear your voice! If your KPA has a nominee for a position on the Committee then please ensure your forms are received by the NKF HQ **no later than Friday 19<sup>th</sup> February**. Forms are attached for your convenience.

For further information please call 01909 544999.

## Annual patients' conference 2016



We are very pleased to announce The NKF Annual Patients' Conference will be held at Hilton Blackpool hotel from 7th – 9<sup>th</sup> October.

There will be a 2 course supper with tea or coffee around 7pm on the Friday evening followed by a quiz.

The programme on Saturday has a wide range of speakers from professionals to patients, with the theme and title being Changes?



There will be a three course gala dinner on the Saturday evening with a pre dinner drink included, followed by a disco.

Sunday morning will see the NKF Council meeting then a Benefits Workshop.

This workshop will provide up to date information and the audience will be able to ask questions.

To book your place, or for further information please call 01909 544999.

	Cost
Friday Supper	£16
Friday Double	£103
Friday Single	£91
Saturday Double 24 hr (inc Gala Dinner)	£225
Saturday Single 24hr (inc Gala Dinner)	£135
Gala Dinner	£31
Day Delegate	£50

### Location

Hilton Blackpool hotel, overlooking the sea and famous Promenade. The hotel is 20 minutes' drive from Blackpool International Airport and 5 minutes' drive from North Station. Blackpool Pleasure Beach, Blackpool Tower and the zoo are within easy reach.

**Plunge into the Hilton Blackpool hotel's indoor pool or relax with a massage in the health club.** Overlooking the beach and Promenade, Blackpool Pleasure Beach is 2.5 miles away.

Bookings are now being taken – please complete and return the attached booking form with payment to NKF, The Point, Coach Road, Shireoaks, Worksop. S81 8BW  
Cheque made payable to NKF

## 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 7<sup>th</sup> June and Friday 10<sup>th</sup> 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](mailto:tim.statham@btinternet.com) or contact the NKF helpline or HQ in Worksop.

Many thanks for considering this

## Priority Setting Partnership



On the 3rd February 2016, a group of 20 kidney transplant recipients, donors and professionals took part in a consensus workshop at the Royal College of Surgeons of England, in London. The group considered the top 25 ranked treatment uncertainties from the PSP prioritisation survey, and after much lively debate agreed a top ten list of priorities for the future of research in kidney transplantation.

Angie & William Beale of NKF Executive Committee and Bristol Area KPA were in attendance representing patients, donors and carers with equal weight to renal clinicians to harvest, analyse and determine the top priorities for future research, agreed by patients, carers and health professionals working with Priority Setting Partnerships.

Listed are the top ten as determined via the surveys, we have worked to exclude questions that were asked but the research is available and we believe this is the basis of what is important to our renal community including the clinicians who serve us.

We would like to thank everyone who took the time to fill in the surveys and rest assured that in our experience this is the first project where our patients have had a real impact in determining the future of research by listening to what we as patients, donors and carers feel is important. Renal nurses, dieticians, doctors and surgeons all gave their views and here are our collaborative results.

The final top ten questions, as agreed, are:

### The Top Ten

The top ten priorities agreed by the group were as follows:

- What is the best way to treat vascular or antibody-mediated acute rejection?
- How can immunosuppression be personalised to the individual patients to improve the results of transplantation?
- How can we prevent sensitisation in patients with a failing transplant, to improve their chances of another successful transplant (e.g. removal of the transplant, withdrawal of immunosuppressive medicines or continuation of these medicines?)
- Can we improve monitoring of the level of immunosuppression to achieve better balance between risk of rejection and side effects? (e.g. T-cell or B-cell ELISPOT, point-of-care tacrolimus monitoring, MMF monitoring)
- How can we improve transplant rates in highly sensitised patients?
- What are the long-term health risks to the living kidney donor?
- How can we encourage tolerance to the transplant to prevent or reduce the need for immunosuppression? (e.g. by use of T-regulatory cells, induction of haemoxygenase 1)

- What is the best combination of immunosuppressive drugs following kidney transplantation? (e.g. azathioprine or mycophenolate, belatacept, generic or proprietary (brand-name) drugs)
- What techniques to preserve, condition and transport the kidney before transplantation allow increased preservation times and/or improve results? (e.g. machine perfusion, normothermic reconditioning, addition of agents to the perfusate)
- Can bioengineered organs be developed to be as safe as human-to-human transplants? How can this be achieved?

## Next Steps

Over the coming weeks, a full report will be prepared for publication, as well as presenting the results at national renal and transplant conferences. We will also be discussing the results with funding bodies and charities in an attempt to promote research in these areas.

## Acknowledgements

We would like to extend a big thank-you to all those who took part in the PSP process, including the [steering group](#), all those who responded to the surveys and the group who attended the final workshop

If you represent a charity or organisation please help disseminate these to as many people as possible by publicising the information within your groups Information can be found by using the following link <http://www.transplantpsp.org/kidney/top-ten>.



## NKF Fundraising

**World kidney day is Thursday 10th March** a day that highlights the fact that 2 million people in the UK have kidney problems, the Charity National Kidney Federation ask everyone to keep their kidneys healthy by keeping them hydrated.

On March 10th World Kidney Day show your support and put down the tea and coffee and only drink water for a whole day and spare a thought for all the people who have kidney disease – Text WKDA16 £3 to 70070 to donate to NKF and make a difference today.

Collection boxes are available please call 01263 722287

World Kidney Day materials are available to download at [www.worldkidneyday.co.uk/campaign-materials](http://www.worldkidneyday.co.uk/campaign-materials)

## We need your support

However large or small we need your help to maintain our vital service we offer to kidney patients.

The NKF offers a vast array of events to take part in at [www.kidney.org.uk/fundraising](http://www.kidney.org.uk/fundraising) or why not take part in your own event, maybe be part of your local fun run or organise your own to raise money for the NKF – for more details please call the fundraising office on 01263 722287



## Helpline



NKF runs the UK Helpline dedicated to kidney patients with two fully trained, experienced advisers providing a 5 day per week service to kidney patients, carers and healthcare professions and Renal Units.

The NKF Helpline is open from 9am until 5pm Monday to Friday on 0845 601 02 09

The NKF Helpline is also the UK's largest provider of kidney related medical information leaflets with a library of over 200 titles written by Nephrologists in simple language for patients and carers. Visit [www.kidney.org.uk/helpline](http://www.kidney.org.uk/helpline) to see all the leaflet subjects.

The NKF Helpline can provide information about Chronic Kidney Disease, Dialysis, Transplantation, Living Donation as well as Benefits information, dietary advice and Holiday information.

Our advisors Pauline and Andrea are waiting to help on **0845 601 02 09**

## **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!



**We now have a very simple way to donate, it takes just two minutes!**



Click on our donate buttons at [www.kidney.org.uk](http://www.kidney.org.uk)



or



[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*

NKF (National Kidney Federation)  
The Point, Coach Road, Shireoaks, Worksop, Nottinghamshire, S81 8BW  
Charity No 1106735 Company No 5272349 Reg. in England & Wales Give as you earn contributions No CAF:GY511

