

NKF In Touch

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

Date: **March 2015** Issue: **Ten**

Welcome to the NKF In Touch newsletter for March 2015. Please forward any articles etc that you would like sharing via the next newsletter to Stephanie Scott (formerly Stephanie Allen) stephanie@kidney.org.uk by 10th April.



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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

Kidney Group

Trusts and Hospitals



Action Point

KPA day 2015



28th

KPA Day is on Saturday 28th March in the Millennium Room at The Arden Hotel, Nr Birmingham: - 10.15 am– 4.00 pm

Enter this code into your SATNAV - B92 0ED (ignore the postal code of the Hotel)

Marion Higgins



It is with great sadness that we have to report the untimely death of Marion Higgins.

Marion became national chairman of the NKF in March 2010 after serving on the Executive committee; however ill health forced her to stand down before completing her three years. Marion was the driving force behind Northamptonshire KPA; along with Jim she set up the Association in 2005. Until last year, Marion had always been the secretary of the NKPA but then took on the role of Chairman with Jacky Burdett taking on some of the secretarial duties, although Marion was still very much at the helm.

Marion was so knowledgeable on chronic kidney disease that she was always the 'go to' person when anyone needed help within the NKPA. Marion has been inspirational to many kidney patients through her work with the NKF, and for her active and persistent promotion of both Home Dialysis and Nocturnal Dialysis. As Chairman of the NKF, she campaigned to improve provision for all kidney patients.

When I first became a member of the NKF Executive, Marion was both encouraging and supportive to me and it was a pleasure to work with her. Marion will be missed by many in the renal community and certainly by everyone in the NKF. Our thoughts are with Jim, Victoria, James and their families.

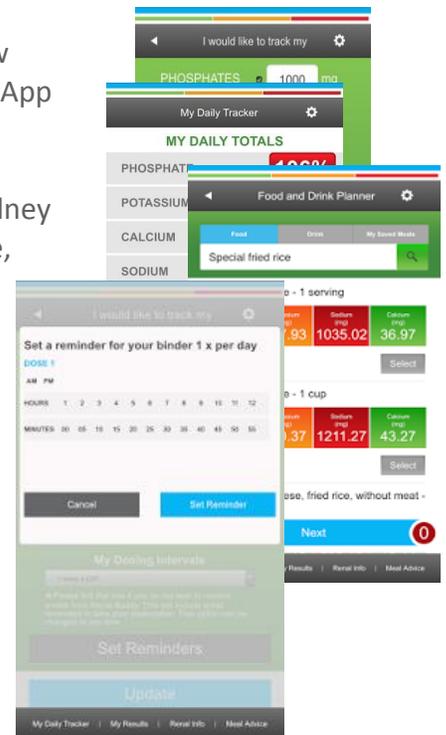
Kirit Modi – NKF Chairman



We are pleased to announce that Renal Buddy® is now available online and through the Apple & Google Play App stores.

This FREE website & App endorsed by the National Kidney Federation helps patients keep track of the phosphate, sodium, potassium, calcium and fluid levels in their daily food and drinks. Renal Buddy also provides them with useful reminders so they don't forget to take their phosphate binder as prescribed.

If you would like to find out how Renal Buddy works, feel free to register as a new user at www.renalbuddy.co.uk or by installing Renal Buddy on your mobile device.



Let Renal Buddy help you manage your daily phosphate intake



NKF Conference 2015 – Living Life to the Full



This years Patient's Conference is being held at The Hilton Reading Hotel 9th to 11th October 2015. Further information is available from headquarters Tel: 01909 544999 or email: nkf@kidney.org.uk Booking forms and further information will be available in the May edition of Kidney Life magazine

Hull Royal Infirmary

Ward 50 at HRI was re-named on Thursday 12 March as 'The Hull Kidney Unit', to coincide with World Kidney Day. The official opening took place at 1pm, with Dr Malcolm Farr, a retired consultant who previously worked with the Trust returning to give a short speech and perform the ribbon cutting ceremony. At the same time, the Dialysis Room was renamed 'The Rosie Ratcliffe Dialysis Room' in memory of Rosie, a former nurse working for the renal service who sadly died two years ago.



Actions Following Adverse Clinical Incidents in Transplantation – Online Survey. Can you help us please? The University Hospitals Coventry & Warwickshire, U.K, in collaboration with Warwick Medical School, University of Warwick, U.K. is conducting a web based questionnaire study looking at actions taken following clinical adverse incidents in transplantation, in

different hospitals. We would appreciate your participation in this survey, which should take about 10 minutes.

The web link for the study, with details included, is <http://www2.warwick.ac.uk/fac/sci/eng/staff/jgh/afacit>

Many thanks for considering participation in this study.



Advocacy Services



Benefits

The Advocacy team continue to receive a range of enquiries concerning benefits including: Disability Living Allowance (DLA under 16's), Personal Independence Payment (PIP) and Employment Support Allowance (ESA) in particular – the financial stress and hardship for many in our community is unabated. We note a continued variation in decision making across the country in assessments and have been working with a range of patients often securing successful results at tribunal hearings.

We use a range of external agencies for information and guidance to support this side of our work and where patients are able to advocate for themselves we kindly suggest www.benefitsandwork.co.uk www.turn2us.org.uk and www.citizensadvice.org.uk for sources of information and help. We also stress the importance of contacting your local MP who can provide support.

