

NKF In Touch

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

Date: **April 2016** Issue: **Twenty Three**

Welcome to the NKF In Touch newsletter for April 2016.
Please forward any articles etc that you would like sharing via the next newsletter to Stephanie Scott stephanie@kidney.org.uk by 10th May



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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



Action Point

Annual patients' conference 2016

BOOK NOW

to NKF

This year's annual patients' conference is already proving to be very popular! On line booking facilities will be available soon. However, bookings can be made over the telephone or by completing and returning the attached booking form with payment to NKF, The Point, Coach Road, Shireoaks, Worksop S81 8BW. Cheque made payable

More information and a booking form will be in the May edition of Kidney Life.

KPA Day 2016

The NKF held its fourth successful KPA Day on 2nd April, in Birmingham.



Many KPAs attended to represent their KPAs and the NKF AGM and Council meetings were held throughout the day.

The new NKF Executive Committee was elected during the AGM and the members are as follows:

Officers

David Marshall – Vice Chairman

William Beale - Treasurer

Denny Abbott – Secretary

Committee Members

Angela Beale

John Burdett

Vanessa Hardy

Jonathan McGann

David MacDonald

Michael Walker

Richard Van Roon

David Davies

Dianne Griffiths



NKF CEO – Timothy F Statham

There were presentations from Six Counties KPA about what their KPA does - Derby KPA about BAME Donation – NKF Chief Executive about his role as the Secretariat for the All Party Parliamentary Kidney Group and Rachel Gair from the Renal Registry about Transforming Participation in CKD.

It was a very informative day and was enjoyed by all.

We look forward to welcoming you all to a similar day next year.

The provision of Immunosuppressant drugs

As you will know NICE have put forward proposals to dramatically reduce the number of immunosuppressant drugs available to clinicians looking after transplanted patients. This is seen by the NKF as short sighted, foolhardy and likely to result in grafts being lost unnecessarily. NKF believes it is merely a cost cutting exercise. NKF has fought this proposal for nearly one year, and has had questions asked of Ministers in the House of Commons. It has also entered submissions to NICE arguing for a re-think. So far this has fallen on deaf ears, however when NKF put forward a case for an APPEAL against this decision that need for an APPEAL hearing was granted. The APPEAL hearing took place in Manchester on 30th March and the NKF was present in force and argued strongly and passionately for a re-think and a reversal of this damaging decision. NKF now awaits the decision – and will inform you immediately it is known.



Share your and/or your team's innovative practice in diabetes care – enter Quality in Care Diabetes 2016 Now open for entry, closing date May 27, 2016

Have you or your team made changes for improved diabetes services and outcomes, in something established, especially by introducing new methods, ideas or products; or introduced something new?

If so put together an entry for Quality in Care (QiC) Diabetes 2016 - download an entry form now for your chance to win a QiC Diabetes 2016 Award

No entry fee, open to all those working in the diabetes arena, view previous winning case studies Eleven categories including nomination for the Diabetes Healthcare Professional of the Year

Supported by Professor Jonathan Valabhji, National Clinical Director for Obesity and Diabetes, NHS England Quality in Care (QiC) Diabetes recognises, rewards and shares innovative practice demonstrating quality in diabetes management, education and services for people with diabetes and/or their families.

Gaining QiC recognition means an initiative has been highlighted by the NHS, patients and industry as improving the quality of life for people living with diabetes.

Any questions?

QiC Diabetes 2016 Contacts

Emma Clear E: eclear@qualityincare.org T: 01372 414220

Siobhan Thwaites: sthwaites@quallityincare.org T: 01372 414200

Visit www.qualityincare.org for all the information and download an entry form



10th
March
2016



World Kidney Day
is a joint initiative of: ISN IFF

UK Campaign Overview 2016

The 2016 World Kidney Day campaign in the UK was, once again, a joint initiative from the Kidney Charities Together group (KCT), comprising The British Kidney Patient Association (BKPA), Kidney Research UK, Kids Kidney Research (KKR), The National Kidney Federation (NKF) and the Polycystic Kidney Disease Charity (PKD).

