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General Election Survey inside: the NKF needs YOUR help

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Message from the Editor

A very Happy New Year, and welcome to Kidney Life Spring 2015. These are indeed challenging times as the threats to kidney care continue. The NKF is determined to keep fighting for a fair deal for kidney patients, but needs your help. The General Election is in less than three months time and it is critical that we continue to have committed members of the All Party Parliamentary Kidney Group in the new House of Commons. So please complete and return the three copies of the very important enclosed survey to help us to identify potential supporters among the candidates in your constituency.

It is been rightly said that knowledge is power, and this issue includes articles about raising awareness of non-matched kidney donation, showing how RenalPatientView can both empower and reassure you, and explaining why we need to know about Addison’s disease. We also say our goodbyes to NKF Chairman Kirit Modi, who is stepping down at the AGM in March. Kirit, thank you for all you have done for the NKF.

Last but not least, World Kidney Day 2015 takes place on Thursday 12th March, and we want to hear about your activities so that we can feature them in the next issue of Kidney Life. So please email your reports on WKD—and any other topic you think others would like to read about—to nkf@kidney.org.uk (marking them: For the attention of the Editor, Kidney Life) by 3rd April for the May issue.

NKF Officers: (left to right) Mick Walker - NKF Secretary, Kirit Modi - NKF Chairman, Michael (Bud) Abbott - NKF Treasurer and Jim Higgins - NKF Vice Chairman

Kidney Life has a current UK patient distribution of 24,993. We would like to thank the following for their continued sponsorship of this magazine:

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The NKF Helpline provides all manner of information and over 200 unique NKF information leaflets to patients, friends and family of patients, and medical professionals. All calls from UK landlines are free to the caller. Open from 9am to 5pm Monday to Friday. If you would like to contact Pauline or Andrea who will handle your call in compete confidence and with sensitivity, please call or email them on:

T: 0845 601 02 09  e: help@kidney.org.uk

The NKF/BKPA has 8 Regional Advocacy Officers headed by Nick Palmer who work on your behalf to help you and your KPA navigate the system and tackle any problems you may encounter. You can get in touch with your Advocacy Officer by contacting the NKF Helpline.

T: 0845 601 02 09  e: help@kidney.org.uk

If you want to raise funds for the NKF, plan an event, make a donation to the NKF or discuss leaving a legacy to the NKF please contact Pete Revell (NKF Head of Fundraising).

T: 01263 722287  e: events@kidneynkf.com

If you require a larger print or audio version of the issue, these are available by contacting the NKF Helpline on 0845 601 02 09 (calls from UK landlines are free of charge)
As many of you know, I will not stand as Chairman of the NKF when my current term of office comes to an end in March 2015. This is because my transplanted kidney is now beginning to fail after 13 years. I am getting ready for dialysis at home and also hope to be added to the kidney transplant waiting list. I was very lucky in having a pre-emptive kidney transplant from my wife, Meena, in 2001 and the transplant has enabled me to complete a successful career in education and contribute to the NKF over the last six years. My energy level is now significantly lower and it is appropriate that the NKF has a new Chairman who can bring both new ideas and energy in shaping its future.

Over the last six years, the NKF has continued to improve the provision for kidney patients and developed as an organisation. The main achievements have included:

- Expansion of the Advocacy Team from three to eight officers, with financial support from the BKPA, to cover the whole of the UK.
- Improved communication with KPAs, patients and carers, the general public and others. We have updated our website, increased the circulation of Kidney Life by over 10% to over 24,000 per edition, introduced a monthly e-newsletter called IN TOUCH and established an annual KPA Day. NKF has a Facebook presence and has increased its membership from 52 to 55 KPAs across the country.
- We have continued to campaign, mainly in Parliament through the All Party Parliamentary Kidney Group (APPKG). We published two Manifestos through the APPKG; one on issues facing Black, Asian and Minority Ethnic (BAME) patients and the other on home dialysis therapies. NKF has taken a lead in successfully campaigning against cuts in dialysis tariffs and is currently campaigning against proposals to change the commissioning of dialysis services in England.
- Our Helpline service has continued to develop and now responds to 50 queries on average per week, via phone and e-mail. We have developed several new leaflets and resources: for example on statistical information (produced in partnership with the Renal Registry), acute kidney injury and exercise, and a DVD and leaflet on issues facing Hindu communities. We have also updated our Helpline and Know Your Numbers cards, and these are available to Renal Units, free of charge.
- The Governance of the NKF has improved significantly. We now have annual development and budget plans, both monitored regularly by the Executive Committee. We have established effective Committee arrangements; for example on the NKF Conference and a Finance and General Purposes Committee.
- The Management of the NKF has improved with the introduction of annual appraisal for all staff, a senior management structure and regular meetings among staff teams.
- The NKF has continued to develop partnerships with a wide range of groups and individuals. This includes individual KPAs, the British Renal Society, NHS Blood and Transplant, other kidney charities (through the establishment of the Kidney Charities Group), industry partners, NKF medical advisors, the Renal Registry, the National Clinical Director for Renal Services and the National BAME Transplant Alliance (NBTA).

Kidney patients will continue to face new challenges in the future and I am confident that the NKF will rise to them. I am most grateful for the excellent support I have had from all members of the Executive Committee during the last six years, particularly from current fellow officers: Jim Higgins, Bud Abbott and Mick Walker. I want to thank all NKF staff for their support to me, particularly from the senior staff: Tim Statham, Nick Palmer, Andrea Brown and Pete Revell. I have had sound advice and encouragement over many years from Marion Higgins, our past Chairman, and Frank Howarth, our President. We are very fortunate in having an experienced team of Executive members and staff. We are always keen to welcome new members to join the Executive Committee to bring new ideas and energy.

