

# NKF In Touch

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

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Welcome to the NKF In Touch newsletter for May 2015. 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 8<sup>th</sup> June.



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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



## Action Point

## NKF Conference 2015 – Living Life to the Full



Bookings are now being taken for this years Patient's Conference which is being held at The Hilton Reading Hotel 9<sup>th</sup> to 11<sup>th</sup> October 2015. A booking form and further information has been attached to this newsletter for your convenience and will be in the next edition of Kidney Life.



## KPA Officers



To help ensure your KPA continues to receive up to date information please inform the office of any changes to your KPA's officers. Please email any changes to contact details including email addresses to [Stephanie@kidney.org.uk](mailto:Stephanie@kidney.org.uk)

## London Marathon 2016



The NKF is looking for one person to represent the charity in next year's London marathon, we only have the one place so we would like to make the most of this place – if you or anyone you know is interested in taking part please email [pete.revell@kidneynkf.com](mailto:pete.revell@kidneynkf.com) telling him how much you intend to raise and how you would raise it plus a little about your running ability.

## Information



**Yorkshire and The Humber**  
**Sharing Haemodialysis Care**  
Improving Outcomes



**Closing the Gap**



**The 4th Shared**  
**Haemodialysis Care 2015**

Please join us!

**Renal patient involvement and interaction in previous years' learning events have played a vital part in their success!**

We would again like to invite patients to join us in sharing your experiences of Shared Haemodialysis Care with other patients and staff from across the region and other parts of the UK. Sharing your experiences and learning from each other is essential to the success of this event. Your participation would be valued in small, informal discussion groups and there will be a number of inspirational presentations on the day, which we hope will be of interest to you as an active participant in your own haemodialysis care.

Y&H Sharing Haemodialysis Care [www.shreddialysis-care.org.uk](http://www.shreddialysis-care.org.uk)

The day is **FREE** and includes lunch & refreshments.

Reasonable Patient & Carer travel expenses will be reimbursed.

Filming and photography will be taking place on the day.

Wednesday 10th June 2015, 09.30 - 16.00

Marriott Hotel, Leeds LS1 6ET

For a booking form please email: [sarah.boul@nhs.net](mailto:sarah.boul@nhs.net) or call on 0113 8253458

An inquest into the tragic deaths of two transplant recipients in Cardiff in 2013 shortly after receiving a kidney transplant from the same donor drew a significant amount of media attention last winter. The cause of the men's deaths was found to be an extremely rare nematode that had been transmitted through the transplanted organ and was unidentified at the time of donation. The coroner concluded their deaths were the unintended consequence of necessary medical intervention.

We spoke to Professor James Neuberger, associate medical director of NHS Blood and Transplant, to find out whether patients should be concerned about undergoing a transplant, how long they should expect to wait for an organ, how successful transplants are and how the consent process works for patients in need of a transplant.

**Should patients waiting for a kidney transplant or patients who may need a transplant in future be worried about what happened in Cardiff?**

“What happened in Cardiff was a tragedy and we were incredibly sad for the families concerned. The families were naturally devastated by their loss. We must remember though that the nematode responsible for the men's deaths had only been seen a few times anywhere in the world before and never before in transplantation.

“While no one can completely eliminate the risks associated with a kidney transplant, we all work hard to make sure transplants are as safe and successful as possible. While we know that all organs are associated with some risk, the level of risk is very small whereas the benefits of transplantation in terms of a better and longer life are considerable. Nonetheless, when harm comes to the recipient, this can be devastating to the patient and their family, so we do not take the risks lightly.”

**How successful are kidney transplants?**

“Kidney transplant success rates have been increasing since they first took place in the 1950s. In fact, now more than nine out of ten (93%) of kidney transplants still function well a year after transplant, and 96% of kidney transplant patients are alive a year after their transplant. 89% are alive five years afterwards.

“The alternative to kidney transplantation is some form of dialysis: Dialysis can be quite restrictive as patients have to spend so long on a machine, often several times each week. Having a kidney transplant can give them back more freedom to live their life again.”

**Should patients be told about the risks of a transplant?**

“The information the clinical team provides to a patient when they are assessing the patient's suitability for a transplant is extremely important. All organs are in one sense 'second hand' as they come from someone who inevitably will have some risk. Some donors, especially those who are older, have more risky life styles or a complex medical history may have a greater risk and the organ itself can carry risks. We are working to give as much information as we can to patients and their families so that, with the support of their clinical team, each person will make the decision that is right for them. Such information can be found on our website ([www.odt.nhs.uk](http://www.odt.nhs.uk)).

