

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

Date: June 2017 Issue: Thirty Seven

Welcome to the NKF In Touch newsletter for June 2017.

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

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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

KIDNEY PATIENTS UK

We have received lots of bookings for the conference so far, to avoid disappointment book your place if you have not done so yet.

The menus for the weekend will be as follows:

Friday Evening

Meat and Potato pie with Mushy Peas and Mint Sauce

Lasagne with Chips and Salad

Vegetarian Lasagne

Dessert – Mini Cream Cakes or Fruit

Tea or Coffee

Saturday Lunch

Cold Buffet

Selection of Chef's daily salads, meat and fish platters and dressings

Hot Meat Dish – Beef Bourguignon

Hot Fish Dish – Cajun Baked Salmon

Hot Vegetarian Dish – Penne Neapolitan

Potato Dish – Jacket Potatoes served with Tuna, Beans and Grated Cheese

Vegetable dish – Roast Mediterranean Vegetables

Dessert – Lemon Tart and Fruit Platter

Saturday Gala Dinner

Pre-dinner Prosecco or Orange Juice

Starter – Duck and Orange Pâté or Melon

Main Course – Baked Chicken Supreme with Pancetta and Sage, Chateaux Potatoes and Seasonal Vegetables

Vegetarian dish – Roast Root Vegetable Wellington, Seasonal Vegetables and Sweet Pepper Coulis

Dessert – Rhubarb Crumble Tart

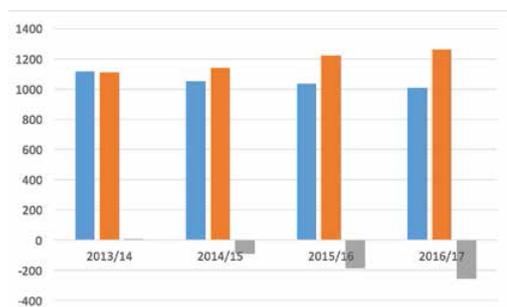
To book your place please use the booking form attached, book online <http://booking.kidney.org.uk/> or call the NKF on – 01909 544999



Concern as the number of living-donor transplants in the UK continues to fall

By Kirit Modi, NKF Life Vice President

NKF is taking the lead in expressing grave concerns at the drop in the number of living-donor kidney transplants carried out in the UK over the past few years. Statistics provided by NHSBT (NHS Blood and Transplant) reveal a substantial drop in the number of living-donor organ transplants (the majority of which are kidneys) carried out year on year. In the year 2013-14, 1147 living-donor transplants were carried out.



By 2015-16 this number was reduced by 72 to 1075 – a 6% drop over two years. Statistics released by NHSBT in April (which may adjust slightly over the next month or so) for the year 2016-17 reveal a further reduction in the number of living-donor transplants carried out over the past twelve months. 1036 living-donor transplants were carried out in the UK in this period of time. This represents a drop of 3.5% on 2015-16 statistics and a drop of nearly 10% on 2013-14 statistics. This trend runs contrary to the targets outlined in a National Strategy committing to increase the number of living-donor transplants year on year, published and signed up to by all four UK governments and NHSBT. This bar chart shows the increasing gap between the numbers of living-

donor transplants compared to the targets set. If this trend continues the target of 1728 living-donor transplants set for the year 2019/2020 will not be achieved. These concerns were shared with the All Party Parliamentary Kidney Group (APPKG) at a meeting on 7th December 2016. The APPKG wrote to NHSBT, NHS England (NHSE) and the Chair of the Transplant 2020 Strategy Oversight Group to seek their views. In addition, NKF met with representatives from NHSBT, NHSE and the Chair of the Renal Services Clinical Reference Group to discuss the matter.

What are the reasons for the drop in numbers?

Possible causes are:

