

NKF In Touch

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

Date: August 2015 Issue: Fifteen

Welcome to the NKF In Touch newsletter for August 2015. Please forward any articles etc that you would like sharing via the next newsletter to Stephanie Scott stephanie@kidney.org.uk by 9th September.



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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 – Hilton Hotel Reading - Berkshire



NKF Conference is fast approaching; please book your place now if you haven't done so already.

May we remind all KPA's that exhibition space is now open for your bookings, please use the booking form which has been sent to you via email or call 01909 544999 as soon as possible to book your space.

We look forward to seeing you all there.



PART TIME ADVOCACY OFFICER – POST REF PTNW

Home based (travel required) - Area North West England
Salary £10,567 per annum

An exciting opportunity has arisen to work as Regional Advocacy Officer for the North West of England. The National Kidney Federation (NKF) wishes to appoint an enthusiastic and ambitious individual who has excellent communication skills and the ability to work with peers, Trusts and health organisations throughout the area. The successful applicant will join our team of experienced Advocacy Officers. Full training will be provided. The position will be home based, but extensive travel may be required. Knowledge of the charity and kidney patient issues would be advantageous.

Applicants must be well versed in using Microsoft Office – Word, Excel and Outlook, be able to drive and own a suitable vehicle.

A full job description and person specification are available from our Headquarters at National Kidney Federation, The Point, Coach Road, Shireoaks, Worksop, Nottinghamshire, S81 8BW, or by email at nkf@kidney.org.uk. The position is subject to a DBS check being carried out prior to commencement.

Applications by CV with covering letter should be marked for the attention of Timothy F Statham OBE and sent to the address listed above, clearly marked 'Advocacy Application' with the post reference (PTNW) on the application

Information

Northamptonshire has just opened two new dialysis units staffed by the NHS in conjunction with Renal Services Ltd. They both are 21 station units and are both able to offer "in unit" nocturnal dialysis, HDF, as well as training rooms for prospective Home HD patients. Both sites offer spacious facilities for the patients and staff, with blood testing facilities in Kettering.



There is an open day on Sept 13th at the Northampton unit, if you would like to visit on this day please let Northamptonshire KPA know 01604 760715 or 01933 384523.

Colchester Kidney Patient Association Committee meets the Queen!

On the 20th May four members of the Colchester Kidney Patient Association Executive Committee were presented to HM The Queen at the Royal Garden Party at Buckingham Palace in recognition of their work. Ben Harvey, President, stated that originally he had nominated Gail Oliver, the Chair, to the Lord-Lieutenant for Essex, Lord Petre, for all her hard work and dedication over the last three years in making the Association such a success.



Gail said “It was such an honour for us all to be presented and to have a conversation with HM The Queen. Her Majesty was very interested to hear about the Association and dialysis. It was a most memorable and exciting day and a memory we will all keep forever.”

Gail currently undergoes chronic haemodialysis treatment for four hours, three times per week, at Colchester Dialysis Unit. The unit currently provides dialysis for 120 patients and is run by Fresenius Medical Care in partnership with Colchester Hospital University NHS Foundation Trust.

The Association’s aims are to provide social events and support for kidney patients and their relatives and carers, and to raise funds to provide items of comfort for patients whilst undergoing treatment at the unit and also to raise the public profile of kidney disease. Some patients have reported feeling lonely and isolated, as well as depressed so it’s of utmost importance that such



Associations exist to make a difference to peoples’ lives.

Over three million people in the UK are at risk of kidney disease, and people with diabetes, high blood pressure, a family history of kidney problems or from a black or Asian background are particularly at risk.

Left to right: Alison Smith, Ben Harvey, Gail Oliver, Claire Matthias



Advocacy Services

More than 475 people attended an interactive community health fair organised by BAPS Charities on Saturday 11 July 2015 at BAPS Shri Swaminarayan Mandir, Neasden, London.

The NKF worked alongside various leading healthcare organisations and charities who provided a range of screenings and health checks along with information stalls, exhibitions, workshops and short seminars.