As a result of increasing demand in this area the Advocacy team is seeking further professional training from www.disabilityrightsuk.org later this month.

Employment

Staying in employment for many working age patients either on dialysis, with a transplant, or facing the side effects of a declining kidney function can be difficult, the pressure of scrutiny and prejudice can be relentless. We would advise patients to share their problems with friends, family their healthcare team and approach the services of their regional advocacy officer who will be able to add further support, advice, information and guidance – we strongly believe in sharing problems and are more than happy to help having secured an individual's job most recently.

Dialysis Away From Base (DAFB)

A 12 week public consultation began 30th January on the commissioning arrangements for dialysis away from base also known widely as dialysis holidays

https://www.engage.england.nhs.uk/consultation/specialised-services-policies/user_uploads/dafb-commissioning-policy-27814.pdf after which point we believe it will be adopted as policy.

The consultation closes at the end of April, please use this link to complete the public consultation which can be found at the bottom of the web page www.engage.england.nhs.uk/consultation/specialised-services-policies

The NKF hope this will be a precursor to similar transparency of standards of commissioning arrangements in other nations of the UK, but know there is still work to be done on achieving greater capacity in popular holiday destinations which is often the first barrier for patients.

Home Dialysis Cost Reimbursement

The NKF is collaborating with the Renal Association to achieve long overdue updated guidance on Home Dialysis Cost Reimbursement in order to achieve transparent, consistent and fair practice across the UK. We understand that this piece of work is high priority. If you have home dialysis and have any further questions please contact Linda Pickering lindapickering@btconnect.com

Think Kidneys



This is the NHS campaign to improve the care of people at risk of, or with, acute kidney injury. The website has a range of valuable information for your KPA to educate your local kidney community and beyond - for more information please visit www.thinkkidneys.nhs.uk

NW Region Advocacy Officer

A reminder that closing date for applications to be received for the NW Region Advocacy Officer 31.03.15. We are keen for this vacancy to be filled please visit www.kidney.org.uk for more details.

For any other information please contact nicholaspalmer.nkf@btinternet.com

Helpline



GREEN NEPHROLOGY

A new leaflet will be launched at the NKF KPA Day on 28th March, 2015. This leaflet contains helpful information about green nephrology and how KPAs and patient groups can help with sustainable health care. Copies of this leaflet will be available after that date from the NKF Helpline by telephoning 0845 601 02 09 and will be available for download from the NKF website at www.kidney.org.uk and from sustainablehealthcare.org.uk/green-nephrology

NKF Fundraising

World Kidney Day



I hope you all had a good World Kidney Day, I believe this year has seen the most activities around the UK so let's hope more of the general public now knows about kidney disease.



The NKF patron Nina Wadia visited the West Byfleet renal unit on World Kidney Day; she met with staff and dialysis patients and spoke about her own experiences with her mother who also had kidney



disease.

WKD Selfie



Thank you to everyone who took part in our World Kidney Day Selfie campaign. After receiving hundreds of selfies for World Kidney Day we have now picked a winner! Congratulations to Lisa Barker's daughter who wins £100 that has been kindly donated by one of our supporters. Once again thank you to everyone who took the time to be part of this great campaign.



NKF Office Staff

All selfies have been posted on NKF facebook page

<https://www.facebook.com/nkfukfundraising>. Thanks for the text donations so far £214

has been raised! It's not too late to donate! **Text the number 70070 and then type WKDA15 followed by the amount you would like to give e.g. WKDA15£5**

Thank you!

We know times are hard and would like you to know we greatly appreciate all your fundraising efforts. Whether taking part in our Prize Draw, holding a cake sale, giving up chocolate for choctober or running a marathon, you **all** help NKF to continue supporting kidney patients and carers.



22nd February saw the first half marathon event run for NKF – thanks to Mira Patel who completed the Bath half marathon and raised an amazing £869!



On April 26th two runners taking part in the Virgin London Marathon will be raising money for NKF. Ceri Barrett who has an NKF place and Daniel Lombard who was lucky enough to secure his own place will be donning their running shoes and hoping for good weather! Good

Good Luck!

Luck to you both. To donate please visit

<http://uk.virginmoneygiving.com/CeriBarrett>

<http://www.justgiving.com/Daniel-Rick>

Draw tickets



Prize £2,000 to brighten up your summer!

Thanks to those of you who have already taken part. If you would like more tickets to sell to your family and friends please contact the office telephone 01909 544999 or email nkf@kidney.org.uk

Parachute Jump

Can you imagine standing at the edge of an open doorway in an aircraft flying at 10,000 feet – the noise of the engines and the wind ringing in your ears with only the outline of distant fields below? Imagine leaning forward out of that doorway and letting go – falling forward into the clouds, skydiving down through the air as you start freefalling at over 120mph!



Stop imagining! All this and more is available on one of our 10,000 feet tandem skydives! There are over 20 airfields across the UK to choose where you can make this happen! Why not encourage a friend to take part, or get a team together? No experience is required as all training is given and if you raise the minimum sponsorship you can receive your skydive for **FREE!** For more details call 01263 722287 or email pete.revell@kidneynkf.com

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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