

NKF In Touch



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

Date: **June 2016** Issue: **Twenty Five**

NKF In Touch has recently celebrated its 2nd birthday!



We hope you are all enjoying receiving NKF's monthly newsletter. We are delighted the mailing list has increased significantly over the last 2 years. Please feel free to forward the newsletters to friends, family or colleagues. Alternatively email stephanie@kidney.org.uk including details of who would like to be included in the distribution.



Should you have any suggestions or items you would like adding, please let us know.

We aim to distribute the newsletter on or around the 15th of each month—deadlines for articles are the 10th of each month.

In Touch is available to read online, back copies too!
<http://www.kidney.org.uk/about-us/in-touch-newsletter/in-touch-downloads/>

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Who NKF seeks to influence:

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



NKF Patients Conference 2016 – Changes?

We are looking forward to welcoming you at the NKF Conference, which will be held at Hilton Blackpool Hotel on 7th – 9th October.



NKF are very grateful to our sponsors Renal Services and NxStage. Their vital support enables the NKF to be able to facilitate this wonderful three day event, for you to all enjoy, meet new friends and maybe learn something new!

We have a full and varied programme which you can find attached.

Please book your place at the conference this year by calling 01909 544999, or using the attached booking form, or via the web booking form <http://booking.kidney.org.uk/>



Are you the person NKF needs?



NKF is seeking to identify a willing volunteer who has experience of identifying and approaching (in writing) suitable trusts and like organisations, to encourage them to fund the NKF activity as either a one off sponsorship or as an ongoing commitment. The post would be part of



the NKF Fundraising department headed by Pete Revell but would work directly to and from the NKF HQ in Worksop. This is work that can be done from home – it requires detailed research using directories and resources the NKF would supply, then a considerable amount of letter writing, and application form filling. Any applicant for this post must possess a suitable computer, space for document filing and a telephone and email address.

If you feel that this is something that you might be willing to help the NKF with then please contact Tim Statham directly at tim.statham@btinternet.com – or write to him via the NKF HQ at Worksop.

The POWER of the Federation working with its KPA's

Kidney Patients will be very relieved to know that the campaign fought by the NKF together with its KPA members has been confirmed as successful in halting the disastrous plan to commission Dialysis at PCT level rather than nationally.

Following the NKF announcement as shown below Lord Warner convened the Specialised Services Commission in December 2015 to help inform the future development of specialised services, drawing on relevant expertise from across the healthcare sector. That commission has now published its report. The report can be viewed in full by following this link:-

<http://www.shca.info/perch/resources/specialised-services-commission-report-final.pdf>

In this report it is clearly stated that Specialised Services are to remain commissioned Nationally as demanded by the NKF and its renal patients – this is a major win for NKF and the KPAs who responded to the NKF's "Call To ACTON". KPAs sought out the opinions of patients and provided the essential evidence that NKF then presented to Ministers via the All Party Parliamentary Kidney Group.

To reverse government intended policy is no small achievement and kidney patients across the UK should be proud of their efforts.

Others will no doubt try to minimise or downplay the effect that the patients, KPAs and the NKF had, or claim the credit themselves, but the simple fact is that YOU did this, working as a Federation should – together and effective – a patient voice loud enough to be heard.

Not many therapy areas within the health environment are so well organised – have patient groups (KPAs) at every hospital, have a national organisation (NKF) to plan a national strategy, and to have an All Party Parliamentary Group to tackle Government and Ministers.

The NKF is not opposed to change – much within the NHS is in need of change, and NKF will follow the development of commissioning as outlined in Lord Warners report with close interest. If we feel that any proposals are wrong we will oppose them – but where they are an improvement we will support them. It was the wholesale downgrading of Dialysis to level three commissioning that had to be halted – and this we did. WELL DONE.

Timothy F Statham OBE

Chief Executive

Continued from page 3

Successful battle with NICE! (The National Institute for Health and Care Excellence)



The NKF is overjoyed to inform all Kidney Patients that our battle with NICE to keep the full range of immunosuppressant drugs available to be prescribed has been successful.