- **There is unexplained variation in the number of living-donor transplants undertaken by transplant centres.** A measure of how many transplants each of the 23 transplant centres in the UK carries out is based on transplants carried out per million local population (pmp). Provisional figures for 2015-16 presented at the Renal Transplant Services meeting in February 2017 reveal that these range from around 8 pmp to around 36 pmp. These figures also indicate that provisionally 15 of the 23 UK transplant centres are below the national average of 15.7 transplants pmp. While there are valid reasons for some variation, the extent of the variation remains unexplained.
- **Some hospitals do not employ sufficient Living Transplant Co-ordinators:** The nurses who support potential living donors and recipients through the process of living organ donation and transplantation are called Living Transplant Coordinators (LTC). They are employed by transplant centre hospitals as well as hospitals which send their patients to transplant centres for surgery. Evidence is emerging that some hospitals do not employ sufficient LTCs to encourage and then cope with demand for living kidney donation. This clearly affects the number of living-donor kidney transplants.
- **The support provided by LTCs to source potential living donors from family members and friends may not be appropriate.** It is very difficult for patients waiting for a kidney transplant to discuss the option of a living donor with close family and friends. Support is provided by the local LTC but the type of support varies. There is some evidence that offering this support in the home of the patient, particularly for patients from Black, Asian and Minority Ethnic (BAME) backgrounds may be more effective than in a group or hospital based setting.
- **Some kidney patients may prefer to receive a kidney donated after death rather than from a living donation.** There is some anecdotal evidence supporting this theory. The average waiting time for a kidney transplant donated by someone after death is now 2.5 years (3 years for BAME patients). Unfortunately, there is no national guidance for patients and donors about the advantages and disadvantages of one system of donation over the other.
- **Who champions living donation in hospitals?** For donation after death, hospitals have to establish a local Organ Donation Committee which is funded by NHSBT. However, other than the existence of a LTC there is no comparable arrangement supporting the system of living donation in most hospitals.

There may, of course be other reasons for the drop in living-donor kidney transplants and these need to be identified.

What is NKF doing about this?

The APPKG will hold a Living-donor Kidney Transplant Summit this year – date to be advised - within the Parliamentary Estate at Westminster. The Summit will include input from key individuals with expertise in living-donor kidney transplantation in the UK. It will investigate the reasons for the drop in numbers, consider what we should do about them and highlight good practice. Following the Summit, the APPKG will publish a Living-donor Transplant Manifesto which will set out clear recommendations for improving living-donor transplantation in England.

How can Kidney Patient Associations and patients help?

Kidney Patient Associations (KPAs) and individual patients have an important contribution to make at a local level. If you are a patient or belong to a KPA affiliated to your hospital please make contact with your hospital's LTC and arrange a meeting with her/him. The issues raised above would provide a good basis for discussion at the meeting. The LTC should be able to provide details of the number of living kidney donations and transplants that have taken place at their hospital over the last couple of years. NB - NHSBT statistics are measured April to end March. From this meeting local issues may emerge and can be pursued further by the KPA.

Next stages

A copy of the Manifesto for Living-donor Transplantation will be emailed to every KPA and will also be available via the NKF web-site. It would be immensely helpful if details of any local discussions about living-

donor kidney transplants could be sent to NKF at NKF@kidney.org.uk Thank you for your support in this initiative.

World Kidney Cancer Day has been established by the International Kidney Cancer Coalition (IKCC), a global body of over 30 cancer organisations focused on improving the lives of people affected by kidney cancer.



The goal of the World Kidney Cancer Q&A Day campaign is to bring a united voice to the global community of patients, carers, health care professionals and local organisations to raise awareness for kidney cancer and start answering the questions that will make a difference for kidney cancer patients around the world.

To mark the first international awareness day, the IKCC and its affiliates around the world have launched the [World Kidney Cancer Q&A Day Quiz](#) – an interactive, seven-question quiz that tests your knowledge about important facts about kidney cancer. For every quiz that's completed online, \$5 will be donated to help fund research to find answers to vital questions about kidney cancer.

How You Can Help

- Take the Q&A Quiz at www.WorldKidneyCancerDay.org. It's just seven questions and once you complete it, \$5 will be donated. The quiz is available in English, French, Spanish, Portuguese, Dutch, Greek and Polish. German, and Arabic are coming very soon.
- Share the Q&A Quiz with your family and friends on your social channels, because every time the quiz is done, more kidney cancer research is funded.
- Spread the word about World Kidney Cancer Q&A Day by following IKCCorg on [Twitter](#) and [Facebook](#) and sharing posts. Use the hashtag #kidneycancer on any of your posts to join the global online conversation.
- Join the Thunderclap! It's a tool that allows people around the world to pledge a tweet or post on social media. Then, on World Kidney Cancer Q&A Day everyone's pledges are released at the same time creating a global flash mob on social media. It takes a minute to add your name [here](#).

Cancer organisations around the world are coming together to mark the first World Kidney Cancer Day on June 22 – Add your voice to the campaign!

For more information go to: worldkidneycancerday.org or contact me for further details about the campaign.

Julia



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Registered in the Netherlands: **Stichting IKCC**, Reg. No. KvK 62070665

22nd June 2017: World Kidney Cancer Q & A Day
Raising Global Awareness of Kidney Cancer

Calling all Young Adult Kidney Patients aged 18-30

Why not come along to this fantastic free weekend (thanks to the BKPA) and meet other young adults going through the same thing. It's a very popular event so book your place now. It's a fun packed weekend of activities to cover all ability's. Ilam Hall is a National Trust property in the Peak District.