I have now started working on a smooth transition as my term of office as Chairman comes to an end. My best wishes to the NKF and all of you for the future.

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A message from Kirit Modi, NKF Chairman

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Kirit, thank you for all your hard work as NKF Chairman. We all send our best wishes for the future to you and Meena.
The three main assaults on kidney care are currently:

1. **QOF payments**

   GP’s are currently paid through the Quality and Outcomes Framework (QOF) to identify patients within their practice who may be at risk of developing chronic kidney disease, stabilise them and prevent them progressing to end-stage renal failure. These payments are now to end.

2. **Tariff payments**

   In the NHS every treatment, every bandage, every safety pin is given a Tariff figure, and for those that provide the treatment, that is all they are recompensed. Because of the financial pressure on the NHS, all NHS Tariff payments are to be cut by 2-3%. However for dialysis patients these cuts are 15%—or at least they were until the NKF screamed from the rooftops and got the promise of a re-think. This battle is ongoing.

3. **Commissioning**

   Transplantation and dialysis services have been commissioned from the centre, currently by NHS England. Now the proposal is to pass dialysis down to GP level so that the service is commissioned by Clinical Commissioning Groups (CCGs). This is fraught with danger and the NKF immediately opposed any reckless implementation of this change. The reason for this change remains unclear, but you can be very sure that behind it lies the wish by someone to offload the cost of dialysis on to someone else’s budget. This fight continues.

These are the immediate battles, but even when they are battles consigned to history, the struggle for a fair deal for kidney patients will go on. There will always be challenges and a need for the NKF to step up and take on the authorities or our political masters. A lone patient struggles to make their voice heard. A patient in a KPA has a much louder voice. A patient in a KPA that is a member of the NKF can have a deafening voice—and deafening voices are the only things that stop politicians in their tracks. **Money counts—but the patients count even more.**

Don’t forget! NKF AGM and KPA day on Saturday 28th March 2015 at the Arden Hotel in Birmingham—starting at 10.15 am. For more information tel: 0845 601 02 09 or e: nkf@kidney.org.uk
Early in 2015 Doug, my Dad, is having a live kidney transplant, and Sue, my Mum, is the donor. This sounds terrifying, and it is. It is the culmination of seven years since Dad had a heart attack; of finding out he had a rare disease called amyloidosis; of bone marrow transplants and horrible, horrible chemotherapy; of having to watch this awful thing grind and gnaw at this wonderful man; of some wretched dialysis machine daring to take away hours of each day.

It is also one of the most beautiful things I can imagine. I am simply in awe of the bond between my parents. Over seven years I have watched them develop from just being Mum and Dad to being the most life-affirming people I have ever met. The ferocity of their tenderness would burn you. It is seeing them sat at dinner when they found out they would have a grandson and his middle name would be Douglas. It is Mum happily going into that operating theatre without a moment’s hesitation because Dad needs her to do it, and that he knows that without even asking her she will. It is knowing what love looks like; that when things really are as bad as they could be, there are two stubborn, unbreakable little people willing to fight.

But what it also provides is hope. Hope for our family that we will be on our way back to normal. If everything goes to plan, Mum and Dad should be back and fighting fit, no dialysis hanging over them, no waiting for a transplant call in the middle of the night. However, we also hope that their journey can benefit other kidney patients. In fact, if it were to benefit just one that would be enough. One family that could have a slightly easier time because of the torrid time we’ve had. And we think that raising awareness of non-matched or incompatible live donations is the way to do that. Live donations from non-matches are not common or well known. Not one single person I have told about the operations knew about the possibility of it in advance, with almost all believing it could not be done.

Kidneys are the only organs that can be used in live donations, but these still only make up roughly one of every eight kidney transplants that take place, the rest coming from donor cards. An even smaller fraction of kidney transplants come from donations from non-matched live donors. The reason for this is that they have so little chance of being

Blood group (ABO) incompatible kidney transplants

There is a greater chance of a successful transplant if the kidney comes from a living person rather than a deceased donor. However, in about 30% of cases, the blood groups of the donor and the person who is receiving the organ (the recipient) do not match or are incompatible:

![Blood group (ABO) incompatible kidney transplants diagram](image)

As shown above, donors with blood group AB can only give a kidney to a recipient with the same group, while recipients with blood group O can only receive a kidney from an O group donor. In contrast, donors with blood group O are known as ‘universal donors’ since O blood is compatible with any other blood group, and in the same way recipients with blood group AB are ‘universal recipients’.

In the past, blood-group incompatible transplants (called ABOi transplants after the blood groups) were not possible because the recipient antibodies would immediately reject the transplanted kidney. However, it is now possible to offer ABOi transplants. The process may differ slightly between transplant units, but generally consists of:

- Treatment with a drug called rituximab to help remove the recipient’s antibodies
- Removal of the antibodies from the recipient’s blood with a machine. This is rather like a haemodialysis session and usually lasts three to four hours. The number of sessions depends on the level of antibodies but most people need two to four sessions.

The transplant will only take place when the antibodies are low enough. Anti-rejection or immunosuppressive medication starts around four to six days before the transplant takes place. After the transplant, doctors continue to monitor the recipient’s antibodies, but further treatments are not usually needed to reduce antibody levels.

The results of ABOi transplants are similar to those of compatible living donor transplants: about 90-95% of donated kidneys are functioning one year after the transplant. However, ABOi transplantation is very specialised and is not performed routinely throughout the UK. So check with your kidney unit for the nearest transplant centre with experience in this form of transplantation.