Today (1st Jun 2016) NICE announced that following the Appeal at which the NKF and others gave evidence, the matter would now be referred back for further consideration, and in the meantime (probably years) the full range of immunosuppressant drugs will remain available to all transplant patients.

Patients will recall that NICE had originally reached a decision to severely restrict the available types/brands of drugs. Realising the horrendous implications of this to kidney patients and their transplanted grafts, NKF opposed this change in an ongoing battle which culminated in an appeal hearing at which NKF spelt out the damage that such a decision would do.

As reported (below) NKF had high hopes of eventually winning – and today the NICE announcement means that we have (for the time being at least).

Tim Statham
NKF CEO

Multiple Technology Appraisal

“Immunosuppressive therapy for kidney transplantation in adults (review of technology appraisal guidance 85) [ID456]

The decision of the NICE APPEAL PANEL is imminent. NKF remains hopeful that our representations will have won the day and that the immunosuppressant drugs being restricted by an unhelpful NICE Final Determination will be rescinded.

Watch this space – as soon as the decision becomes public we will let you know whether we have been successful – NKF tried very hard on behalf of patients and we are hopeful that we will have won the day.

CHECK HERE EVERY DAY – this matters if you are a transplant patient or expect to become one.

*Tim Statham
NKF CEO”*

The Royal Devon and Exeter NHS Foundation Trust has confirmed the Barnstaple based unit will open at some point during November, with an exact date set to be confirmed soon.

The new unit will be able to cope with up to 60 patients a day, with 20 state-of-the-art dialysis stations available for patients.

Fresenius Medical Care will operate the unit.



NKF Helpline 0845 601 0209

Since the last edition of In Touch the Helpline has been busy printing and preparing over 400 medical information leaflets and 200 flyers. The information was recently displayed on our Helpline stand at the UK Kidney Week in Birmingham. Also displayed were our three most requested booklets, **Food For Thought Cookbook**, **CKD Health Check** and **Help! I've got kidney failure**. If you would like a copy of any of the above booklets, please contact the Helpline.



The first week of posting out the summer edition of **Kidney Life** magazine always keeps the Helpline busy, generating extra calls and requests for further information.

Life Insurance



We are pleased to be adding the Insurance Surgery to our list for Life Insurance cover, as well as holiday insurance. As a Broker they can usually get great results for kidney patients. The Insurance surgery specialise for people in high risk categories.

<http://www.the-insurance-surgery.co.uk/forms/referrer-quote-life-insurance?ref=tis36>



NKF Fundraising

Congratulations from all at NKF!



In June 1976 a 9 year old girl called Jan had a kidney transplant, which back then was very unusual - this month it is the 40th anniversary of Jan Taylor's kidney transplant! As you can imagine Jan and her family and friends are celebrating, they have been raising money to support kidney patients for close to a year! On 8th May son Greg completed a half marathon in Germany. On 17th April Jan's sister Jo also put on her running shoes and took part in a 10k run in Brighton and during the past year son Daniel Mosley has completed several runs covering miles & miles! Not to mention cake stalls – the list goes on..... So far an amazing £2,347 has been raised for the NKF. **Thank you**



Photos top left – Jan and her younger sister ready to sell cakes – Top right Jan's son Dan (yellow shirt) with friend Dan Jones following St David's Day 10k – bottom right Jan with sons Greg and Dan – bottom left Jan Taylor

A special thank you



Sadly we cannot thank everyone who has fundraised or donated to the NKF in our newsletter but we do want to say a special thank you to Florence a young lady from Dorset pictured with her friend Jess – (Florence is on the right) who had a 12 hour Table Tennis Challenge last month starting at 8 in the morning, her Grandma Jan had a kidney transplant 13 years ago -



£757.70 has been raised – last year her brother Barney climbed Snowdon with his dad also for the NKF!

Still looking fresh after 12hours!
Florence with family and friends – the motivators!

A big **thank you** to you all!



