

NKF In Touch

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

Date: September 2015 Issue: Sixteen

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



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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



HURRY! HURRY!

It's just 3 weeks to NKF Conference! **Please book your place now! We will be closing bookings very soon! Places are limited!**

Please call 01909 544999 **NOW** to book your place.

We look forward to seeing you there!



Can you help with ideas? - NKF annual patients' conference 2015 is just around the corner and we are already preparing for conference 2016! Perhaps you can help. Do you have ideas of where you would like the conference to take place? Do you know of a suitable venue which could accommodate around 300 delegates? Could you be a speaker or do you know of a speaker? Perhaps you know of a photographer or an entertainer. We want to know your thoughts and ideas on how you'd like the conference to be. We welcome your feedback. Email nkf@kidney.org.uk



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



Campbeltown Dialysis Unit Opens

The well documented campaign to have a dialysis unit in Campbeltown has reached a successful fruition with the opening of the new facility on Monday 10th August. The centre is to be called the Kintyre Community Dialysis Unit and puts an end to 12 hour days for the areas dialysis patients.

Instead of 3.5 hour+ each way journeys on top of 4.5 hours on dialysis, most patients will now have a journeys as short as ten minutes to get from home to the centre.

The unit's furthest travelled patient now will travel from the island of Gigha, taking the short ferry ride, then the 30 minute journey to the hospital.

This has been a triumph for the NKF-led campaign, working in conjunction with the local fundraising group and NHS Highland to get this facility open.

BKPA were significant contributors to the funding of this new unit and the patients report that they are enjoying the new local facility. The unit can dialyse up to 8 patients.

Invitation to join a study – Understanding Thoughts about Chronic Illness

Sabine Topf is a psychologist and PhD student at University College London (supervisors are Prof Rob Horne & Dr Sarah Chapman). She is currently running a two-part online survey regarding chronic illnesses with an emphasis on how patients think about their chronic illness and related health topics. Details about the study can be found online <http://tinyurl.com/IllnessExperience>.

Participants will receive a £3.75 Amazon voucher for a completed survey as a thank-you for their time.



Advocacy Services



Bute Kidney Support Group have begun a campaign to have a dialysis unit situated on the island.

At present five patients make the journey to Inverclyde Royal on the mainland or to Glasgow hospitals for regular dialysis, three days per week.

The campaign group will hold a Public Meeting on the island in mid October to canvass the islanders for support.

The NKF Advocacy Team are supporting this campaign, but have warned the Bute group that they will have to raise in the region of £350,000 towards the costs of building a dialysis unit

The group were buoyed by the success of the Campbeltown campaign and hope to emulate their achievements in due course.

TRANSPLANT SPOR↑

Every year, Transplant Sport brings together transplant athletes from over 60 hospitals across the UK and NI. It's an opportunity to represent their transplanted hospital at The British Transplant Games www.britishtransplantgames.co.uk The event travels to a different city each year, and in August 2015, it was held in Gateshead, Newcastle. The event helps to promote and raise the awareness of organ donation, and to encourage families to discuss their wishes with their loved ones. Newcastle welcomed over 700 transplant athletes who competed in various sports from bowling to badminton.

Four kidney transplant recipients from Norwich competed in the games. Tim Adamson, Val Cooper, Sarah Moody and Trevor Emery represented Addenbrookes Hospital Transplant Games Team www.atgt.org.uk

The opening ceremony was held at Newcastle City Hall on Thursday 30th July to kick start the sporting weekend and the first Gold medal was won by Tim, Sarah and Val as they competed for the volleyball team.

Many more medals were bagged over the weekend in badminton, squash, athletics and track and field. A closing gala dinner took place on the Sunday evening, with guest Jeremy Kyle on stage to congratulate all, and to show his support in raising awareness of organ donation. During the evening, presentations were made, and Sarah Moody was presented a trophy for achieving most outstanding female as she won 5 gold medals in 5 events. After waiting nearly 35 years, Addenbrookes Transplant Games Team were also announced "Best Team", and presented with The Ross Taylor Rose Bowl.

Later this month, Tim Adamson and Val Cooper will be heading off to Argentina representing GB & NI at The World Transplant Games. We wish them both all the very best.

If you would be interested in finding out more information about competing at The British Transplant Games, please visit the Addenbrookes Transplant Games Team website www.atgt.org.uk



During Transplant week Kim Branson PA to the matron at Peterborough renal unit, was joined by Tobias Payne the Chair of the Organ Donation Committee at PCH in having a stand to promote organ donation This was held in the Atrium at Peterborough Hospital Kim has recently joined the Peterborough KPA to help raise the profile in whatever way she can. She will certainly be a great asset to the KPA both in enthusiasm and energy.

DAVID DAWSON'S 30-YEAR LONG WAIT FOR NEW KIDNEY ENDS



A renal patient's 30-year wait for a new kidney is over after a successful transplant at Queen Elizabeth Hospital in Birmingham.

The 52-year-old from Milton, Stoke-on-Trent, had given up hope of ever getting a suitable donor organ after one failed transplant in 1984.

"I had accepted that I would be on dialysis for the rest of my life" he said. It is absolutely brilliant; I am on a high right now. The operation went well, I am feeling well and the Doctors are pleased with me."

When the transplant co-ordinator called David at 4am on Tuesday 30th June, he nearly did not answer the telephone because he thought it would be a crank call. But 12 hours later he was undergoing the operation he had been dreaming of for three decades.