More information on ABOi transplants:

- The British Transplantation Society guidelines for antibody incompatible transplantation include information for patients (click on Guidelines and Standards: Current at www.bts.org.uk)
- Patient information on ABOi transplants is available online from UK transplant centres, such as: Queen Elizabeth Hospital Birmingham (http://tinyurl.com/nv5502c) and Guy’s Hospital, London (http://tinyurl.com/q23puwgy)
What love looks like…giving a kidney

By Stuart Hodgson

Sue and Doug Hodgson with their grandson James Douglas, who was born on 4th December 2014, weighing in at 8lb 14oz.
a viable option, let alone being a successful one. Most people would fail at the first hurdle when being tested for the possibility of a non-matched live donation. For example, my Dad would not be able to donate to my Mum, despite it being different the other way around. So when you’ve only got a 15-minute window to see your doctor—who is two hours behind schedule through no fault of their own and with pages of test results and treatment plans to work through—it’s small wonder that neither side thinks to spend this time talking about this unlikely option.

However, for some people non-matched donation might be an option. It might be the best and only option. For some people, like my parents, it is the option that could have prevented renal failure. That could have prevented Dad having to spend two hours every day hooked up to a machine in the spare room. That could have meant I was sitting down over a seven-year period. That would be worth it because we’ve gone through would be worth it because this unnecessary stress and pain would be worth it, wouldn’t it? All one other family wouldn’t have to.

So what about a poster? Dead simple. “Have you asked about non-matched live donation?” That would be it. There are loads of posters in hospitals. Loads of them in transplant departments. But none about live donations from a non-matched partner. In fact, the department where my parents went didn’t even have “Live donations” written on the room list. It was there, but why would it be advertised?

Non-matched live donation is so obscure and with such a small chance of working that you can’t blame the doctors and nurses for not thinking about it when they are so busy trying to save people’s lives. But what’s important is that for one person it might be the answer, just sitting there waiting to be discovered, just waiting for one person to ask the right question. Now imagine if that question were written in great big letters on a giant poster in a waiting room where this one person, if they are anything like my parents, will spend nearly three months sitting down over a seven-year period. What if, just once, the right person asked the right question and found this beautiful answer? That would be it. We want to create a poster for every kidney and transplant department in the country. That’s it, just a poster, just in case someone sees it. But we also want to raise awareness of the possibility of live donation, and of the life families can enjoy post-operation. This summer, my Mum, brother, sister and I, along with a number of others, are cycling from Paris to Cambridge to do just this. And Dad will be coming along too, although his bike might have four wheels and a sunroof.

We want to raise money to fund our poster campaign and to help the National Kidney Federation, but most importantly we want to benefit that one person. We don’t know who they are or how they will find out. But whether it’s seeing a woman cycle 350 miles after donating a non-matched kidney, or by seeing the poster, or simply by public awareness being raised—if we can put one person down a path they otherwise would not have gone down, then everything will have been worth it.

For more details of how you could take part in the Paris to Cambridge bike ride please visit the NKF web site www.kidney.org.uk/paris-to-cambridge.
We go to the polls on 7th May this year, and in this edition of Kidney Life you will find three copies of a General Election survey.

The purpose of this survey is to identify promises of support from potential MPs individually. It is not about publishing the level of support for a particular topic within any one political party—that would now be illegal under the new Lobbying Act. From these survey forms will emerge the All Party Parliamentary Kidney Group (APPKG) of the future.

All three copies of the General Election survey are for your IMMEDIATE use.

First step
Please enter your own name and address in the top right-hand corner of each form.

Second step
NKF requests that you look up the names of the three candidates in your own constituency with the best chance of winning the seat. Then we ask that you arrange to go and see all three of them at their campaign headquarters. (It may be a good idea to check the names of your candidates and their HQs on the Internet.)

If you really cannot visit any or all of the candidates, then it would be okay for you to post the form with a letter. However, this is very much a second-best solution. The letter should ask for the form to be returned TO YOU

Third step
Ask the candidates to answer the six questions, sign the form and then return it TO YOU (not directly to the NKF).

Fourth Step
Once you have extracted all the information you require locally, put the three forms in an envelope and post them to:
NKF, The Point, Coach Road, Shireoaks, Worksop, Nottinghamshire S81 8BW

All completed forms should reach the NKF either during the election campaign or within seven days of the result being declared (i.e. by 14th May 2015).
An exciting opportunity has arisen to work as Regional Advocacy Officer for the North West of England. The National Kidney Federation (NKF) wish 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 and 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 and covering letter should be addressed to Timothy F Statham OBE at the address above and clearly marked Advocacy Application with the post reference on the application

Closing date 31st March 2015
Every second Thursday of March, we celebrate World Kidney Day (WKD) to raise awareness of kidney disease and highlight the urgent need for action to prevent and treat this serious health condition.

Around 10% of the population suffer from some form of kidney damage, and every year millions die prematurely of complications related to chronic kidney disease (CKD).

World Kidney Day is celebrated worldwide, bringing together millions of people in over 150 countries and uniting them to produce a powerful voice for kidney health awareness. Every year, countless local and national events are organised by kidney charities, healthcare professionals, healthcare authorities, and individuals who want to make a difference.

Since its inception in 2006, the global campaign highlights a particular theme every year, which for 2015 is:

**Kidney Health for All**

Once again the UK initiative is being led by five leading kidney charities including the NKF.

If you’re planning to hold an event on World Kidney Day 2015, please tell us about it by posting it on UK Facebook page www.facebook.com/worldkidneydayuk or email info@worldkidneyday.co.uk. Further details are available through the UK website: www.worldkidneyday.co.uk where you will find support, advice and ideas for activities and downloadable material to help with your event.

**What are YOU doing for World Kidney Day 2015?**

At Kidney Life, we also want to hear about your WKD 2015 activities so that we can feature them in the next issue.

