



Annual Report of the Executive Committee 2017 January 2017 to December 2017

NKF Remains Steadfast

The immense change within the UK during 2017 has affected the provision of renal treatment, the ability of the NHS to deliver at all levels, and the resolve of politicians to pursue with any certainty an acceptable health care model. It is not just Brexit that has affected these matters, it is also internal disagreement within all political parties that has diverted attention and allowed holes to develop and widen in the safety net that should be protecting us all – particularly the sick and needy.

Change is happening, it cannot be avoided, however NKF has determined that whatever surprises lie ahead, the charity has to deliver its core functions, namely to seek continued improvements in the provision of renal care, better renal treatments, and the support of its patients and carers.

That is why the NKF remains the voice of kidney patients.

Changes at the head of the NKF

The AGM and KPA day on 1st April saw David Marshall elected as Chairman and Michael Abbott as Treasurer.

The Executive Committee elected on that day were: - Denise Abbott – now sadly deceased, James Barr, John Burdett, Jim Higgins, Wajid Iqbal, David Macdonald, Guy Richards, Rajesh Sanghani, Tracey Sinclair, Richard Van Roon. Holly Loughton joined the Executive committee later in the year, and Tracey Sinclair became Secretary.

Ken Tupling was appointed again as President.

Tim Statham NKF CEO had given five years notice of his intention to retire on 31st December 2018 following 20 years' service, and so work has been undertaken by the Executive committee to appoint a successor on a date which will allow for an overlap period for the exchange of vital information.

Deborah Duval stood down as Kidney Life Editor in October 2017, and plans are also underway to find her successor. Kidney Life has now returned to four issues a year (the winter edition is ONLINE only)

NKF HQ at Worksop have two new members of staff – Fiona Broomhead and Stephen Emmerson. Linda Fores and Andrea Goodall have retired.

NKF Executive Committee have noted with pleasure that the NKF chairman, David Marshall will be cycling from London to Paris to raise awareness of Kidney Disease.

Organ Donation System

The Prime Minister has announced that a consultation will take place during the first three months of 2018 to advise whether a change from OPT IN to OPT OUT should be undertaken in England. The NKF advises all KPA's and all renal patients to make their voice heard on this important topic. This can be done online via the NKF website. The NKF has supported such a change to the system for nearly 20 yrs.

A drop in the number of Living Donors

In 2014/15 the NKF observed a fall in the numbers of kidney transplants carried out in the UK using living kidney donors. This fall continued throughout 2015/16 and 2016/17 and was completely at odds with the rise in transplants from cadaveric donors. The NKF began to explore the reasons for this drop and embarked upon a consultation within the renal community. Following that consultation, the charity asked the All Party Parliamentary Kidney Group (APPKG) in parliament to hold an exploratory Living Donor Transplant Summit within the parliamentary estate. That Summit was held on the 22nd November 2017 under the chairmanship of Madeleine Moon MP. The findings of that Summit, together with recommendations, will form the content of a published Manifesto and a call for remedial action. The NKF wishes to thank life Vice President Kirit Modi for his work towards this.

NKF has issued press releases to highlight the problem amongst health journalists and the public.

General Election and the All Party Parliamentary Kidney Group (APPKG)

The APPKG, consisted of 106 MP's and peers prior to the 2017 election. It had been in existence for the last 17 years. There are 500 different all party parliamentary groups. When a General Election is called it becomes a complicated process to ensure the group can continue afterwards. When an unexpected General Election is called it becomes even more difficult because NKF uses Kidney Life magazine to distribute 75000 surveys forms that patients use to try to get candidates to commit to the APPKG. This process, using patient power, is NKF's main strength. The unexpected general election in 2017 was so sudden that there had been no time to complete this process, instead, Timothy Statham wrote to all existing members of the group to request that if they were re-elected would they commit to joining the group. The group had to be suspended until after the General Election. NKF is pleased to report the successful reforming of the group, the inaugural meeting was held on the 5th July 2017, and only a minor change in the numbers of personnel within the group (now 102) was the result. Ronnie Cowan MP replaced Glyn Davis MP as a group Vice Chairman. The 2017 terrorist attack at Westminster has led to increased security and stringent rules that the APPKG has to comply with.

Kernow - The decision on Dialysis Transport charging

NKF has been shown a letter from NHS Kernow Chairman, Dr Iain Chorlton, which sets out the revised decisions being made by the CCG following the outcry from patients (supported by the NKF and the All Party Parliamentary Kidney Group) to the threat of charging for transport to and from lifesaving dialysis treatment. Whilst the NKF is pleased that for patients in Kernow the threat of charging has been mainly lifted, we remain saddened that the principle of “Free at the point of delivery” for health care patients has been lost in favour of individual assessment. Overall NKF believes this to be a retrograde step.