As has been the format for the past two years, the agreed objective was to galvanise the wider renal community into supporting WKD and provide resources and inspiration to empower smaller groups (e.g. renal units, patient organisations and individuals) to take part by trying to do something to raise awareness and promote kidney health, with a focus for 2016, on kidney disease in children. This allowed for alignment to a degree with the global theme but without the additional strapline – Act early to prevent it’ as it was felt this would be hard to achieve given that many childhood conditions are inherited. Adopting this theme also opened up the opportunity to work closely with the British Association of Paediatric Nephrology (BAPN) who remained extremely supportive throughout the campaign.

Budget

Unrestricted grants totalling £4,500 from Fresenius Medical Care, Pharmacosmos and health insurance company, Westfield Health, supported the 2016 campaign. An additional £4,000 was donated by the KCT charities creating a total budget of £8,500. This allowed for an update of the UK website (www.worldkidneyday.co.uk) and the design and limited production of new downloadable materials including the printing of 15,000 copies of the A5 kidney health awareness flyers, 50,000 WKD logo stickers and 250 support packs of materials which were sent out on request. This was a different approach to previous years and was felt to be a better use of resources knowing that the materials would actually be used for an event as opposed to being sent out speculatively. The balance of the budget supported project management and media relations.

Materials and Support Packs

As required by the team at the global WKD office, all materials produced in the UK include the IFKF/ISN affiliation and WKD copyright. Downloadable versions of all materials developed for the UK market were uploaded onto the website in mid January and 250 support packs of printed materials together with the total supply of A5 flyers and stickers sent to the BKPA to fulfil requests for the pack. Individuals specified how many flyers and stickers they needed which were added to the standard pack before despatch. The supplies were all used up and sent out to support over 200 separate events – a fourfold increase on 2015. Given the



theme of kidney disease in children and with support from the team at Great Ormond Street Hospital, an additional kidney health poster was designed and 250 copies produced which specifically targeted children. These were issued to all paediatric renal units and all contacts who had expressed an interest, particularly those running events in schools and nurseries.

Email campaign

An email campaign commenced at the end of January to a just over 800 individuals representing a range of contacts through previous WKD campaigns, and those contacting the 'info@worldkidneyday.co.uk' email address, plus selected stakeholders including charities, industry contacts and researchers to ensure they were kept up to date and encouraged to take part. This included the announcement that the new materials were available to download through the website and that if they were running an event that they should apply for a Support pack. The opening rate was 30% of total sent, NB the average in UK for email effectiveness is 22.8%, so we're certainly above average.

A second reminder and call to action to Clinical Directors took place at the end of February – the opening rate was 19.5%.

A follow up email to everyone applying to info@worldkidneyday.co.uk for the 2016 campaign at the beginning of March to wish them every success had a 47.9% opening rate.

Events and Activities

Those organising events were asked to keep us informed of their plans via the 'info@worldkidneyday.co.uk' email address, posting on the WKD UK Facebook page and adding to the global map operated by the international WKD organisers. Although we were aware of over 200 events taking place around the UK perhaps we weren't as proactive in encouraging people to add to the map, nor did we allocate a volunteer from Kidney Research UK to physically add them on, hence the map looks less populated (NB this could be added retrospectively if thought to be worthwhile).