Please email your reports (with your photos please) to nkf@kidney.org.uk by 3rd April, marking them: For the attention of the Editor, Kidney Life.
As the NKF passes its first 30 years, I thought it timely to reflect on the progress and changes that have happened to your charity during the latter half of its existence, the 16 years that I have been your CEO.

Arriving at NKF HQ, I found a largely dilapidated end-of-terrace house full of serious structural cracks, which was being squeezed out of existence by an ambitious garage business. The downstairs two reception rooms were the office, the hallway and stairs were for the computer and the bathroom acted as the print room. The damp cellar, only five foot 3 inches tall, was for the storage of paper, and ringing in my ears were the words of the then chairmen: “We are not immediately broke, but we really exist because of one sponsor, a pharmaceutical company that provides 75% of the £90,000 annual income.” Apart from the enthusiasm of the founding KPAs and the patient members, a staff of four, plus myself, were the main—and from what I could see—the only tangible asset that the NKF had.

Contrast that with today. NKF now has a modern, fit-for-purpose HQ (owned outright) on a secure business park, a staff totalling 19, and annual income in excess of £500,000 and more than £1 million in assets.

NKF successes

But there is no point in a charity existing if the progress and expansion does not directly enhance the objectives of the charity: in our case the lot of the kidney patient. I am pleased to say, that the improvements here easily outweigh the practical matters already explained.

First up was the launch of the All Party Parliamentary Kidney Group (APPKG), initially chaired by Evan Harris MP (no longer an MP following his defeat in the 2010 General Election). Begun with just 20 qualifying members, the group now boasts 129 MPs and Lords. Next was the launch of the Telephone Helpline, a free-to-call service that over the years has benefited more than 41,000 patient callers. Then there was the conversion of Kidney Life from a paper leaflet that looked like a ransom note to the full-colour magazine that you are reading today and is distributed free of charge to 25,000 home addresses of patients.
Finally, but probably the jewel in the crown, was the introduction of the now famous NKF advocacy service. Begun with just one officer to cover the whole of the country, the service now has eight officers (with financial support from BKPA) covering England, Scotland, Wales and Northern Ireland.

NKF’s campaigning successes include the introduction of a Renal National Service Framework, a Dialysis Manifesto, a Transplant Manifesto, a BAME Manifesto and a Home Dialysis Manifesto—all of which have been used to drive up the provision and quality of treatment on offer to kidney patients.

Sadly patient numbers increase, and the campaigning battle is far from over. But I am immensely heartened to see an NKF ready for those challenges and the recognition by KPAs of the essential role that NKF plays in improving kidney patient lives.

The following announcement shows that the campaign by the NKF, together with KPAs, patients and other stakeholders, has reversed the Government’s harmful plans to alter the way dialysis services are commissioned in England. The NKF wants to both thank and congratulate all renal patients and KPAs who played an active part in this campaign. Well done—together we turned back the almost overwhelming tide!

NHS England will continue to commission specialist renal and morbid obesity services in 2015-16 after concerns were raised by organisations including NHS Clinical Commissioners, who said patients could be put at risk if the services were transferred this April. The proposal to transfer responsibility for commissioning these services to clinical commissioning groups (CCGs) will be kept under review, but NHS England says that any changes will not happen before April 2016.

Richard Jeavons, Director of Commissioning Specialised Services at NHS England, said: “We all want what is best for patients, and we have listened extremely carefully to their views and those of CCGs. For the time being we will continue to directly commission these services, which will give us head room to work through the proposals in more detail and address the issues that have been raised with us.”
The National Institute for Health and Care Excellence (NICE) has issued a new Quality Standard on renal replacement therapy (RRT, dialysis and transplantation). It’s especially important for kidney patients and KPAs to know about this new Quality Standard following NHS England’s proposals to transfer dialysis commissioning to clinical commissioning groups (CCGs). This is because the eight concise statements of the Quality Standard define very clearly the standards or quality of care that we should expect to receive from the NHS when we need treatment for kidney failure. This includes important areas of continuing concern for patients and their families, such as pre-emptive transplantation, the availability of home dialysis and the quality of patient transport.

The Health and Social Care Act 2012 sets out clearly that the NHS should consider NICE Quality Standards when planning and delivering services. So the RRT Quality Standard is designed ensure that:

- Commissioners purchase high-quality, cost-effective services that improve the quality of patient care
- Health professionals make decisions about treatment and care based on the latest evidence and best practice
- Service providers can quickly and easily assess the quality of care delivered by their organisation.

The RRT Quality Standard has been endorsed by the NKF and the BKPA, as well the British Renal Society, the Royal College of Pathologists and NHS England. All these organisations have agreed to work with NICE to ensure that commissioners and service providers are aware of and are encouraged to use the Quality Standard.

To find out more about these Quality Statements, go to www.nice.org.uk/guidance/qs72. You can also read NICE’s guidance for commissioners on using the RRT Quality Standard, together with information for the public (http://tinyurl.com/pqf67cb).
We realise not everyone can fundraise by jumping out of a plane or walking up a mountain... Below you will find other ways of supporting the great work of the NKF.

Supporting the NKF each month

A regular donation from you (if you can afford it) will help the NKF to reach each and every kidney patient in the UK below is an indication of how your monthly contribution can make so much difference.

- **£20 a month**
  Will help with the ever increasing printing costs to enable our Helpline to continue to produce, and distribute, patient information leaflets. There are over 150 titles in the Kidney Matters series which are printed “in-house” and distributed, free of charge, to all patients calling our (freephone) Helpline telephone number 0845 601 02 09.

- **£10 a month**
  Will help towards the ever increasing postage costs incurred in sending out information to patients, and renal units nationwide.

