Why I gave away one of my kidneys
by Claire Ramsden

Mat Dibb...on the road to a transplant...

Participants needed for research into experiences of kidney checks in primary care

Why I am joining the NKF
by Nina Wadia
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Kidney Life has a current UK patient distribution of 22,000. 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 complete 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: 01480 389791 e: events@kidneynkf.com

Nina Wadia joins NKF as Patron.
We would like to extend a very warm welcome to Nina Wadia (actress) who has accepted our invitation to become a Patron of the NKF. Nina’s personal connection to kidney failure can be found on page 11. We all look forward to working with you Nina!

Message from the Editor
Welcome to your Spring 2014 issue of Kidney Life and a brand new year. 2013 saw a shift in the way much of our care is organised and Dr Richard Fluck took up the post of National Clinical Director of Renal Services in the UK to oversee the implementation of these changes. Kidney Life went to visit him in Derby to talk about his plans for our future care. This very interesting interview can be found on page 6 and is well worth a read. Black, Asian and Ethnic Minority group’s (BAME) matters have also come into sharp focus and Kirit Modi, our chairman has written a report on the impressive progress being made here too.

And it seems that many of you who got the fundraising bug in 2013 are upping the ante in 2014 and planning even greater challenges to raise even more funds to help the NKF draw attention to the plight of kidney patients in the UK and enable it to continue to press for improvements in our care. We could not do this without you...so thank you! Don’t forget World Kidney Day is 13th March this year. Please send in as many pictures of what you and your KPA did to mark the day and we will do our very best to print as many as possible in the Summer issue of Kidney Life. The deadline for contributions to the next (Summer) issue of Kidney Life is 11th April. We’d love to hear from you.

Deborah Duval
Editor
Following the success of our KPA day last March, we are very pleased to invite KPA representatives to our second KPA day. The KPA Day for 2014 will take place on 29 March 2014, between 10.15 am and 4 pm, and will be held at the Arden Hotel, Coventry Road, Bickenhill, Solihull, Birmingham, B92 0EH.

The format of the day will be as last year. There will be presentations from representatives from other KPAs on ‘What my KPA does’, an update on the arrangements for opting out in Wales, and we will hear from our Advocacy Team, our Helpline Manager and our Head of Fundraising on what a typical day for them might be; as well as an opportunity for general discussion about the NKF’s work. We will, of course, have our AGM and a Council meeting during the day, details of which are below.

YOUR KPA Day 29th March 2014

There is no charge to attend this important KPA day but KPAs will need to fund any travel expenses incurred by their own representatives attending. The NKF will not pay for any travel costs this year. We hope as many KPA representatives will join us for this important event in the NKF/KPA calendar. A pro-forma will be sent to all KPAs to confirm their attendance numbers. May we please ask that this completed form is returned to NKF Headquarters marked for the attention of Margaret Parkin by 7th March 2014. See page three for NKF HQ Address and contact details in case of any queries.

Nearest Railway Station – Birmingham International (not Birmingham New Street) - only a 2 minute taxi-ride to the Arden Hotel.

NOTICE is hereby given of the Annual General Meeting of the National Kidney Federation – 29th March 2014

Henley Suite, Arden Hotel Birmingham

1 Full Member Associations may send representatives.

2 Associate Members, Affiliated Members and Friends Members may attend and may speak on non-policy matters, but are not entitled to vote.

3 If the official representative of any Full Member Association is unable to attend, then a substitute representative may attend and vote on behalf of that Association: Written notification of the substitution to be given prior to the meeting. The Council shall consist of one representative from each Full Member Association. At the AGM the Council will elect the Executive Committee. Up to three Executive Committee members may be individuals who are members of the Federation, but not members of any member Kidney Patients’ Association. Any such individual must have their nomination proposed or seconded by one of the current Trustees. Any individual who is a member of a member KPA may stand for election to the Executive Committee, subject to a maximum of two individuals from any individual KPA. All nominations must be proposed, seconded and submitted in writing to the Federation to arrive no later than 42 days before the date of the annual general meeting.

4 Either the proposer or seconder MUST be a member of the nominee’s own KPA. No individual may propose or second more than two nominees for election to the Executive Committee in any one year.

5 Full and Associate Member Associations may propose candidates for election and may submit propositions and items for the Agenda.

6 The Executive shall consist of not less than 11 and no more than 16 members elected by representatives of Full Members of the Federation, including a maximum of 6 officers. All Trustees shall retire annually, but are eligible for re-election provided that no Trustee may serve for a period of more than seven consecutive years except in respect of existing officers who wish to continue beyond the seven years limit in order to complete a three year term of office to an elected position already held. No individual shall be eligible to stand for election as Chairperson until he or she has served for at least 12 months as a Trustee. No KPA shall have more than one person who is a member of that KPA serving as an officer of the Executive Committee. Ballot papers shall be given to Full Members at the annual general meeting and the counting of the ballots will take place at such meeting. The election of Trustees shall be carried by a simple majority of the votes cast and in case of equality of votes the Chairperson shall decide between those candidates by lot, and proceed as if the candidate on whom the lot falls had received an additional vote. The Chairperson shall announce the results at the annual general meeting. Where there are no more nominations than vacant posts the candidates shall be declared elected at the annual general meeting without the necessity of a vote.

