

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

Date: July 2017 Issue: Thirty Eight

Welcome to the NKF In Touch newsletter for July 2017.

Please forward any articles etc that you would like sharing via the next newsletter to Fiona Bromhead fiona@kidney.org.uk by 10th August.

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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 – 13th – 15th October 2017

Hinckley Island Hotel, Leicestershire



Conference sponsor

KIDNEY PATIENTS UK



Conference Sponsor

It is now less than 3 months until the conference.

Exhibition and delegate spaces are filling fast – book your place now to avoid disappointment!

For further information or to make a booking please call 01909 544999, visit www.kidney.org.uk or use the attached booking form.

Challenges facing Living Donor Kidney Transplantation in the UK

NKF is very concerned about the downward trend in the number of live kidney transplants in the UK and wishes to initiate a national debate on this matter. We need to understand the reasons for the drop in numbers over the last three years, consider what more needs to be done to address these and highlight good practice. I am requesting you to consider the Discussion Paper and submit your views to the NKF by the end of August 2017.

Please find a copy of a Discussion Paper on Challenges facing LDKT in the UK on the NKF website - <http://www.kidney.org.uk/home/news-2/living-donor-discussion-paper-nkf-seeks-your-views/> .

The Discussion Paper has been developed by Kirit Modi, Life Vice-President of the NKF, on behalf of the NKF. We are most grateful for the input and support of a number of colleagues in the development of the paper. However, the views expressed are of the NKF.

Once we have had responses from the kidney community, we will request the All Party Parliamentary Kidney Group to arrange a Summit on Living Donation, sometime in the Autumn of 2017. This Summit will hear from a range of experts on Living Donation and we plan to publish a Manifesto on Living Donation, setting our recommendations for meeting the challenges we face.

I would be most grateful if you would submit your response to the Discussion Paper to Andrea Brown at nkf@kidney.org.uk by the end of August 2017.

With many thanks.

David Marshall
Chairman, NKF

STOP PRESS

Many of you will have received notice the BKPA have changed their name to Kidney Care UK.

PLEASE BE ASSURED THAT NKF HAS NOT CHANGED – WE ARE STILL NKF, run by kidney patients for kidney patients and the largest kidney patient charity in the UK.

Helpline



NKF HELPLINE

**Great News! Our NKF helpline is now free to call
0800 169 09 36**

Calls are answered directly by our trained Helpline staff between 9am to 5pm Mon-Fri

The NKF runs the only 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.

My tips for staying safe in the sun

I have recently joined the team at NKF and as a kidney patient I would like to share my thoughts of being careful in the sun as a patient. In recent weeks we have seen some very warm weather and strong sunshine. If you are a dialysis or a transplant patient it is important to take care in the sun. I always wear a hat and keep my arms covered in the sun and do not stay in the sun longer than I have to. Sometimes I cannot avoid being in it so I make sure I use a high factor sun cream to protect myself from the sun. It is ok enjoy the sun but I understand the risk it has if I stay in it too long so I always protect myself and I am cautious of the length of time I spend in the sun. The sun and the heat make me tired. As I have had a transplant now when it is hot weather I drink extra fluid than I normally would. When I did dialysis I was on fluid restriction so to drink extra fluid was not possible so then I stayed in the shade as much as possible and avoided the direct sun. I found ice cubes to suck on quite useful and sometimes I added a splash of dilute orange or lemon juice to the ice to make my mouth feel fresher.



Stephen – Helpline and Office Administrator

Fundraising

An amazing evening of **Marriage of Figaro** was enjoyed by around 140 people on 24th June. The evening was organised by a group of singers and musicians called Felici, who have supported the NKF for a number of years. The event was held in Margaret and Peter Johnson's garden in Pirton, Hertfordshire. Margaret Johnson, Music Director for the event, said *"We are thrilled that the event sold out and that our audience were so appreciative of our performance of this wonderful opera. Set in a summer garden, with lighting twinkling, it was truly magical. We are delighted to say that £720 was raised in support of the NKF"*.



On behalf of the NKF, Kirit Modi thanked Felici and everyone who gave their time so generously for the NKF. He said *"We had an amazing evening; an excellent meal followed by great music in magical surroundings!"*



Trolley Key Rings

Thank you to everyone that managed to buy one of our new trolley key rings, we ran out of stock in just ten days but the good news is we have new stock that is now available.

As we all know the new 12 sided £1 coin has just been introduced and the old one is being taken out of circulation forever. Supermarkets across the UK are changing their trolleys to accommodate the new £1 coin. But, I hear you shout 'I have a trolley key ring token'. NKF to the rescue...we now have the new 12 sided £1 coin trolley tokens available to buy at £1.50 (includes P&P). And you will be supporting NKF by purchasing yours through us.



To purchase yours – and one for friends and family too – please go to <http://store.kidney.org.uk/> or call 01909 544999

London to Paris Bike Ride 2018

Have you been watching the Tour de France on TV? Next year you could watch it in person on your own bike! The NKF London to Paris Bike Ride, Tour de France Finale



Day 1 – Registration for challenge early morning in Croydon and start cycling at 7am through Kent to Dover. Ferry to Calais. Distance – 86 miles

Day 2 – Cycle from Calais to Arras through charming villages and along quiet country lanes. Distance – 80 miles

Day 3 – Cycle from Arras to Compiègne passing numerous WWI memorials and monuments through the Region of the Somme. Distance – 74 miles

Day 4 – Cycle to Paris, up the Champs-Élysées, round the Arc de Triomphe and finish overlooking the Eiffel Tower from the Champ de Mars. Celebratory meal. Distance – 68 miles

Day 5 – Free day in Paris to watch the finale of the Tour de France, until making your own way to Gare du Nord to catch the evening Eurostar to London where you are re-united with your bicycle.

For more details email pete.revell@kidneynkf.com or call 01263 722287. Places are very limited



This Month's Fund Raising Events

On Sunday 18th June was a garden party in the grounds of one of the NKF supporters in Norfolk, this was the third year that the family had organised this, live acts entertained throughout the afternoon with refreshments and a raffle adding to the fundraising. The event raised £3,500 for the NKF with plans already in place for a bigger and better one next year.

June has been a very busy month for fundraising – the majority of the activities were a Ben Nevis trek where 11 people took part to raise money for the NKF, more events included two other garden parties - one other event we must not forget that took place in June was Total Warrior where Andrea Brown, the NKF Office Manager, encountered 30 punishing obstacles, 10 tons of ice, 100 tons of mud, barbed wire and even live electric to shock her on route. She raised £570 for the NKF.



Transplant games

If you are going to this year's Transplant games in Scotland at the end of this month please visit the NKF stand on the Sunday, we have something you may enjoy and can take away with you!

To unsubscribe from this newsletter please email nkf@kidney.org.uk

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