- **£5 a month**
  Will help the NKF to spread the word about the importance of Organ Donation

- **£2 a month**
  Pays for your Kidney Life magazine

Become a Friend for Life of the NKF

Whether you are a Kidney Patient yourself, a carer or just a friend who would like to support the NKF in its work supporting kidney patients, please consider making an annual donation to the NKF.

Just send us your name and address (or simply fill in the form overleaf) and post it, together with your donation to the NKF at: NKF (National Kidney Federation), The Point, Coach Road, Shireoaks, Worksop, Nottinghamshire S81 8BW. An annual subscription of £20 entitles you to be classed as a “Friend for Life”. All donations for whatever amount will be acknowledged. Note: Remember to notify us if you no longer pay an amount of income tax or capital gains tax equal to the tax we reclaim on your donations (28p for every £1 you give). Also if you are a UK taxpayer, and complete the Gift Aid Declaration, overleaf, the NKF will be able to reclaim the tax on all donations you make to the NKF.

Leaving a Legacy to the NKF

One way of helping the NKF is to include a legacy to the charity in your will. More than two thirds of adults die without a valid will, which results in their estates being allocated according to the law, instead of according to their wishes.

A will is a legal document, so it’s best to get the advice of a solicitor to make your instructions legally valid. To find a solicitor you can look in the Solicitors Regional Directory which is available in your local library. You will find more information to help you make your will at: www.solicitors-online.com & www.make-a-will.org.uk. The NKF Helpline on 0845 601 02 09 can give you advice on how to include the NKF in your will.

There are now three ways to pay the NKF

- **Option 1**
  Online at www.kidney.org.uk - Book or pay here using a credit or debit card

- **Option 2**
  Place your order using a Credit or Debit Card by Calling 01909 544999

- **Option 3**
  Pay by direct debit, fill in the form overleaf and return to the address at the bottom of the page.

For all of those of you who are giving or going to give. All the staff at the NKF would like say THANK YOU... You really are making a difference.

Look out for the Direct Debit form overleaf.
Direct Debit instruction

Name: .................................................................................................................................................

Address: ................................................................................................................................................

............................................................................................................................................................

............................................................................................................................................................Post Code: ..........................................................................................................................................

I would like to donate £ _____ every Month/Year (Delete as appropriate).

First donation to start Month: ............... Year: ............... Your direct debit to be withdrawn on the 20th of the month

Please claim Gift Aid on my donation. I confirm that I am a UK tax payer and have paid income and/or capital gains tax at least equal to the tax to be reclaimed in this tax year by the charity. I agree that Gift Aid can be claimed on all donations that I have made in the last four tax years, and all donations that I will make from this date until I notify you otherwise. I understand that I must pay an amount of income tax and/or capital gains tax in each year at least equal to the tax that the charity will reclaim from the HMRC on my gift aid donations.

Name of account holder: .................................................................................................................................

Bank sort code: [Blank] My account no: [Blank]

Name and full postal address of your bank: To the Manager: ..................................................................................

...............................................................................................................................................................Post Code: ..........................................................................................................................................

Signature: .................................................................................. Date: ........................................................................

Originators Identification no:

Instruction to your bank

Please pay National Kidney Federation Direct Debits from the account detailed in this Instruction subject to the safeguards assured by the Direct Debit Guarantee.

NKF Bank details:
Sort code: 306776 Account Number: 43986268

Please return to: National Kidney Federation, The Point, Coach Road, Shireoaks, Worksop, S81 8BW
Charity No 1106735 Company No 5272349 Registered in England & Wales
Why you need to know about Addison’s disease

Addison’s disease—named after the doctor who first described it—is a chronic problem associated with the adrenal glands. These glands sit on top of both kidneys and their name comes from Latin: ad (near) and renes (kidneys). The adrenal glands are responsible for releasing hormones (and are therefore called endocrine glands) such as corticosteroids and catecholamines.

Former US President John F. Kennedy was a famous sufferer of Addison’s disease, which is a primary problem with adrenal insufficiency. This means that the adrenal glands themselves fail to release sufficient or any amounts of cortisol, but there are many reasons why adrenal insufficiency can occur. The adrenal glands may get destroyed from autoimmune disease (this is Addison’s disease), infections, haemorrhage or cancer spread. Rarely, some individuals may have genetic abnormalities so they don’t have properly working adrenal glands (called adrenal dysgenesis).

Kidney patients at risk

Kidney patients are at risk of adrenal insufficiency due to variety of reasons but the commonest are probably secondary causes such as steroid withdrawal. Many renal patients will be taking (cortico)steroids, either because they have inflammatory kidney diseases or have received a kidney transplant. If we are taking steroids for a long period of time, our adrenal glands stop producing the natural corticosteroid hormone cortisol (important for fighting illness and coping with stress).

Below a certain threshold dose of steroids, our adrenal glands will start to produce cortisol naturally again and take over. However, the glands need time to do this and this explains the importance of not abruptly stopping steroids as your body is relying on the steroid tablets to get enough cortisol. It also explains why steroid doses are often increased if you are feeling unwell, as your body requires more cortisol to cope. In both circumstances, there is a risk of adrenal insufficiency.

Adrenal insufficiency

Adrenal insufficiency is characterised by very non-specific symptoms but they can include any of the following: weakness, tiredness, abdominal pain, nausea, weight loss, diarrhoea, constipation, dizziness, confusion and/or irritability. On your investigations, doctors may notice some of the following: low blood pressure, high calcium, high potassium, low sodium, low glucose and/or increased blood acidity.

In certain circumstances adrenal insufficiency can become severe enough to progress to an ‘Addisonian crisis’ that involves very low blood pressure, shock and coma—this is a severe illness that can be life threatening unless quickly recognised and treated.