The NKF were promoting awareness organ donation in particular with attendees signing-up to the organ donor register on the day and many more increasing their awareness of CKD.

The NKF would like to thank all who supported our stand including those pictured together with Bina Doshi, Ramnik Doshi, Louis Toussaint and Asmita Palmer.

Pictured from left to right are: Sanjiv Gohil, Meena Modi, Kirit Modi, Nick Palmer & Minesh Mehta



National Transplant Week 7th – 13th September 2015



NHSBT will be leading National Transplant Week with their campaign "7 Days to Say I Do".

At the time of writing their plans are "well underway" and they "are looking forward to sharing more details soon". NKF HQ is eagerly awaiting forthcoming detail!

According to their website, "The campaign this year will be focusing on encouraging individuals to discuss their decision about organ donation with those closest to them. If organ donation is a possibility when a person dies, we would wholly rely on their family's support to fulfil their decision of becoming an organ donor and we have found that significantly more families say yes to donation, when they know what their relative wants. We will be launching some very exciting activity to get people talking about organ donation and there will be some great ways that you can get involved in your community".

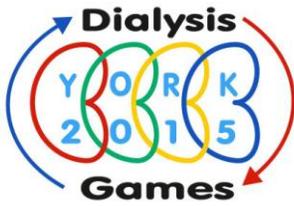
Please watch this space for more details. If you have any queries about getting involved please contact marketing.comms@nhsbt.nhs.uk

As ever National Transplant Week provides an opportunity to spread awareness both within and outside hospital settings about CKD and its treatment with obvious emphasis on transplantation and organ donation. It would be great to hear what's going on in your area during the week – feel free to get in touch with your photos via twitter, Facebook, email and post!

Views sought about organ donation

On the subject of organ donation it would also be useful to have your thoughts on the use of social media e.g. Facebook & Twitter, in raising awareness and engaging society about organ donation? What do you think are the advantages of using social media or do you think there are risks in engaging the public through social media?

Your views are important and would be heard at the European Society of Transplantation conference in September. Please respond to nicholaspalmer.nkf@btinternet.com by the 31st August 2015, thank you.



Dialysis Games taking place in York on Sunday 13th September supported by the NKF

Compete not Defeat

The Dialysis Games 2015 is an inclusive sports and activity event for people in Yorkshire and the Humber, (but not exclusively as we have teams coming from Wales and Exeter), with kidney disease... who need to dialyse. The event is being held at Joseph Rowntree School, Haxby Road, York, YO32 4BZ and is the first of its kind held in the UK.

Sports on offer will include Archery, Badminton, Cycling, New Age Kurling, walking football, indoor bowls, table tennis and Tennis along with taster sessions in pilates, tai chi, yoga and karate. It is a completely free day for patients and their families.

The games will start with registration at 10-10.30 and continue until 4.00 when there will then be a short break before food and drinks will be served to the sound of the jazz band until 9.00 in the evening for those of you who can last that long.



For further information contact;

Vicky.Pursesey@York.nhs.uk

Helen.Rowen@York.gov.uk

Dietary information

In the summer edition of Kidney Life an interesting article appeared from Dr Elizabeth Lindley about 'phosphate additives' – for many of us something new to learn about. For those that already knew about phosphate additives it perhaps highlights the often variable education or information we as patients receive, how easily it is understood and perhaps how often our diet knowledge is reviewed when receiving dialysis treatment.

The NKF are beginning to forge closer links with the British Renal Society (BRS) Renal Nutrition Group (RNG) and again it would be useful to have your perspective this time of receiving dietary information, especially around phosphates i.e. what information do you receive; do you get extra support from staff, what do you know about the drugs you receive to control phosphate levels?

Your views are important and would be heard at the RNG meeting in October. Please respond to nicholaspalmer.nkf@btinternet.com by 31st August 2015, thank you.

It's Time to Choose' supermarket sweep of Wales

Monday August 10th saw the start of the 'It's Time to Choose' organ donation public information roadshow, which visited 21 supermarkets throughout Wales in just five days.

