

# NKF In Touch

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

Date: **September 2016** Issue: **Twenty Eight**



Welcome to the NKF In Touch newsletter for September 2016.  
We hope you have all had a lovely summer.  
Please forward any articles etc that you would like sharing via the next newsletter to Andrea Brown [andrea@kidney.org.uk](mailto:andrea@kidney.org.uk) by 10<sup>th</sup> October.

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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



## Action Point

### NKF Conference 7<sup>th</sup> – 9<sup>th</sup> October – CHANGES?



Conference Sponsors



NKF Conference is proving to be very popular as usual this year.

There are very limited rooms left in the hotel, so please get your booking to us as soon as possible.

Online bookings are now closed and telephone bookings will close on Friday 23rd September.

For further information or to make a booking, please call 01909 544999.

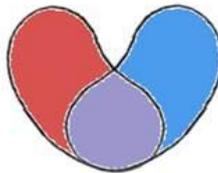
We look forward to seeing you there.



### NKF - National Kidney Federation - Open Day

The NKF Open Day was held on Thursday 8<sup>th</sup> September.

Thank you to everyone that came, we all had a wonderful day.



## Save the Date!

### Setting up services for young people: Perspectives, Practice and Planning

First national meeting of the British Renal Society Supporting Young Adults/ Shared Decision Making Special Interest Group

When : Thursday 1<sup>st</sup> December 2016 – Approximate timings – 10am – 4pm

Where : Frank Rifkin Lecture theatre, Salford Royal Hospital, Stott Lane, Salford, Greater Manchester, M6 8HD

### Objectives

To highlight, share and explore the practical aspects of improving health outcomes for renal transition and young adult patients and learn from good examples of patient centred care.

This study day would be relevant to all involved in the provision of young adult and transition services, regardless of discipline.

### Get involved

This event is all about sharing best practice.

If you have a service or idea you would like to share, a problem to solve or a question you would like to ask, please let us know.

We won't ask for lots of preparatory work, just a willingness to talk through your experience.

And please bring along any young adult patients who would like to come

### Agenda to follow

If you have any queries or would like to register for this event please contact Rachel Gair – [rachel.gair@renalregistry.nhs.uk](mailto:rachel.gair@renalregistry.nhs.uk)

The Transition and SDM Network is supported by a grant from the BKPA

**This is a free event**



## NKF HELPLINE

It is hard to believe that the month of October is fast approaching again. For the Helpline this means a very busy time printing many leaflets and flyers, packing cookbooks and preparing for this year's conference in Blackpool.

The Helpline stand at the NKF Open Day, at the Head Office on Thursday the 8<sup>th</sup> September was a great success. The Citizen Advice Bureau attended and it was good to know that the Helpline was all clued up on Benefits advice for its patients. Lloyd's pharmacy attended to take blood pressure and we all learned a lot from each other. It was nice to open our doors to the patients and public.

# Poetry

Kirsty Adams got in touch with NKF HQ and sent her poem to pass on her success and hope to others. She is a happy healthy, working wife and mum who had a kidney transplant 20 years ago, at Nottingham City Hospital, when she was 19 years of age. Kirsty is very proud to say, all the years and life experiences later, things are still going strong.

## TRANSPLANT ANNIVERSARY 1996 - 2016

### TWENTY YEARS AGO

"A match has been found, an end to the wait.  
Come straight to the hospital and don't be late".  
Was the awaited call, when all were in bed.  
In the middle of the night, the family sped.  
All hooked up, to machines and drips.  
Flashes and alarms, beeps and blips.  
Off we go! The theatre awaits,  
"we forget the kidney", for goodness sake!  
With kidney plonked at the end of the bed.  
'This is it' I say in my head.  
A tearful bye as others cannot come.  
But beside me all the way is my wonderful mum.  
Many hours later, darkness and pain.  
Then voices and lights, I'm back again.  
Filled with fluid and strong medication,  
I'm sick and hurting and a little frustrated.  
One day hunger? Mmm, custard creams.  
Then bananas and chocolate, this is a dream!  
Appetite and energy for so long gone.  
Then I remember, somebody's lost someone.  
A steady recovery, a long road ahead.  
Hospital trips and a life time of meds.  
The 3 'F's' support me and help me with care.  
Without faith, friends and a family I wouldn't get there.  
But, what to do after transplantation?  
With new found confidence and determination.  
I'm going to live, and work, and follow my heart.  
Make the most of each day, as each one's a new start.  
All the things I dreamed of, start coming true.  
A soul mate, a marriage a life anew.  
The birth of a baby, I was told may not be.  
A miracle gift and so precious is she.  
I've come a long way, from a 'sickly' child, shy and awkward.  
Now a wife and a mother, as well as sister and daughter.  
I was given the chance to spread my wings.  
To experience the wonders that this life brings.  
So much has happened between then and now.  
And I wouldn't change a moment, I'm stronger somehow.  
Life can be tough, that's how life can be.  
It's how I continue that's making me, me.  
Here's to the future, may I hold my head high.  
And continue onwards to reach for the sky.