Although signs and symptoms will give clues, doctors will sometimes ask for a ‘short synacthen test’ to assess the function of your adrenal glands. It works by testing the natural response of cortisol production from your adrenal glands to a ‘stress’ (synacthen is a hormone that stimulates the adrenal gland). Doctors will then interpret the cortisol levels in your blood as a response to the synacthen to see whether you have adrenal insufficiency or not.

The best way of managing adrenal insufficiency is to be aware of the risk and to carry steroid cards if you are currently taking these tablets to alert any healthcare professional. It is very important that steroid tablets are not missed and doses may need to go up if you are unwell (sometimes this has to be given by injection if you are very ill and not able to eat and drink). The primary focus is to replace the hormones that are missing and often you may also need additional hormone replacement on the advice of your doctor (this would depend upon your blood tests and other signs and symptoms).
We need YOU

Last year the NKF saw a record number of people taking part in sponsored events to raise vital funds for the charity. In 2015, we want to encourage even more people to go that extra mile so we can support kidney patients right across the UK.

On our website at www.kidney.org.uk/fundraising/ you will find a vast range of events.

If you are into cycling, 2015 offers so many different events and dates. These include a special cycling event from Paris to Cambridge that has been organised by a lady who is donating one of her kidneys to her husband (see page 6). We also offer a very popular London to Paris ride. Not only has this event been reduced in price, but we also have a few dates to choose from.

As you will see from our website, we offer so many ways that you can help the NKF with fundraising: from cycling to running, walking and even a Tough Mudder event*. But if you fancy organising your own event, however large or small, our events team are on hand to offer you support, advice and take any hassle out of the planning side.

Everyone who raises money for the NKF receives a fundraising pack that includes sponsor forms, promotional material and a guide to setting up a Just Giving Page.

Please call the Fundraising office on 01263 722287.

*In case you, like us, were wondering what a Tough Mudder event is…it’s a military-style obstacle course that’s designed to test your team’s mental as well as physical strength. Definitely something to go for if you like a challenge!

Spring clean your wardrobe for the NKF

If you would like to raise funds for the NKF and make space in your wardrobes and cupboards at the same time, why not try Clothes for Charity? Sue Lyon describes her experience.

I prefer to recycle clothes through a charity rather than simply putting them in the council recycling dumpster, but we don’t have a shop nearby and charity bags left outside the house have been stolen. So I was delighted to learn that I could donate unwanted clothes online and help the NKF at the same time by using Clothes for Charity.

It was really easy. I registered on the Clothes for Charity website, nominated the NKF as my favourite charity and requested a donation bag, which arrived by post. I was a bit worried at first as it’s a big bag, and I needed to fill it up to at least 75% to ensure the maximum benefit for the NKF. The bag must also weigh at least 15 kg to be collected by courier.

However, I had no problem filling the bag. Clothes for Charity will accept clothes, shoes, bags, belts, jewellery and other accessories as well as towels and sheets, as long as they are in good, usable condition. My neighbour was keen to help and soon I had a 16 kg bag full of things I hadn’t worn for ages (including some of those mistakes that look good in the shop, but not when you get home!). I arranged a courier collection via the Clothes for Charity website, and a few days later received an email to let me know that my bag had arrived safely.

To find out more about Clothes for Charity, visit www.clothesforcharity.org.uk
After all these cold dark nights and the nasty winter weather, I think we are all looking forward to the summer.

On Thursday May 7th one lucky person will have £2,000 to spend as they wish—maybe you are thinking about a summer holiday, a garden makeover or just paying off the bills.

This could be YOU, because £2000 is the first prize in the NKF Summer Draw. Inside this edition of Kidney Life you will find three books of raffle tickets to purchase and help support the vital work of the NKF.

If you would like more tickets, don’t hesitate to call Pete Revell on 01263 722287.

Thank you to everyone for supporting the NKF and kidney patients throughout the UK!

Don’t forget! NKF AGM and KPA day on Saturday 28th March 2015 at the Arden Hotel in Birmingham—starting at 10.15 am. For more information tel: 0845 601 02 09 or e: nkf@kidney.org.uk
Receiving a transplant can bring relief after potentially years of ill health. However, it can also bring a heavy responsibility to care for that transplant, keeping it healthy and working for as long as possible. In my experience, those who are most likely to enjoy a longer period of good health are the ‘expert’ patients.

What does an expert patient look like?

An expert patient is one who is willing to learn from, listen to and work with their transplant team. There can be a lot to take in after receiving a transplant; various health carers will each be doing their best to equip you with the information and advice needed to keep you and your transplant as healthy as possible.

Being an expert patient does not mean knowing everything, but it does mean asking questions and doing your best to take advice on board. The time you have with your healthcare team can be limited. Therefore, it is important to go to your appointments prepared with any questions you have and be ready to discuss anything that is proving a challenge for you in terms of caring for your transplant.

Most patients will sit somewhere between struggling to adjust to life with a transplant and being an expert patient. Behaviours and attitudes towards health after transplantation can depend on many things. For example, how long it is since transplantation, how settled home life is and how many other illnesses have to be managed. Keeping a good channel of communication open between you and your transplant team can help to minimise the impact these factors could have on the continued care of your post-transplant health.

What are the benefits of being an expert patient?

Expert patients are more likely to take all their medications as agreed. It is known that patients who do not adhere to their medication schedule are at a higher risk of rejection of the transplanted organ.1

- Expert patients ask what their medications do for them; because they understand the benefits of their medications, they are more likely to make sure they take them1
- Expert patients make informed decisions when presented with various treatment options. For example, if offered once-daily versus twice-daily immunosuppression, expert patients understand the positive impact that fewer tablets could have on their medication taking2

- Expert patients are honest with those involved with their post-transplant health. They do not tell their transplant team or family members what they think they want to hear. Instead, they discuss any issues they are having and try to find solutions.

