



THE LARGEST KIDNEY PATIENT CHARITY IN THE UK RUN BY KIDNEY PATIENTS, FOR KIDNEY PATIENTS

Embracing Changes





Annual Report of the Executive Committee 2015 January 2015 to December 2015

A Year of Success and Concern

The NKF has achieved some remarkable success in 2015, however the success has been to reverse harmful decisions by Government, the NHS, Monitor, NICE and the Department of Health. Without the tireless campaigning that NKF has led, the treatment of kidney disease would be in a parlous state – however these successes just mean that the care and treatment of renal disease is at a “stand still” whereas NKF would much prefer to be advancing care year on year.

Finance, or the lack of it, continues to bring the NKF daily headaches and difficult decisions. Gone are the days (Pre the ABPI code of conduct) when pharmaceutical companies could be generous with their support and sponsorship of charities – instead we now have to constantly search for new ways to bring in an income sufficient to sustain our services to patients.

There are however exciting developments, new machines and drugs on the horizon that hold much promise for Kidney Patients. The NKF is trying to ensure that renal in the UK is seen as an attractive place for such emerging businesses – we don't want the UK to be the last to reap the benefits that arise from new technology.

New Faces

Kirit Modi decided that he would not stand for election as NKF chairman for a final third year – we thank Kirit and his wife Meena for their unstinting support over many years. At the AGM in March Raymond Higgins (Jim) was elected chairman and will undoubtedly carry on the excellent work of both Kirit and Kirits predecessor Marion Higgins. Marion, Jim's wife, was NKF chairman between 2010 and 2013 – sadly Marion passed away earlier in the year. In support of the Chairman the following team were also elected:-

Chairman – Raymond (Jim) Higgins

Vice Chairman – David Marshall

Treasurer – Michael (Bud) Abbott

Secretary – Michael (Mick) Walker (elected at the Executive meeting on 9th May)

The executive committee elected also at the AGM were as follows:-

Denise Abbott, Michael Abbott, Angela Beale, William Beale, John Burdett, Vanessa Hardy, Jim Higgins, David Macdonald, David Marshall, Jonathan McGann, Robert Price, Rajesh Sanghani, Richard Van Roon and Michael walker.

Frank Howarth retired as President and in his place Ken Tupling was declared appointed by the Executive committee. Our thanks are recorded to Frank for many years of sound advice and support.



2015 also saw the appointment of Andrea Goodall as a second pair of professional hands in the NKF Helpline based at Worksop.

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

In May the country held a General Election, which means amongst other things that All Party Parliamentary Groups are basically disbanded. Thanks to the superb work by patients in KPAs during the campaign, the All Party Parliamentary Kidney Group survived virtually unscathed, Madeline Moon MP was elected APPKG Chairman, supported by five officers and 106 MP members. They have already held critically important meetings for renal patients in the remainder of the year.



Commissioning

NKF is very pleased to report that the imminent threat to renal posed by an NHS England proposal to downgrade dialysis from a level one commissioned service to a level three service was rebutted. This followed extensive campaigning led by NKF and supported by the APPKG. If NKF had failed in this campaign (over a one year period) the consequences to kidney patients might well have been dire.

Dialysis Tariff

Proposals (Announced over the 2014 Christmas break) to cut the relevant Dialysis Tariff payments by up to 15% were exposed by the NKF and vigorously resisted. NKF mustered a “whole renal community” fight back which brought an instant reprieve for one year. When it emerged again this year we were ready, and once more we have stopped these swinging cuts in their tracks. Thanks again to the APPKG for their support in this battle.

NICE

At the end of 2015, Nice had not only published initial plans to restrict the prescribing of certain immunosuppression drugs, but has considered and rejected the renal cries of anguish that immediately were relayed back to them. Now it is up to the renal community to mount an appeal against this decision – NKF is involved in this and has already enlisted the support of the APPKG.

National Renal Clinical Director

In December the NKF wrote the following letter opposing the withdrawal of the National Clinical Director for renal

“I am writing on behalf of the NKF (National Kidney Federation) to register this charities support for the retention of a renal National Clinical Director.

The NKF has been representing renal patients for 38 years. There are upwards of 2 million patients with early stage CKD in the UK, and 60,000 patients with end stage who are either on Dialysis or have been transplanted.

About 15 years ago the service provided by the NHS was vastly improved when the first National Clinical Director was appointed. Working from the Department of health in Waterloo he quickly

began addressing the serious service provision issues that befall kidney patients and created a sub department “Kidney Care”. The work that Kidney care undertook was magnificent and renal services improved rapidly as a direct result.

Recent reductions in available finance then led to a diminution of the National Clinical Directors role – and the disbanding of “Kidney care”. This was not a good thing, and although the provision of renal services still continues, it is not without difficulty. Without a full time National Clinical Director for renal there are constant mistakes, mis-reading and mis-understanding of the renal patient journey (pathway) Examples of this have been the recent ill advised attempt to alter the commissioning arrangement (thankfully now abandoned or postponed) and the ridiculous attempt to impose a Tariff reduction of 15% on Dialysis – again abandoned after two very traumatic years of argument and explanation. The cost of these mistakes has been legion – both for the NHS and for those who have had to fight to bring common sense back onto the table. A National Clinical Director with a small staff would have prevented these misunderstandings and would have cost a fraction of what the mistakes have cost NHS England.

Now the NKF understands that far from re-instating a full time Renal National Clinical Director, there is a proposal to do away with the post altogether.

The NKF is utterly against such a move.