Members of the Organ Donation Wales team, along with volunteers whose lives have been affected by organ donation, were at supermarkets across South, West, Mid and North Wales providing information about the changes to the consent system for organ donation, which come into effect in Wales on December 1st.

The roadshows helped to encourage people living in Wales to think about their organ donation choices and to talk to their loved ones about them. Those who called into their local supermarket were also informed of how they can register a decision to opt in or opt out of becoming an organ donor in advance of December 1st.

Welsh Government Health and Social Services Minister Mark Drakeford said;

“On December 1st, Wales will become the first country in the UK to introduce a soft opt-out system. We hope this will help save lives by transforming attitudes towards consent to organ donation. The “It's Time to Choose” Organ Donation Wales information roadshow is designed to stimulate conversations about organ donation and I hope people will continue talking to their loved ones about their organ donation choices.”



Lynne Callow Advocacy Officer
(Wales and Northern Ireland)

For more information on how organ donation is changing in Wales go to organdonationwales.org or call **0300 123 23 23**.



Helpline – 0845 601 02 09 (free to call from UK landlines)

Can I Travel If I'm On Renal / Kidney Dialysis?

Worried about jetting off on holiday? Here are the six questions to ask yourself before planning a trip...



Being a dialysis patient doesn't mean you can't enjoy going on holiday. But there are some important factors to consider while planning your trip and you'll need to make sure all your treatment needs are taken care of before heading off. Here are six key questions to help with the process:

Am I fit to travel?

Start by speaking to your current renal unit team. It's important that you are fit to travel, aware of everything travelling abroad will entail and feel confident that your treatment needs will be met. "Checking with your renal unit that they're happy for you to travel, and that you're ok getting there, and knowing exactly what you'll have to do for yourself, is a good first step," says Pauline Pinkos, helpline manager at National Kidney Federation (NFK, www.kidney.org.uk).

Is there a suitable dialysis centre I can use?

"Finding a renal unit is often the hardest part of planning a holiday," notes Pauline. There are a number of things to consider, including the unit's location – is it near enough to where you'd like to stay? You'll also want to research whether the unit is somewhere you'll be confident about having treatment.

Of course, it is possible to find trustworthy units overseas, but in some countries, it isn't always easy to know for sure whether standards are up to scratch. For example, Pauline notes that, in order to avoid the risk of infection, NHS units wouldn't recommend that patients go to units overseas that accept patients with HIV and Hepatitis B and C, particularly if it's unclear whether they're being treated in isolation on a specialist-cleaned machine. Once you've found a suitable unit, you'll need to ensure the unit can accommodate you – and also that you can book your holiday accommodation and flights/transport for the same period.

Are there companies that can do all this for me?

While many people prefer to plan and book everything themselves when going on holiday, for a dialysis patient, this process is trickier. "There are other organisations we can refer people to for more information about renal units overseas, and there are also some companies that will book holidays for you, and they'll actually go there and check the facilities," says Pauline. Freedom (www.holidaydialysis.co.uk), organise holidays for dialysis patients across numerous locations in Europe, USA, Canary Islands, Egypt, Australia and the Caribbean, as well as cruises, as does Holiday-Dialysis Dr.Berger (www.dialysis-travel.com).

Who pays for dialysis treatment abroad?

If you're travelling within the European Economic Area (EEA), the cost of your treatment should be covered through your European Health Insurance Card (EHIC), provided you are treated in a State run facility, not a private unit. It's vital you have a valid EHIC before you travel – they are free and easy to obtain (see the NHS guidelines on applying here: www.nhs.uk/NHSEngland/Healthcareabroad/EHIC/Pages/about-the-ehic.aspx).

If travelling outside the EEA, you will be expected to cover the costs of your dialysis treatment yourself. Pauline notes that costs for private facilities can vary greatly, so do some research and make sure you're aware of all of the costs upfront.

The British Kidney Patient Association does sometimes offer grants for some individuals and families unable to afford the full cost of a holiday. Visit www.britishkidney-pa.co.uk/holidays).

What about my other medications and treatment needs?