We would like to encourage as many new attendees as possible so if there is a great demand then there will be a waiting list. If you have been before please share this with your fellow renal patients as this year's venue has better access for disabled young adults and we have even more spaces available than before. It has a bar, pool table, table tennis tables, table football and board games as well as a TV and Wifi (not the best but you will be having too much fun to worry about that!)

- We must have confirmed final numbers by 13th July as otherwise the BKPA have to pay cancellation fees and it may prevent someone who wanted to go going.
- Please be aware to attend you will have to complete a medical form that has to be signed off by your consultant and you will have to sign a code of conduct.
- We are trying to arrange mini buses where possible to collect people but if that is not possible you will need to book a train ticket and as long as you do not cancel after the cut off date we can reimburse the travel costs (except if your cancellation is for e.g due to ill health) Anyone wanting to book after the cut off date is likely to have to fund their own travel.

What you need to do:

Private message Tracey Sinclair on Facebook or email her at tracysinclair68@btinternet.com giving all of these details.

Name, Age, Gender (for room allocation as these are bunk bedded sharing rooms)

Contact telephone number and email

How many times you have been before

What hospital you come under and the town you live in

And whether you are on dialysis or have a transplant

We will then forward your name onto the organiser who will be in contact nearer the closing date.

Thanks



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Dietary acid is causing progression of Chronic Kidney Disease

Dr Caroline Passey, RD, Lead Renal Dietitian, Wessex Kidney Unit, Portsmouth.

Evidence is emerging that dietary acid is causing chronic kidney damage and accelerating the rate of progression in people with CKD. Dietary acid comes from the food that we eat. When metabolised, most animal protein e.g. meat, fish, eggs and hard cheese will generate acid and most fruit and vegetables will generate alkali. Most people eat a diet with too many acidic foods and not enough alkaline ones so that the excess acid from the diet has to be excreted by the kidney. This causes kidney damage. Patients at all stages of kidney disease will benefit from reducing the acidic foods in their diet i.e. from having smaller

portions of meat, fish, eggs or hard cheese and using more vegetable protein e.g. nuts, beans, chick peas and lentils in their diet. Increasing the consumption of vegetables and fruit is also essential. Green leafy vegetables like Kale, cabbage, broccoli, rocket and lettuce (but not spinach) are particularly beneficial. Patients should try and have vegetables at two meals a day (i.e. have some salad or salad vegetables with their lunch) and include green leafy vegetables daily. Using wholegrain cereals and wholegrain products is also beneficial together with cutting back on processed foods, salt and fizzy drinks. This is a similar dietary pattern to that recommended by the Mediterranean Diet or DASH (Dietary Interventions to stop Hypertension) Diet. Both of these dietary measures have been associated with slower rates of progression or a lower incidence of CKD.

Patients who have increased serum potassium should only institute these dietary changes under the guidance of a renal dietitian as a low acid diet will generally have a higher potassium content than the normal diet. Patients on ACE inhibitors, ARB's or potassium sparing drugs will also benefit from expert advice while implementing these dietary changes.

Reducing the Dietary Acid Load: How a More Alkaline Diet Benefits Patients with CKD

[http://www.irnjournal.org/article/S1051-2276\(16\)30188-1/fulltext](http://www.irnjournal.org/article/S1051-2276(16)30188-1/fulltext)



HealthUnlocked

A new app connecting people with the same health conditions together

Search 'HealthUnlocked' on the App Store

On Tuesday 13 June, we are officially launched the HealthUnlocked iOS app for iPhone globally and we need your help!

The app will support access to your online community on HealthUnlocked and engagement within it. Today and over the next week, we would ask you to join us in promoting the app on your HealthUnlocked Community, organisation's website and social media accounts.

We have prepared some promotional materials (attached below) that your organisation can use to share this news, help spread the word and encourage your community members to download it. We will be using the hashtag #UnlockYourHealth on twitter.

The app makes it easier than ever to access your community and follows the successful UK launch earlier this year. We hope you and your members enjoy using the new app.

You can download it from the app store.

Kind regards,

Alexa Chaffer

Head of Communications

HealthUnlocked www.healthunlocked.com



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.

Beware – Insurance (not just medical)

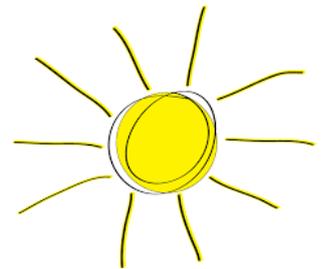
When dealing with Insurance Companies it may well be in your interest to be aware of your complete medical history. If you give authorisation for your GP to pass them on (this is called *subject access request*) it may result in all your medical records being disclosed, rather than just the things considered relevant. You can see what is being passed on before it is sent, and can refuse to disclose it- although insurers may refuse to pay out.