2016



2015



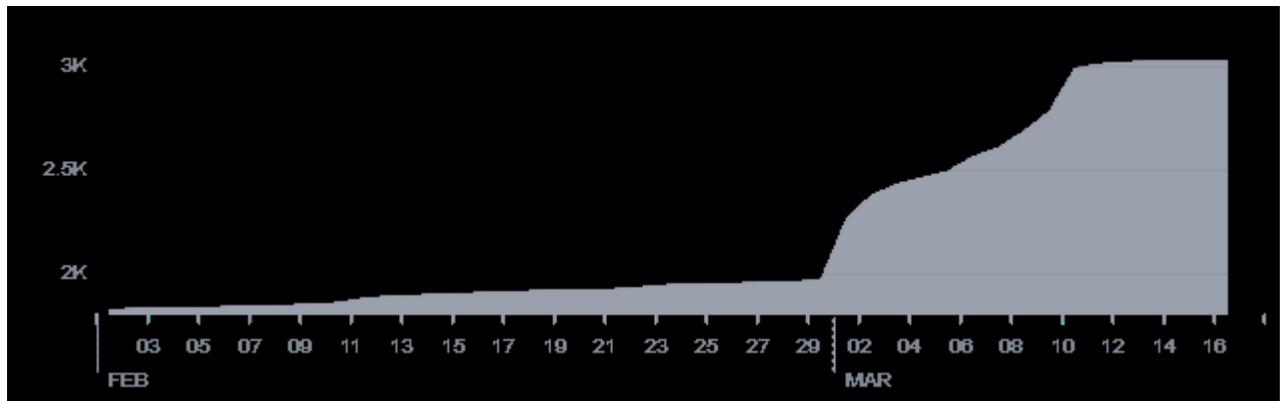
2014



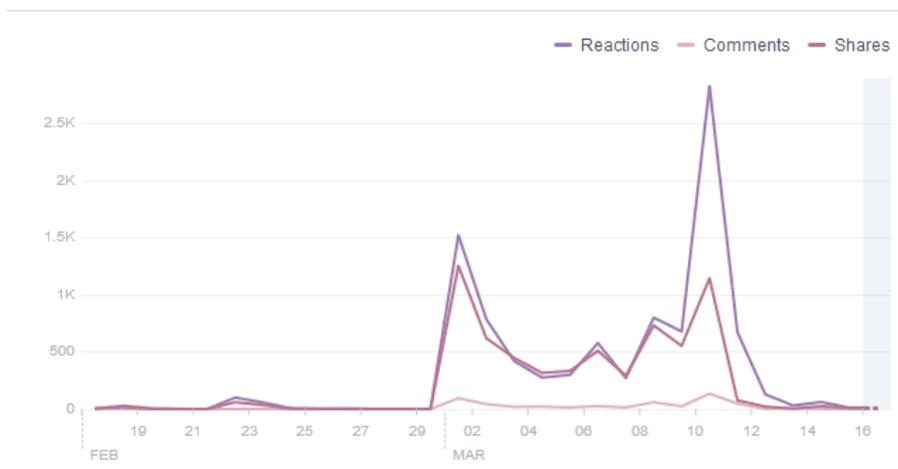
Website and Social Media

Regarding the UK website, webstats reports indicated that interestingly the 2015 WKD received more visitors (3052) than this year (2374). The Kidney Facts and Get Involved pages had higher engagement than last year and overall the site analytics showed a slight increase over last year on Twitter traffic. It is possible that the direct communication with KPAs and those interested in running events was more effective than driving people to website to download artwork?

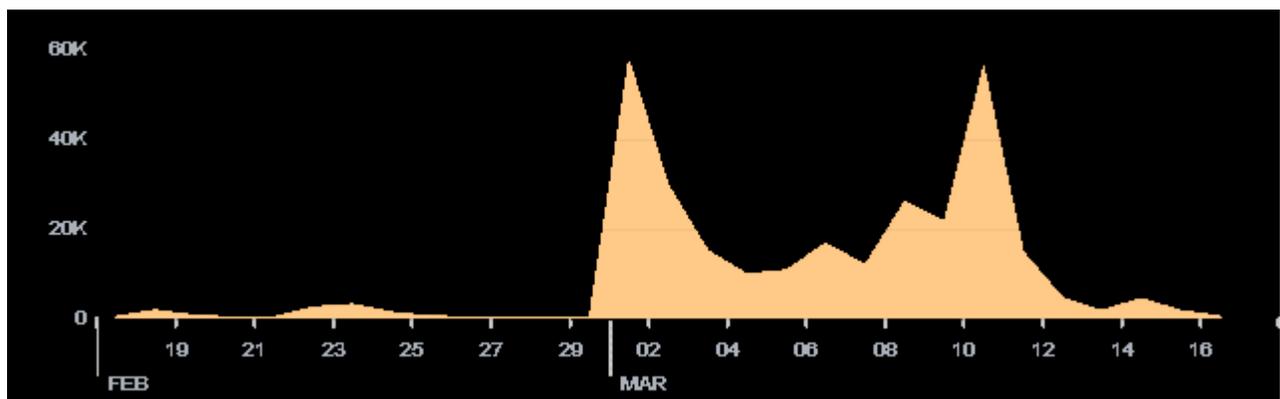
Reflecting a general internet trend, the UK Facebook page had significantly more activity as compared to 2015 with just over 3,000 likes – double the figures for 2015 and three times higher than 2014. There were an additional 1,000 new likes in the period from 1st-10th March, due almost certainly to the series of kidney facts which were released during this period.