“We, together with British Transplantation Society, created *Guidelines for consent for solid organ transplantation in adults*. This guidance seeks to ensure that potential transplant recipients can make informed decisions about the type of organs they would accept as well as the consequences of rejecting an organ to wait for an organ they perceive to be better quality. It is a balance that surgeons and patients face every day.

“The guidelines set out the information potential transplant recipients should be given when they are listed for a transplant and also when they are offered an organ. As time is pressured when an organ becomes available, the more detailed discussions between the clinician and patient take place at the time of listing and annually during the patient’s wait for an organ. When an organ becomes available for a patient, we recommend that the patient should be told about any additional risks relating to the donor or the organ itself so the patient can make an informed decision whether or not to go ahead with surgery. This may include, for example, specifics about known infection transmission risks or the cause of the donor’s death.”

**Is it possible to predict how long you’ll be waiting for an organ after being listed?**

“We appreciate that the wait for an organ can be an anxious time for patients and for their families. It’s helpful to have some idea of how quickly a matched kidney will become available. While on average adult patients can expect to wait approximately three to four years for a deceased donor kidney transplant and paediatric patients approximately one year, there is considerable variation according to patient characteristics.

“We have a probability calculator on our website. Patients can put in various information, such as their blood group, age at registration, previous graft history and the transplant centre where they are listed, and it will give an indication of how long you could wait for a kidney transplant. We also have introduced another calculator to help patients decide whether it would be better for them to join the incompatible kidney paired donation scheme. The latter scheme is when a person needing a kidney transplant has a living donor whose donated kidney is not compatible. We recommend that you use these calculators with your doctor or nurse.

“It’s important to remember that they are probability calculators rather than tools that give you exact timeframes, but we hope they are useful resources for patients and their clinical teams. You can find the calculators at:

[www.odt.nhs.uk/transplantation/guidance-policies/tools/](http://www.odt.nhs.uk/transplantation/guidance-policies/tools/)”

**Would a surgeon always accept an organ offered to him or her for one of their patients?**

“When NHS Blood and Transplant offers a kidney to a transplant unit for a specific patient, the surgical team assesses whether or not to accept the organ by weighing up the risks with the particular patient in mind. They do this using knowledge of the potential recipient and the available information about the donor’s history and organ function. It is not unusual for a surgeon to decline a kidney for a patient and there are many reasons why they may do so. Reasons include that the organ may not be the right size for their patient, or that they may deem the function inadequate for their patient, for example if the kidney has come from an older donor and their patient is much younger. If a patient is highly sensitised (so that they are likely to reject the kidney) they may only get a kidney offer every five years so the surgeon may be more likely to accept the kidney than if the next offer for their patient is likely to be in six months’ time.

“Surgeons and their teams have to balance the risks of using a donated kidney with the risks of waiting for the next offer for their patient. When a surgeon rejects a kidney for their patient, it is offered to the surgical team for the next patient on the offering sequence.”

### **It is unusual for a kidney rejected by transplant units to be used?**

“We want as many donated kidneys as possible to be used for transplant but only if the outcome will be good for the recipient. Over the last few years, we have introduced Kidney Fast Track Schemes to help optimise the use of kidneys. Kidneys are put through the Fast Track system if the time to transplantation is becoming too long so there is a risk that the organs will become unusable or if they have been declined for the first five patients to whom they have been offered (3 for donors after circulatory death). At that point, the organs can be offered to all other transplant centres that are part of the Kidney Fast Track System at the same time. Twelve of the 23 UK kidney transplant units are currently part of the scheme.

“Between 1 November 2012 and 30 April 2014, 291 kidney transplants were carried out after the organs were offered through the Fast Track Kidney Scheme (115 DCD kidneys and 176 DCD kidneys). Both the patient and graft outcomes are similar to those offered outside of the fast track scheme. These figures show that kidney transplants can be successfully carried out after being declined by other transplant units. A surgeon will always consider using an organ with a specific patient in mind, so the decision whether or not to use an organ is made on a case by case basis.”

### **If you could change one thing what would it be?**

“This is an easy one for me to answer. I’d want every patient in need of a transplant to get the organ they need and to undergo a successful transplant. For this to happen, we need more families to agree to donate their loved one’s organs. Currently four out of ten UK families say no to donation. So what I want is for everyone in the UK to decide if, in the event of their death, they would like to become an organ donor and save and improve other people’s lives: if they do, to make sure their family and close friends know their wishes so they can help those wishes be fulfilled.