Whilst the most obvious motivation for being an expert patient is to avoid failure of the transplanted kidney and a return to dialysis, there are many other benefits. These include:

- The opportunity to spend quality time with their family, and to minimise the burden patients feel they pose if they were to get ill again
- A wish to get back to their careers without needing to take sick leave
- A desire simply to eat and drink without such strict restriction as when they were on dialysis.

How can you become an expert patient?

With the right support, everyone has the potential to become an expert patient. This support could come from your family, your GP or your transplant team.

There are many challenges that you may face on the journey to becoming an expert patient. For example, you may have a busy family or working life, and feel you do not have time to think about your health and your transplant; there might be language barriers to understanding all the information and advice you are being given; or you might simply want to avoid feeling as though your life is dominated by your transplant.

Being an expert patient requires ongoing attention.

Throughout your life with your new kidney, transplantation and treatment options will improve and your needs will change too. By drawing on the knowledge and advice you are offered, you can help your transplant team to provide the best long-term treatment for you.

So in answer to the question:
Are you an ‘expert’ patient?

You could be!

1 Transplant International 2005;18:1121-33
2 Patient Preference and Adherence 2014;8:73-81
This article has been sponsored by Astellas Pharma Ltd
EuroCYST: building a network of European ADPKD study centres

Autosomal dominant polycystic kidney disease (ADPKD) is the most common inherited kidney disease, affecting about 600,000 people in Europe. However, much remains unclear about the disease.

The EuroCYST initiative includes 14 kidney units and genetics centres across Europe including the UK. It aims establish an observational group of ADPKD patients to study factors influencing the rate of and possible predictors of disease progression, patient outcomes, and possible ways to modify the disease.

EuroCYST aims to enrol 1100 patients who will be followed for least three years. To be included, patients must have clinically proven ADPKD and an estimated glomerular filtration rate of 30 and above, and should not have been involved in a drug treatment trial one year before enrolment.

For more information on EUROCYST go to http://tinyurl.com/o8qh7um

Nephrology Dialysis and Transplantation 2014;29 Suppl 4:iv26-iv32

Special care needed for post-transplant pregnancy

Women who have had a kidney or liver transplant are just as likely as other women to have a successful pregnancy, with 75% of all pregnancies ending with live births.

This study also found that the risk of rejection and organ loss after delivery is about 10%. It is slightly higher in liver transplant recipients than kidney recipients, but it is rare to lose the transplant directly because of pregnancy. However, the researchers emphasis that women who become pregnant after transplantation need special care:

• Strict control of high blood pressure to reduce the risk of pre-eclampsia and raised blood pressure after birth
• Screening for infection
• Immunosuppressant drugs that will not harm the baby
• Supplementation with vitamin D and iron to lower the risk of preterm delivery.

Best Practice Research Clinical Obstetrics and Gynaecology 2014;28:1123-36

Safe to expand UK altruistic donor programme

Unspecified (non-directed altruistic) kidney donation (UKD) is becoming increasingly common in the UK, but the motivation of these donors has been questioned and there are concerns that they may suffer long-term problems. This study shows that UKD have similar outcomes to people who donate to a relative, spouse or friend (specified kidney donors; SKD), and that the programme can continue to expand safely across the UK.

Based on 190 responses to a survey of living donors (110 UKD and 80 SKD):

• UKD are older (54 versus 44 years), predominantly white (99.1% versus 78.5%), and donated more recently (1.3 versus 2.6 years)
• There is no difference between UKD and SKD in their psychiatric history or personality type, current depression, anxiety, stress, self-esteem, or wellbeing
• There is no difference in the physical outcomes of donation, although UKD recover more quickly
• Very few donors regret their decision to donate (3.7% UKD versus 7.5% SKD).

Transplantation 2014;98:1182-9

Buttonholing is not always best

Buttonhole needling should not always be first choice for people on hospital or home haemodialysis (HD). This conclusion is based on 23 studies comparing the buttonholing with rope-ladder needling of arteriovenous fistulas.

After reviewing the evidence, the researchers found no difference between buttonholing and rope ladder in the amount of needling pain. However, compared with rope ladder, buttonholing appeared to be associated with an increased risk of local infections at the needling site and systemic infections affecting the patient’s whole body.

American Journal of Kidney Diseases 2014;64:918-36

Belatacept better for kidney transplants?

An analysis by the respected Cochrane Database shows that belatacept has some advantages over calcineurin inhibitors (CNIs; ciclosporin and tacrolimus), but concerns remain about its side effects. Belatacept is the latest anti-rejection drug to become available in kidney transplantation, and is given by a 30-minute infusion into a vein every four weeks.

After reviewing five studies comparing belatacept with CNIs and including 1535 kidney transplant recipients, the researchers report that up to three years after transplantation:

• Belatacept and CNI-treated recipients have a similar risk of losing their kidney transplant and returning to dialysis, and having an episode of acute rejection
• Belatacept-treated kidney transplant recipients are 28% less likely to have chronic kidney scarring and more likely to have better kidney function than CNI-treated recipients
• Blood pressure and cholesterol are more likely to be lower with belatacept than with CNIs
• The risk of new-onset diabetes after transplant is reduced by 39% among belatacept-treated compared with CNI-treated recipients
• Risk of post-transplant lymphoproliferative disorder (PTLD) appears to be similar in belatacept and CNI-treated recipients.

The researchers comment that belatacept seems to have some advantages over CNIs. However, the evidence concerning the precise risk of the serious side effect of PTLD with belatacept has been poorly reported to date. It also remains unclear whether belatacept’s advantages will be maintained and will translate into better long-term transplant survival. Longer-term, fully reported studies comparing belatacept with tacrolimus are needed to determine which patients might benefit most from using belatacept.