For further advice see link below.

<https://www.bma.org.uk/advice/employment/gp-practices/service-provision/medical-information-requests-from-insurers>

SEASONAL INFORMATION FROM THE NKF HELPLINE

If you are lucky enough to be getting away on holiday this year please stop to consider a few important points. The tips and guidelines below are there to remind you of the extra precautions you may need to take so that you have a very enjoyable holiday!



TRAVELLING WITH MEDICATIONS AND MEDICAL EQUIPMENT...

When flying with PD equipment, please check in advance with your airline what their policy is on travelling with medical equipment. Some airlines will wish you to check your machine into the hold and others will wish you to pass the machine to airline staff to keep safe for you in the cabin during the flight. Also you may need a letter from your doctor regarding your medications, needles etc. Your airline will tell you their policy on this.

When travelling with medication make sure that you have enough for your holiday period. Please ensure that you always carry your medications in their original packaging bearing the name of the pharmacy and the prescribing doctor. You should keep the original prescription that the doctor gave you and ask your GP to write a letter stating what medication he has given and that he is aware that you will be travelling with it.

Get advice from your pharmacist on how to store your medication. For example, to keep your medicine at the right temperature, as you may need to store it using a cool bag or insulated pouch.

BE CAREFUL IN THE SUN...

If you are on a fluid restriction, try sucking frozen grapes to quench your thirst. Remember to take your phosphate binders and check that your medications will allow you to drink alcohol. Low potassium choices are white wine, champagne, liqueurs and spirits but do include this within your fluid restriction.

Ask for a slice of lemon in your drink so that you can suck this to quench thirst. When eating in restaurants, ask the chef to prepare your food without salt.

If you are taking immunosuppressant drugs it is important to be careful in the sun.

- Do not try to get a tan
- Try to stay out of the sun between 11am and 3pm when the sun is strongest
- Use sun cream on all exposed skin – remembering the back of your neck! This should be factor 30 or higher
- Wear a hat
- Wear long sleeves

Even in the shade you are still prone to damage from the sun and remember that the sun's rays can be reflected on water, snow and even concrete. Buy bottled water abroad or use boiled water. Avoid salads unless you have washed them and/or made them yourself and avoid ice cubes unless you have made them from boiled water.

BE SAFE IN THE SUNSHINE!

Fund Raising

NKF £1 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 that even more have been ordered and will be back on sale this week.



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



Ben Nevis

Good luck to the 11 people who are climbing Ben Nevis on the weekend of June 24th, Danielle Goldstein, Tracy Browne, Gurjit Bhambra, David Douglas, Fiona Boyd, Rob Pattrick, John Fraser, Kevin Cooney, Afzal Shaikh, Fiona Hendry and Memoona Murray – each have raised an amazing amount of money for the NKF and we really appreciate your support.

Total Warrior

Good luck to two of the NKF staff who will be taking part in the Total Warrior event in Leeds on June 25th, Andrea Brown and Donna Blizard will face 30 punishing obstacles, 10 tons of ice, 100 tons of mud, barbed wire and even live electric to shock them on route, they have already raised £180 for the NKF but would love more
<http://www.justgiving.com/Andrea-Brown26>



London Bridges Trek



How far - 25km. How many - 16 of London's finest bridges. When - Sat 9th Sept. Join us and over 2,000 supporters as we venture across the Capital taking in magnificent views of the London skyline from its very best vantage points. We set out from Putney Bridge and head east towards the City, zig-zagging over its many famous bridges - each with its own fascinating story. We have a mid-way pit-stop in Vauxhall for some snacks & drinks and then, 25km later it's a Southwark finish line celebration at Tower Bridge.

This is a great opportunity to get out, get fitter, meet others and explore the very best of London!

For more detail please call Pete Revell on 01263 722287 or visit the NKF website at

<http://www.kidney.org.uk/fundraising/donate-to-the-nkf/sponsored-events/walking/thames-bridges-trek-2017/>

This
Weekend

This looks like it's going to be a fantastic afternoon, Lazy Sunday afternoon is in the beautiful gardens of the Grange in Northwold in Norfolk that was featured on BBC TV. Entertainment from BAFTA nominated singer entertainer Richard Digance, East Anglia's top folk band The Broadside Boys and many more - it's all raising money for kidney patients. Come and join us this Sunday the 18th from 1pm, £10 on the gate, children under 14 free. Please see attached poster.



Did you know we have a facebook page? Keep up to date with the latest updates from NKF.

<https://www.facebook.com/KidneyNKF/>

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

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