“Real life stories of successful transplants are incredibly powerful as are the stories of what it’s like waiting for a transplant and that’s why it’s great seeing people share their stories publicly to encourage the public to donate.”

## **Calling All KPA’s!**

One of our members has generously donated the money she has saved from giving up smoking to fund hairdressing and manicure services for kidney inpatients. If any of you have spent a while on a ward you will know how something like having your hair washed, or nails cut can make all the difference to feeling like a normal human being!!

We think it is a great idea, but probably not the easiest thing to set up. Have any of you had any experience in this area – or have such services at your hospital? Any advice would be gratefully received.

Jackie Fisher

Royal London Hospital KPA [rlhkpa@googlemail.com](mailto:rlhkpa@googlemail.com)



## Looking for Sporty and Fit Kidney Patients

The Leicester Kidney Exercise Team would like to get in touch with kidney patients from around the UK who participate in sport or undertake exercise training at higher intensities or duration than the average kidney patients does e.g. those who train for running, cycling etc. As part of the launch of the new National Centre for Sport and Exercise Medicine at Loughborough University, we are holding an event in July for these unusually fit and active individuals to talk about their experiences and any difficulties they face, and to showcase the new National Centre, its facilities and the work that is going on there. We anticipate that most of these people will be kidney transplant recipients but we are equally keen to hear from anyone managing to engage in sport or fitness on dialysis, PD or with earlier CKD.

We would love to hear from patients that fit this description so we can invite them to the July event. Travel expenses will be reimbursed, and we can arrangement overnight accommodation for anyone who needs it. We hope it will be an interesting and enjoyable day for all the attendees.

### **For Further information please contact:**

Dr Alice C Smith BSc MSc PhD

[aa50@leicester.ac.uk](mailto:aa50@leicester.ac.uk)

Hon Senior Lecturer and Team Leader

Leicester Kidney Exercise Team

Follow us on Facebook : <https://www.facebook.com/LeicesterKidneyExerciseTeam?ref=hl>

Leicester Kidney Exercise Team, UoL Academic Unit, Leicester General Hospital, LE5 4PW

Tel : 0116 258 4346



**Helpline – 0845 601 02 09**

## **BUDDY SCHEME**



Kidney patients calling the Helpline sometimes ask to speak with someone who has been through similar medical problems that they are experiencing themselves. Internet forums are not always an appropriate place for such conversations.

We are calling upon Kidney Patient Associations to ask if you know a suitable representative who would be willing to join our buddy list so that patients can be put in touch for a helpful chat about matters which only kidney patients understand.

This will involve direct contact with kidney patients via telephone or email from time to time.

If you know a suitable kidney patient, with the time to spare to help another kidney patient, please contact our Helpline on 0845 601 02 09 or email [help2@kidney.org.uk](mailto:help2@kidney.org.uk) for more information.

## NKF Spring Draw



Congratulations to June Haynes from Somerset who has won £2,000 in the NKF spring draw, thank you to everyone who took part.



## London Marathon



Congratulations to Ceri Barrett who ran the London marathon to raise money for the NKF, not only did she run the route in 5 hours and 5 minutes but raised over £2,000 for the charity – thank you Ceri!



## Greetings Cards



We have teamed up with a card company to offer you personalised greetings cards.

Every card you send the NKF will receive a donation of at least 20p, they have a huge range of high quality greeting cards all of which can be personalised for any occasion – birthdays, Christmas, Easter, invitations - you name it they have got it. If they haven't got exactly what you're looking for you can customise many of our greeting cards by using your own images or you can use any of their 4 million images for free! Please visit <http://store.kidney.org.uk/>

## Coming up!

We would like to thank the following people and wish them all the best with their events which take place in the next couple of weeks ....

Laura Bradley in the 'Edinburgh Marathon'

Clare Michelmores and four of her friends in the 'Windsor Half Marathon'

David Healey and Ray Steane taking part in the 'Way of the Roses' cycle ride

Ian Hope in the 'Mohawk Challenge'

Tom Fenton and friends trekking the 3 peaks



## Fancy taking part?

If you would like to take part in an event to raise money for the NKF please visit our web site [www.kidney.org.uk/fundraising](http://www.kidney.org.uk/fundraising) or contact Pete Revell on 01263 722287 or email [pete.revell@kidneynkf.com](mailto:pete.revell@kidneynkf.com)