Cochrane Database of Systematic Reviews 2014;11: CD010699

Want to know more?

The source of the studies is listed by publication title, year of publication, volume and page numbers (or for early-online studies: first author’s family name and initials, publication title, date). For more details about a study, go to www.ncbi.nlm.nih.gov/pubmed/citmatch. Complete the boxes and click ‘Search’. There may be a link to the complete article, but access may involve a fee.
Why YOU should join (Renal)PatientView

I would like to write about my experiences of using RenalPatientView (RPV, now called PatientView), but before that I will give a quick background. I have had kidney failure for 50 years and 27 years ago started CAPD. I had a transplant that failed in 1991. I was then on dialysis for 20 years. Hospital haemo, CAPD, home haemo and a transplant—all the treatment modalities!

I have just looked at my figures on RPV and the earliest result is from January 2005, and I have accessed it regularly since then. I was living in Edinburgh when the website began. Professor Neil Turner, who is still involved with RPV, was my Consultant and his staff often asked patients for their views and they have been steadily improving the system ever since.

I think it was in 2009 that I went with my husband William and another dialysis friend to a conference in Manchester, and found professionals’ reactions to RPV most interesting. One memorable quote and an example of dedicated staff not seeing the wood for the trees is that their research showed that patients log in more than any other time during the first two days after their bloods are taken! Do!!!

Over the years, professional attitudes to RPV have changed from scepticism to enthusiasm. The assumed resistance from a mainly elderly, not computer literate group of patients has been shown not to be true. The other physician fear was that the system would generate a renal army of hypochondriacs has also proved not to be true. Indeed, countless hours have been saved as well as possibly my transplanted kidney.

Shortly after my transplant I was having a period of rejection. We identified that my creatinine was rising 24 to 48 hours after my tacrolimus levels, which were higher than average. My consultant wanted a biopsy, but I agreed that I would have it as a last resort as we had identified this trend. My consultant knew this could not cause rejection, but went through the records again and discovered that he had missed that my calcium was high, which can cause high creatinine.

When travelling in Europe using holiday haemo slots, it has been useful to access RPV to show bloods and other information that the Holiday Co-ordinator may have missed. In France, Holland, Germany and Denmark the units have been so impressed with the system and wished it were available locally. The only missing test is MRSA but there has been discussion about including this over the last decade.

During an emergency hospital admission on the Costa de Sol in Spain, I shared my results and medication, and the doctors have found this a great advantage. RPV is the tool that is taken seriously abroad, and has allowed good communication between the overseas Emergency Department and the On-Call Renal Registrar in the UK.

I have used RPV since its inception and without it I would have been much more worried. Having kidney failure is not easy, but seeing good results is reassuring and bad results empowering in that I can take action before it is too late. I cannot imagine life without it.

If you have not yet joined RPV and would like to find out more, go to www.patientview.org

From RenalPatientView to PatientView2

RenalPatientView became PatientView in late 2013 when the system began to be extended beyond kidney disease. PatientView2 works in just the same way as before, but has been redesigned so that it is easy to use on tablet computers and mobile phones (half of all log-ins are now through these devices).

What’s different?

On PatientView2, the first view of your Results is shown as a series of numbers rather than as a table. You can see each result as a graph by clicking on ‘View more details’ under each number. If you prefer, you can still see a table of your results by clicking on ‘Table View’. It’s now possible to choose the results that you see, and in what order.

PatientView2 does everything that the old system did but does them much better. There are lots of exciting plans for PatientView2, so we definitely all need to ‘watch this space’!
Mermaid Dialysis Unit

Whether you’re looking for a relaxing beach holiday or want to explore the diversity of East Anglia there is something for everyone.
The North Norfolk Coast is famous for its long, sweeping beaches, wonderful walks, bird watching, seal trips, golf courses, historical estates and much more all on your doorstep.

The Unit, which forms part of the Wells Community Hospital Trust, is situated on the outskirts of the picturesque town of Wells-next-the-Sea and is staffed by experienced Renal nurses and health care assistants. We now offer not only Haemodialysis (HD) but Haemodiafiltration (HDF). Each station has its own individual television and free wifi.

“efficient staff, bright and comfortable surroundings”
“amazing unit, good communications, kind and very professional staff”
“one of the best units I’ve been to”

For more information contact us on 01328 711396 Or email us on mermaid.dialysis@wellshospital.org.uk
Please take a look at our web site www.norfolk dialysis.com Charity Reg No: 1154540 CQC No: 1-302830763

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The unit’s facilities offer the following:

- Eight station unit with dialysis facilities all year round
- Opening times are 8am to 7pm (Monday-Saturday)
- The unit is staffed by well trained nurses and the Director, having over 35 years experience in this area of care, ensures a warm and friendly atmosphere is maintained at all times
- Direct online booking so patients can check availability and book at a pace that suits them
- Benefit from staying at a private facility which is covered by NHS funding for UK patients (please double check with your unit whether they fall under this scheme)

Now you can book your dialysis and accommodation all in one place!

Our unit now offers 3 newly refurbished self catering holiday apartments for our patients. So now patients have the peace of mind knowing they can book their treatment and self catering accommodation all at the same time, whilst remaining close to the unit and the beach.

To celebrate our 20th anniversary we are offering patients the change to win a free one week stay in Bournemouth. Either at one of the reputable hotels in Bournemouth town centre or, if you prefer self catering, one of our newly refurbished holiday apartments.

For more information please go to
www.kcdialysiscentre.com/prizedraw/
or contact us directly.

For further information telephone 01202 422311
www.kcdialysiscentre.com • admin@kcdialysiscentre.com
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