There was a peak of over 900 looking at the page around WKD itself and a massive reach of over 57,000 on both the 1st and 10th March.



Reach



The major increase is probably attributed to the planned social media campaign in releasing 10 kidney facts, daily, from 1st-10th March on both Facebook and Twitter which were extensively shared, re-posted and re-tweeted.



There were a significant number of photos posted of events taking place all over the UK and it was excellent seeing the WKD 2016 collateral being used to promote the day including flyers, poster and pop-up banners.

Twitter – a programme of tweets were set up to be issued in the final 3 weeks including the 10 kidney facts. Having profiled the planned social media campaign through various stakeholder channels in the weeks leading up to WKD itself, and encouraging numerous groups and individuals to follow the @kidneydayUK account, WKD was actually ‘tending’ for much of the day on 10th March – a major improvement on previous years. A number of MPs re-tweeted and even Sarah Ferguson was following at one point.

WKD profiling

A WKD 2016 advert was prepared and appeared on all KCT group websites as well as numerous other key stakeholders sites. The January, Feb and March editions of KPA ‘In Touch’ newsletter contained adverts and a call to action. The Renal Association, BRS, BAPN, Think Kidneys, Diabetes UK, InfoKid amongst others, had details on their website, an advert appeared in the Journal of Renal Nursing and all were encouraged to email their members with details (The January and February Renal Association e-news contained details).

Media Release and coverage

A joint KCT media release was produced, focussing on the increase in childhood obesity and the risk of future kidney problems, as well as general kidney health messages. The release cited the Kidney Research UK YouGov stats on a continuing lack of awareness, and quotes from both David Hughes (President of BAPN) and John Feehally as one of the founders of WKD globally. Direct enquiries were limited and were handled by the Kidney Research UK press office, providing kidney experts, patients and spokespeople where required. There were however a number of other kidney related releases issued around WKD (Think Kidneys, Natural Hydration Council, NHSBT etc) which focused on kidney stones and organ donation which probably helped to ensure a very high level of media coverage across the regions, both broadcast (radio and local TV) and print. The media monitoring service for the UK picked up 410 clippings across print, web and broadcast which gave a reach of just under 35 million and if paid for, would have been valued at approximately £486,000. A selection of coverage can be found here <https://www.dropbox.com/sh/4zpp7z9978gjbar/AAC0INosVIQ97GYdSU4yBmV1a?dl=0>

NIHR activity:

We worked quite closely with the NIHR comms team with Professor John Feehally writing a 'blog' on the history of and overview of the aims of WKD, on their main website yesterday - <http://www.nihr.ac.uk/newsroom/blog/setting-up-world-kidney-day.htm>. They also put together a series of short films with Professor Phil Kalra who leads the renal disorders speciality group, and a kidney patient, Michael Lomax talking about kidney disease and research - <https://www.crn.nihr.ac.uk/news/network-supports-world-kidney-day-2016/?h=28>

KCT Activities:

The 5 member charities also held various events and activities to mark World Kidney Day:

The **BKPA** co-hosted an event with the Royal College of GPs to highlight the importance of kidney health in primary care and showcasing the great work that had been done under the joint Strategic Clinical Priority Programme with the College. They also had stands in GOSH and Guys and St Thomas's to promote world kidney day.

Kidney Research UK encouraged staff, Trustees and supporters to post photos on social media of their pledges for better kidney health.