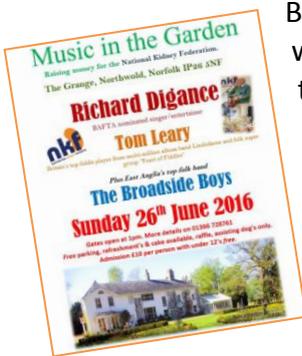
Swaminarayan School Summer Fair, London.



The NKF will be attending the Swaminarayan School Summer Fair in Neasden on the weekend of the 18th and 19th of June. They will be promoting organ donation and “Have your Kidneys been checked?” with the NKF ribbons plus bottles of Fonthill water will be handed out to keep kidneys hydrated. Come and join us – 1pm – 9pm Brentfield Road Neasden, London NW10 8HE.

NKF Garden party, Northwold, Norfolk.

Sunday June 26th will be music in the garden to raise money for the NKF, BAFTA nominated singer/entertainer Richard Digance will take to the stage along with Tom Leary - Britain’s top fiddle player from multimillion album band Lindisfarne plus also joining them East Anglia’s top folk band The Broadside Boys.



Gates open at 1pm, refreshment’s and cake available. Admission £10 per person with under 12’s free. The Grange, Northwold, Norfolk IP26 5NF.

Have you got a kidney health ribbon yet?



Have you got a kidney health ribbon yet? The NKF are supporting a campaign to check your kidneys, the

idea came about from the patient board at Fresenius and was kindly funded by the Masons.

If you have not got one of the eye catching chequered ribbons, you can purchase them from the web shop at <http://store.kidney.org.uk/> the ribbon comes on a card where it has facts about kidney disease but also how to keep your

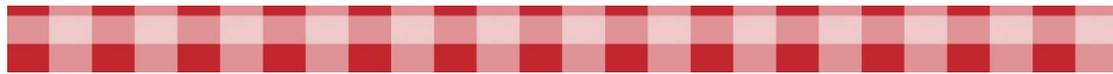
kidneys healthy – please help us promote kidney health by wearing one and also selling them to friends and colleagues.

Climbing for the NKF

This month sees 13 people trek in the heart of Scotland’s Western Highlands to the highest point in the British Isles and climb 1,343m to the top of Ben Nevis.



Good luck to Rachel Hucknall, Karla Salt, Mapole Nhlapo, Olivia Chappell, Rachel Firman, Roger Ward, Alison Ballantyne, Lily Chen, Alison Campbell, Kaylee Maclellan, Lorna Haddow, Gary Ballantyne and Audrey Hudson.



Join us on our **Thames Bridges Trek** as we venture across the Capital taking in unrivalled



views of the skyline from its best vantage points. Setting out from Putney Bridge - we head east towards the City, zig-zagging over the array of historic bridges - each with its own fascinating story to tell. Riverside, and 25km later, it's a finish line celebration next to the majestic Tower Bridge. A great opportunity to get out - get fit - and explore the best of London!

More details can be found at:

www.kidney.org.uk/fundraising/donate-to-the-nkf/sponsored-events/walking/thames-bridges-trek-2016/

YOUR CHANCE TO WIN



This year the NKF have teamed up with the bottled water company Fonthill water, they have kindly put the NKF logo on the bottle label to help raise awareness to kidney health.

Bottles of the spring water are available in Iceland, Staples and large Asda stores; we would love you to hunt these out, have a photo taken with one of the Fonthill water bottles, and then email it to nkf@kidney.org.uk where you will go into a draw to win your very own water cooler for your home or work place. Why not post the photo on Facebook?

www.facebook.com/nkfukfundraising

So get hunting, the closing date is August 1st 2016.

Whether you fancy climbing Ben Nevis, taking part in the Thames Bridges Trek or supporting NKF in any other way please visit www.kidney.org.uk or call 01263 722287



Please help NKF save money!

From 1st January to 19th May 2016 **201** Kidney Life magazines were returned to the office because the addressee had moved house! To tell us of a change of address please call 01909 544999

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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