I give thanks daily, to a person unknown.  
For the gift of life and the strength once shown.  
For that second chance and helping me believe.  
I hope they are proud of what I've achieved.

Good luck to others, going through the same.  
Be happy, be strong, be determined, and aim.

Kirsty Adams

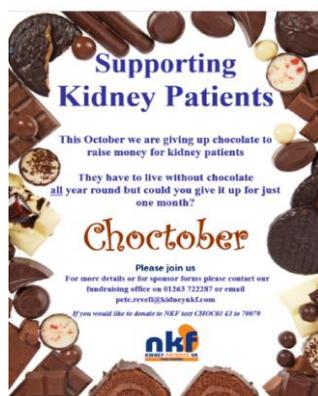
## Live Kidney Transplant Numbers Going Down

It is worrying to note that the number of live organ transplants, mostly kidneys, in the UK has gone down for a second year. In 2015/16, there were 1075 transplants, compared to a target of 1223 transplants; a shortfall of 148 (12%). The national Living Donor Kidney Transplantation Strategy, approved by the four governments and NHS Blood and Transplant (NHSBT) in 2014, is unlikely to meet its 2020 target of 1608 transplants which is an increase of 523 (49%) transplants on the current number. Kirit Modi, Life Vice President of the NKF, has written an article about this in a personal capacity and you can find this attached with the newsletter.

All KPA Chairs are requested to consider raising this matter with their local Living Donor Co-ordinator and find out what is happening in their area. Kirit will be very happy to hear about outcomes from these discussions; please do not hesitate to contact him at [kiritmodi1@hotmail.com](mailto:kiritmodi1@hotmail.com)



## NKF Fundraising



### Please join the *Choctober Challenge* 2016

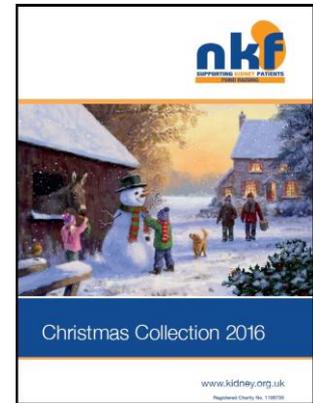
Come and join us and take part in *Choctober* next month – we have already sent out so many *Choctober* fundraising packs.

All you have to do is give chocolate up for one month in support of those kidney patients that cannot eat any chocolate at any time of the year – are you up for the challenge?

Email [pete.revell@kidneyuk.com](mailto:pete.revell@kidneyuk.com) with your name and postal address and we will send out a pack.

## Christmas cards

We may still be having BBQ's and putting on sun tan lotion but Christmas is on its way and here at the NKF we are in full swing in sending out Christmas cards – hopefully you will have received our 2016 Christmas brochure in the latest Kidney Life magazine but if you haven't we have a Christmas shop packed full of cards, wrapping paper and money wallets – please visit [www.charitycardsonline.com/nkf](http://www.charitycardsonline.com/nkf)



2016 has been such a busy year for people taking part in events to raise money for the NKF and we very appreciate your support.

On our web site we have a vast selection of events for next year <http://www.kidney.org.uk/fundraising/> if you are planning an event of any kind please contact our fundraising office on 01263 722287 or email [pete.revell@kidneynkf.com](mailto:pete.revell@kidneynkf.com)

A Special  
Thank You

One of our supporters is Tracey Perry, her husband sadly passed away in May of last year, from that day she has been looking at ways to raise money for other kidney patients – On May 1<sup>st</sup> she ran the Birmingham 10k and now this month she held a fundraising evening and had her hair shaved, to date she has raised over £750.



Kidney Life has arrived, as well as lots of interesting articles it will contain the Christmas draw tickets there are ten 10 prizes up for grabs!

If you don't subscribe to our free Kidney Life magazine and you would like to be included in the mailout email [nkf@kidney.org.uk](mailto:nkf@kidney.org.uk) we will send you a copy and add you to the list.



Should you wish to unsubscribe to this newsletter please email [nkf@kidney.org.uk](mailto:nkf@kidney.org.uk)

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