Kids Kidney Research launched an excellent new video about the difficulties children facing with renal-specific diet

The **NKF** ran a social media campaign through [young@nkf](https://www.nkf.org.uk/young@nkf) in response to the 2016 theme

The **PKD Charity** launched their telephone befriending scheme at an event at Guys and St Thomas' Hospital, London

Supporting Organisations:

Westfield Health were particularly engaged this year taking support materials for internal use and information on WKD and their support appearing on their website. They also issued a press release themselves (<https://www.westfieldhealth.com/press-media/press/2016/03/09/world-kidney-day-campaign-in-the-uk-supported-by-donation-from-westfield-health>) and their CEO tweeted a photo holding some of our materials. Indeed their Twitter account followed ours throughout and they retweeted all of our kidney facts and had a WKD reminder in the days leading up to WKD. Both Pharmacosmos and Fresenius were also sent materials and kept informed through but seemed less inclined to profile their support for the campaign.

Thanks to Angela Lumsden, project manager for Kidney Charities together World Kidney Day sub-committee for compiling this campaign overview

World Kidney Day in the UK is led by the Kidney Charities Together Group



Contact us

info@worldkidneyday.co.uk • www.worldkidneyday.co.uk



[@kidneydayUK](https://twitter.com/kidneydayUK) and use #worldkidneyday



www.facebook.com/worldkidneydayuk



NKF Helpline

The Helpline has been busy this month working on a new information pack; we are targeting Renal Units, as well as KPA's. We are promoting the HELPLINE here at the NKF to remind Staff and patients of all the useful information and advice the Helpline can offer. We currently assist patients and hospitals with dietary advice through to transplant. We can also help with updated Benefits and Holiday information, not forgetting the phone line **0845 601 02 09** should you need a person to talk to. Visit www.kidney.org.uk to get essential help when completing PIP and ESA application forms.

Please look out for your information pack arriving, it should be with you very soon.



NKF Fundraising

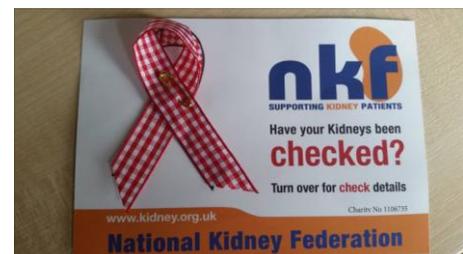
Charity Ribbon

The NKF would like to share a project with your Kidney Patient Association, as you are very aware the general public are not mindful of kidney disease and it is always difficult to change this.

The NKF have decided to make some charity ribbons that are slightly different from others in hope that people will ask about them – giving the wearer the opportunity to explain and to ask people to have their kidneys checked by the doctor.

As you will see these ribbons are chequered and quite eye catching (see photo), they have information about kidney health with each ribbon and sell for £2 each – this is the good bit, we would like to give £1 to your KPA for everyone you sell.

Please can you email pete.revell@kidneynkf.com if you would like to take part in this kidney health awareness campaign, we will then send out 100 ribbons in the post for you to sell.



NKF Draw



Thank you to everyone who has returned draw ticket stubs to be entered into the spring draw on 11th May, if you have not returned your tickets yet but want to take part and have a chance to win £1,500 first prize please make sure you return them by 29th April

Event Fundraising – Thank you to ALL our fundraisers

The NKF would like to say a special **thanks** to Teresa Davidson who took part in the Alloa Half Marathon on 20th March, Teresa set a very high fundraising target of £2,000 – after asking friends and family to support her, the final amount raised was an amazing £4,325!!!
WELL DONE!

Another **thank you** goes to Ed Gorman who has fundraised for the NKF for a fifth year by running a marathon; this year on 3rd April he took part in the Milan Marathon.



Cheers!

Ed enjoying a well deserved beer following the Milano Marathon



On the subject of Marathons, Claude Vella will be proudly wearing the NKF running vest and running the 2016 London marathon, we wish him all the best and **thank** him for his fundraising.
(If you're watching it on the telly look out for a bright orange vest and the NKF logo!)

Good Luck to Barry Augood who is taking part in a parachute jump, Vanessa Paldano who is doing a head shave and Anna Taylor who has organised an Opera evening.

If you fancy taking part in an event and raising money for kidney patients – please contact 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

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