Kidney Disease is not like a broken leg – it is highly complex and patients who have kidney disease have it until the end of their lives.”

Kidney Research

The NKF has been pleased to be part of the development of a publication detailing a strategy for renal research in the future. Because of our close ties with the APPKG (the NKF Chief Executive is also the Secretariat for the APPKG group) we have negotiated a potential launch of this strategy within the House of Commons should the steering group decide to launch this important document within that political forum.

Fall in Organs transplanted

The NKF was surprised and disappointed when NHSBT revealed the first fall (5%) in the number of Organs Transplanted for eleven years – this despite an ongoing national campaign to increase the numbers. NKF immediately registered its concern and demanded an assessment of why this had happened. NKF are also keen to see how WALES fares now that a form of soft presumed consent is in force in that country.



the gift of life

NKF has also asked NHSBT to request that Passport applications contain a section enabling people to elect to be organ donors.

NKF is also pleased to see the reintroduction of a donor card that carries a box indicating that relatives of the potential donor are aware of this wish. - NKF had been pressing for something very similar (the dual signature donor card) .

Organs from Accident and Emergency Units

NKF was pleased that its six yearlong campaign to include Accident and Emergency Units within the Transplant system had been accepted within the NHS. This means that organs from deceased donors are now retrieved from A&E as well as from Intensive Care Units

NKF Conference



For the first time, the NKF Conference was held at the Hilton Hotel Reading during October. The attendance was a little down from previous years but was by all other measures a very successful conference enjoyed by all. It was particularly well supported by those who had stands in the accompanying trade exhibition. Well done Denny Abbott – your first conference as Conference chairman. Thanks also to Renal Services, our Conference 2015 sponsor.



Kidney Life



Financial constraints meant that only three issues of the magazine could be produced in 2015, this is a great shame as the missing issue was felt by patients and advertisers alike. Thanks must go in large measure to our editor Deborah Duval who dealt with this change despite being very poorly herself for part of the year. Let's hope that it won't be long before we can return to four issues of the magazine.

In Touch

Another form of communication is the monthly Newsletter sent out electronically to KPA officers and a further 200 contacts. This enables NKF and KPA's to exchange News and best practice. It is warmly welcomed by all in receipt.



The NKF Helpline – 0845 601 02 09

At the time of this report the Helpline has 110 medical document controlled Information leaflets; these are reviewed every two years by NKF's professional medical advisor. The helpline also provides printed downloads (i.e. Kidney Life articles etc) and cookbooks, new patient support books, organ donor literature and information from other organisations (i.e. travel insurance, religious aspects holiday information, leaflets regarding skin/dressings/conservative management).

They are produced, printed and distributed by the Helpline – this on top of all the incoming calls and cries for help and information that they receive. The content of all information leaflets can be downloaded also from the NKF website. The helpline also diverts more serious cases towards an advocacy service where more direct and personal help and advice is available. Thank you, Pauline and Andrea Goodall.

Professor Rob Higgins, the author and reviewer of much of the NKF medical information has now retired – we wish him a happy retirement and thank him for his work. NKF is currently negotiating with the renal Association who have indicated that they are prepared to take this essential task on.

The NKF website



www.kidney.org.uk remains the leading online source of support for kidney patients in the UK. Consisting of breaking news, Help and information, organ donation, fundraising, NKF shop, Young @NKF, Kidney Disease facts, KPAs, Information about the NKF and the Helpline and a host of other kidney related matters. Over 1,000 pages of information accessed worldwide.

Thanks to Bob Hammond and Chris Shepherd for looking after the tech bits.

The staff

Remain as follows:-

- *Chief Executive - Timothy Statham OBE*
- *Office Manager - Andrea Brown*
- *Office Administrator - Stephanie Scott*
- *Assistant Office Administrator - Linda Fores*
- *Senior Office and Accounts Administrator - Donna Blizzard*
- *Accounts assistant - Heather Mooney*
- *Helpline Manager - Pauline Pinkos*
- *Helpline Administrator - Andrea Goodall*
- *Head of Fundraising - Pete Revell MInstF*



Fund Raising

Is an area of NKF work that must be expanded during the coming year(s). Our Head of Fund Raising Pete Revell has recently identified these areas of potential income:-

- Lottery draws
- Companies willing to select the NKF as charity of the year
- Annual “special events” such as Choctober
- Work with KPA’s such as Tour De Dialysis
- Direct Donations to the NKF
- Trust Giving
- Money raised indirectly by promoting the profile of the NKF
- Clothes recycling
- Selfie campaigns
- Legacies



The NKF remains open to all suggestions for future fundraising

World Kidney Day



The 2015 World Kidney Day was organised in the UK by the Kidney Charities Together group (NKF, BKPA, KRUK, PKD and KKR) and cost £4,000. This year the 10th March 2016 campaign will be similarly organised however the cost has been set at £6,000. All KPAs are urged to take part – details are on the NKF website.

Ceapir

NKF remains a member of Ceapir (European Kidney patients Federation) and has appointed David Marshall (NKF Vice Chairman) as its representative.

The Transplant Games

NKF were disappointed at the remote location of its stand at the Transplant Games 2015, and have requested a better location in 2016. NKF is also involved in a new group emerging from this gathering that aims to bring together all the various bodies interested in donation and transplantation to unify their respective messages to ensure better public understanding and harmonisation of messaging.



I commend this report to you

A handwritten signature in black ink, appearing to read 'R Higgins'.

Raymond (Jim) Higgins
NKF Chairman



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