"I just wondered who the hell could be calling so early" he said. "But the telephone went 3 or 4 times and I eventually decided to go downstairs and answer it. It was the transplant co-ordinator Sheryl Parsons from the QE Hospital. She told me they had a possible match and that I needed to get to Birmingham as quickly as I could. Tissue typing and cross-matching had to be done at that stage and I had to go on dialysis for 4 hours when I arrived at the QE. Just before I came off dialysis, Sheryl came and told me that the kidney was a match, and I just broke down and cried."

David's kidney problems only came to light when he went for a routine medical as a 16-year-old.

"I wasn't ill before I was diagnosed. I just went for a medical before starting a job and the urine test showed some blood. That's when it all started" he said.

David underwent a transplant at North Staffordshire Royal Infirmary in 1984 but unfortunately that kidney failed after only nine months and he had been waiting for a second chance ever since. He was believed to be amongst the longest waiters for a transplant in the whole country.

"You see other people getting transplants after a matter of months and you get to a point where you think, this is not going to happen. But the message I would give to people in the same position now is to never give up hope, never say never. It can happen no matter how long you have been waiting.

David is now looking forward to enjoying a more normal life. "I will be a lot fitter and free from the dialysis of course, which has taken up 3 days of my life every week", he commented. "The problem will be finding things to do with myself now".

The former jewellery repairer can't wait to start enjoying some of the foods he has not been able to enjoy whilst on dialysis. "I will be now able to go and have a pint" he said. "But believe it or not, I am really looking forward to having a banana and one of the first things I intend to do is to have a Costa coffee because I have never had one – they weren't about 30 years ago!"

Consultant renal surgeon Clare Pattenden, who performed David's transplant said: "About one third of patients waiting for a donor kidney are considered significantly sensitised. This means they have high antibody levels that react to foreign tissue (or a transplanted organ). If you have high antibody levels it is harder to match that patient to a donor kidney. People develop antibodies as a response to exposure to foreign tissue, such as a previous transplant, a blood transfusion, significant infection or pregnancy. Relatively few highly sensitised patients receive a transplant and they wait significantly longer than unsensitised patients for a compatible donor."

"The scoring system for sensitisation is expressed as a percentage and David was 97% sensitised. That means he had antibodies to approximately 97% of the population. This understandably made it difficult to find a compatible kidney for him. "

Clare Pattenden continued “obviously David being offered a kidney for the first time in nearly 30 years was remarkable considering this and transplanting him gave us all great joy. For a man to wait so long and remain in such good health is a clear demonstration of his excellent ongoing renal care from the Stoke Nephrology team at University Hospital of North Midlands”.

“There are hundreds of highly sensitised patients in this country waiting in similar situations, many of whom will never receive a transplant and either become too unfit or pass away on the waiting list. The message is simple: more patients will have the opportunity to receive a life-changing transplant if more people join the organ donor register.

FOOTNOTE: David is in regular contact with Mark Davis (West Midlands Advocacy Officer) who continues to offer support and guidance to him.



The SKF Conference will be held in the Carnegie Conference Centre Dunfermline on Saturday 17th October 2015. Registration from 9.30 a.m. Conference begins 10.00 until 4.00.

At the close of conference there will be a Balloon Release. Each of the 493 balloons represents a person on the kidney transplant waiting list.

Bookings and further information about the conference can be had from The Secretary on scottishkidneyfederation@yahoo.co.uk or telephone 01475 672272.



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

HOLIDAY BROCHURE 2016



If you know of any holiday dialysis units which you could recommend, both at home and abroad, which may be suitable to put into the NKF Holiday Brochure 2016 please send brief details to us on help2@kidney.org.uk or telephone the Helpline number on 0845 601 02 09. Help us to compile a directory of holiday units which will be helpful to both patients and the nursing staff at your

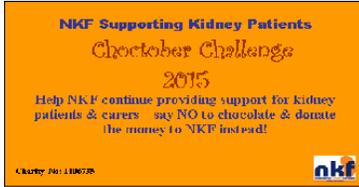
hospital.

Thank you for your help.



NKF Fundraising

Choctober



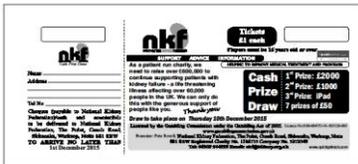
Next month is **Choctober**, a month when we ask you to give up chocolate and raise money for kidney patients. It's not too late to join us – please email your name and address to pete.revell@kidneynkf.com and we will send out a choctober fundraising pack.

Christmas Cards



We may still be having BBQ's but like it or not Christmas is just around the corner and the 2015 Christmas brochure is out full of gift wrap, money wallets and a fantastic range of cards. These can be viewed and purchased by going to our web shop at <http://store.kidney.org.uk/> or call 01909 544999 to receive a Christmas 2015 brochure

2015 NKF Draw



By now you should have received 3 books of draw tickets within your kidney life magazine, if you have not and would like some please call 01909 544999 – when returning the tickets please only return sold ones with your payment and good luck !

Thankyou!

Thank you to everyone that has taken part in events in the past month including Donna Eke walking from London to Cambridge, Rebecca Fleetwood and 6 friends climbing Snowdon, Karen Bornhoft getting all muddy in the Nuts challenge, Desiree Taylor, Emma Reast, Gurpreet Virdee doing the Thames Bridges walk and finally Richard Pepper, Lynda Lambert, Chris Paxton, Chris Roome, Kareema Hay and Lisa Cowie who ran in the Great North Run.

Good Luck!

Good luck to Olivia Wheeler, Holly Bartlet, Amelia Hackett and Leah Grosvenor running in the Worchester 10K, Charlotte Keen running in the Ealing half marathon and Rachel Stevens taking part in the Tough Mudder. Thank you for supporting the NKF.

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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