As is the case for anybody on long-term treatment, make sure you take plenty of medication with you when you travel, and if necessary, allow time to order in enough supplies before you head off. It's also advisable to take a list of useful contacts (your UK consultant, pharmacies near your resort), plus the names of any medications you may need, in case you find yourself needing to stock up while you're away. "If you're flying, speak to the airline in advance too," says Pauline, "so they know what medication and medical equipment you're going to be travelling with, and they can advise on any policies they have for storing it during the flight." Split your supplies – put some in your hold luggage and some in your hand luggage – so that, should any of your bags go missing, you still have enough.

"If you're a peritoneal dialysis [PD] patient, you'll also need to make arrangements for your peritoneal fluids to be delivered to your accommodation, and stored in a suitable environment for you," notes Pauline. "And that there's a suitable, clean place where you can do your fluid exchange, and suitable way you can dispose of the waste."

What about vaccinations?

If you're travelling to a region where vaccinations are required, speak to your medical team about whether they're suitable for you. "For instance, transplant patients, because they're immunosuppressed, can't have live virus vaccines," says Pinkos. "We advise people to speak to their GPs about possible alternatives and advice on what vaccines they can and can't have. "There are also organisations people can speak to for general advice about vaccinations and how important they are for where you're travelling to, like Masta [www.masta-travel-health.com], and Boots the Chemist are also good."

For further advice, call the **NFK helpline** on **0845 601 0209** (9am-5pm, Mon-Fri)

Where to get travel insurance?

MedicalTravelCompared.co.uk is a specialist comparison site for people with medical conditions and searches over 25 specialist insurers that cover all types of pre existing medical conditions including kidney disease and renal dialysis. Here you will be able to compare quotes and cover levels from a variety of insurers, which not only helps you to save money but time too! Although travel insurance won't cover the costs for you to have planned dialysis whilst away, it can cover you if you become unwell and need to cancel the trip or require emergency medical treatment whilst away.

Thankyou!

Everyone at the Church Stretton Golf Club for raising £1,500
 All the team that took part in the Elsevier express cycle ride – the money is still coming in!
 Michelle Riddle and her father who took part in the Grand Union Challenge
 Ollie Power and James Mroch who held a boxing match raising £1,500 for the NKF

Good Luck!

Everyone taking part in the Thames Path Challenge for the NKF including Desiree Taylor, Emma Reast, Gurpreet Virdee and Manpreet Saggoo.
 Everyone taking part in the Great North Run for the NKF – Chris Paxton, Chris Roome, Lynda Lambert and Richard Pepper.
 Also good luck to Martyn Oliver and Tom Lee who are parachuting for the NKF.

Kidney Life Magazine

Any time now you should be receiving your copy of our kidney life magazine, if this is not the case please call our office and we will pop you on the mailing list 01909 544999.

In this edition you will find tickets for our Christmas draw, you could win a cash prize or an ipad! If you would like additional tickets please let us know by calling our office on 01909 544999 – also in this edition is the 2015 Christmas brochure where you will find a great selection of cards, wrapping paper and more, these can also be ordered through

our Christmas shop <http://store.kidney.org.uk/> or by telephoning 01909 544999 (debit/credit card payment)



Fundraise

It is not too late to fundraise for the NKF in 2015, if you would like to support kidney patients please visit our events pages at <http://www.kidney.org.uk/fundraising/> also 2016 events have now been added with special offers!

If you would like to organise your own event or need some ideas on how you can support the NKF please call Pete on 01263 722287 or drop him an email pete.revell@kidneynkf.com

SEE THE FINALE OF THE TOUR DE FRANCE IN THE HEART OF PARIS!

We are offering 2 amazing routes in July 2016 giving you more choice. Our London to Paris Bike Ride in July 2016 combined with watching the exciting finale of Tour De France is the best cycling experience in Europe. Register today and secure your place!

Cycling from London to Paris is by far one of the best fundraising events in Europe, Join our London to Paris Bike Ride for a truly inspirational experience, and a great way to raise funds for the NKF.



Contact our fundraising office on 01263 722287 or visit <http://www.kidney.org.uk/fundraising>

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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