Madeleine Moon MP (Chair of the All Party Parliamentary Kidney Group) is to look into the possibility of drafting a ten minute rule bill to raise the “Payment for Transport to Dialysis” (Kernow) issue. The purpose would be to explicitly enshrine in legislation that transport is integral to renal dialysis treatment and transport to and from dialysis should be free.

While this probably won't become legislation it will serve as a useful tool to raise awareness.

NKF has also noted that other CCG's are considering similar changes

World Kidney Day

WKD was held on the 9th March 2017, and widely thought to have been the most successful day yet. Tim Statham has now stood down as chair of the oversight group and his place has been taken by Sandra Curry who is making plans for WKD on 8th March 2018. The theme will be Kidney Disease and Women's Health.

The Transplant Games

NKF had a very successful stand at the Games in July 2017 (North Lanarkshire) – manned by the Head of NKF Fundraising, Pete Revell, it featured a photo booth which created maximum interest and drew crowds to the stand.

British Renal Society (BRS)

Two staff members, Andrea Brown and Donna Blizzard, manned a stand at the BRS four-day event in April – it was a much busier stand than BKPA (now KCUK)

NKF Conference

The Conference at Hinckley Island Hotel in October was successful despite the loss of the Conference chair, Denise Abbott. Pulled together by Andrea Brown, NKF Office Manager, and supported by NKF staff and Executive Committee members it was extremely enjoyable and highly informative. The 2018 Conference will be held in Blackpool on 19th, 20th, 21st October 2018. It is hoped that by further subsidising the cost to patients in 2018 more will be able to attend this “must be at” event. Holly Loughton will be Conference chair in 2018.

Kidney Charities Together

This group consists of NKF, Kidney Research UK, Kidney care UK, and Polycystic Kidney Disease. It meets three times a year and considers matters of importance to the charities involved. It aims to ensure full cooperation and the avoidance of unnecessary duplication and overlap.

Industry Partners

The restrictions placed on pharmaceutical companies by the ABPI code of conduct now means that NKF receives less money in sponsorship than it once did – however the partnership working with these companies is beneficial to both renal patients and the companies. NKF continues to host three joint meetings with Industry partners a year. NKF is pleased to welcome MOLOGIC and “Peace and Quiet” as new Industry partners.

The NKF has noted with concern that Fresenius is reported to be buying NXStage. NKF believes the existing competition between companies was a useful positive

Social Media

The Executive Committee has been keen to increase the charities use of social media, and to achieve this all staff have received new instructions which will, it is hoped, lead to an increase in the NKFs presence on Facebook and Twitter. The NKF wishes to thank Tracy Sinclair for her advice in respect of these matters.

The Helpline

The NKF helpline continues to lead the charities interface with patients who are in need of help and advice. The NKF has introduced a new “free to use” Helpline number 0800 169 09 36

Head of Fundraising

It has been agreed that Pete Revell should attend every second meeting of the Executive committee in order to be fully in the picture regarding activities and issues faced by the charity.

Renal Clinical Reference Group (CRG)

On Thursday 16th March the CEO had a one to one meeting with Richard Baker Chairman of the Renal CRG at Worksop. This meeting followed NKF disquiet that the charity had missed out recently in opportunities to influence CRG discussions. This was a very positive meeting and it is thought that the relationships between the NKF and the CRG will be strengthened as a result. David Marshall is reminding Richard Baker to extend invitations to the NKF from now on.

2018 AGM and KPA Day

The 2018 NKF AGM and KPA Day will be held at the Glebe Hotel in Warwick on Saturday 7th April 2018.

NHSBT Kidney Patients Group Meeting

David Marshall (NKF Chairman) has been elected to co-chair these annual meetings which seek to inform NHSBT of patient views in respect of Transplantation issues.

NKF is still waiting for NHSBT to answer NKF questions relating to the large regional variance of patients being suspended from the Transplant list.

PITHIA

A trial called PITHIA will be held in every transplant centre in the UK over the next eighteen months. Its aim will be to determine whether subjecting kidneys for transplant to biopsy tests will improve outcomes for the transplanted patient and the transplanted kidney.

KQUIP

David Marshall has been asked to lead one of the newly formed KQUIP work streams on patient development. KQUIP aims to create uniform renal quality and best practice.

Kidney Cancer UK

NKF has facilitated the charity Kidney Cancer UK to seek support in Parliament for their proposal to create a set of UK wide standards for their health condition – similar to the National Service Framework for renal disease instigated by the NKF 19 years ago.

British Journal of Renal Medicine (BJRM)

NKF continued throughout 2017 to write a column for this important renal publication read by clinicians and specialist – the column alerts them to the “patient view”.

Data Protection

NKF is taking all necessary steps to ensure that it is fully compliant with the May 2018 General Data Protection Regulations (GDPR) when they come into force. All readers of Kidney Life will need to complete a written request if they wish NKF to continue posting Kidney Life magazine to them. A form for this purpose will be contained in the February 2018 Kidney Life magazine.

I commend this report to you

David Marshall
NKF Chairman

20.1.2018