7 All nominations must be accompanied by a brief statement supporting their candidature together with a signed “Charity Trustees Eligibility form.”

8 The quorum at an AGM shall be 30% of Full Member Associations’ representatives.

ALL NOMINATIONS MUST BE SUBMITTED IN WRITING to the Federation at: The Point, Coach Road, Shireoaks, Worksop, S81 5BW - TO ARRIVE NO LATER THAN 10 FEBRUARY 2014

The agenda will be circulated to each member association representative no later than 3rd March 2014

Full copies of the Memorandum and Articles of Association are available upon request
Kidney Health Matters—help reduce the risk to your kidneys

Despite the Kidney Alliance disbanding, plans for World Kidney Day 2014 in the UK are continuing at full steam. The five charities, NKF, KRUK, BKPA, Kids Kidney Research and PKD (now collectively known as Kidney Charities Core Group) immediately formed a working group to pick up where the Kidney Alliance left off. Each of the five charities plan to have pages on their own website devoted to WKD. This in addition to the usual WKD website at: www.worldkidneyday.co.uk - shortly to be brought up to date and will include support, advice and ideas for activities and downloadable materials.

Please keep checking this website, or the NKF website, for the latest messages and materials to use. But above all start planning your events now. We want every KPA, every hospital, every renal unit, every willing company and every reader of Kidney Life to put something on that will draw public attention to kidney disease, what can be done to protect kidneys before disease strikes, and assist patients who already have chronic kidney disease (CKD).

For further information please email: info@worldkidneyday.co.uk or check out the Facebook page by searching for World Kidney Day UK. If you use Twitter, follow @kidneydayUK and @NKF_UK and use #worldkidneyday and #reducekidneyrisk

Make Thursday March 13th COUNT!

World Kidney Day planning continues apace!

Wear your T shirt with pride!

The NKF has a new range of T shirts to promote kidney donation and transplantation. If you are a live donor, the one you will need says ‘I gave the gift of life’ and for those of us lucky enough to have received a transplant/s then we will be ordering the T shirt that says ‘I received the gift of life’. The T shirts cost £10 each and are available from the NKF online shop at http://store.kidney.org.uk/ or by calling the NKF Helpline on 0845 601 02 09 (freephone from all UK landlines).

I will be wearing mine on WKD..will you be wearing yours?
Have you taken over from Donal O’Donoghue in exactly the same role?
No. Donal was employed by the Department of Health (DOH) and I am employed by NHS England. So the important thing for people to realise is there has been a shift in how the NHS is organised. And this is an important thing for people to realise on an individual basis. So, we still have a DOH and we still have a Health Minister but we have a new body called NHS England and this new body is responsible for running the NHS within England on a day to day basis. The idea behind this shift was to free the NHS from as much political influence as possible. So now the DOH and the Minister agree a mandate of standards NHS England should be working on over the next year or so, and it is for NHS England to go away and deliver these. This way NHS England can put clinicians and patients at the forefront of the decision making process. This is an important change and one that is as good a change for the clinicians delivering the care as it is for patients, who can now share as many of the decisions affecting their care as they feel able to. This is an important change and a big step forward for us all.

How does the new structure work?
As one of 24 National Clinical Directors appointed in April (2013), I have been appointed into a role that works within NHS England. All 23 of my contemporaries and I report directly into Sir David Nicholson (Chief Executive NHS England) and Sir Bruce Keogh (NHS England’s National Medical Director) via a group of Domain Leads. So in this framework, not only am I reporting into Sir Bruce Keogh on all matters concerning kidney care but I am now going to be working with other Clinical Directors charged with the care of patients with conditions that are associated with kidney problems. So this means I will be working alongside the Clinical Directors of conditions such as heart disease, stroke and diabetes because we are the four National Clinical Directors who work around the cardiovascular agenda. Most patients will identify the common link here. Diabetes is the single most common cause of kidney failure in the Western World.

How does this strategic change affect the information and choices available to a patient as he or she is referred into formal kidney care by their GP?
Well there are multiple ways that people realise they have kidney disease. The first of these is how we improve the early detection and care of chronic kidney disease (CKD). So there are already lots of things that people are already aware of - NHS Health Checks for instance. We need to look at the ways in which GPs manage people when kidney disease has been identified in a Health Check. And this must mean that if a specific kidney problem is identified, we need to ensure that that patient is referred to a kidney specialist with specific knowledge of that kidney problem. Then we need to empower patients and empower carers at an early stage to understand more about this condition and the choices available to them so that they can manage more of their condition on a day to day basis themselves. This will undoubtedly improve outcomes. So, for instance we would encourage people to sign up to Renal Patient View. This facility allows people to better understand how and at what pace their condition is developing, and what effect their attempts to assist in their own management is having on their results and overall wellbeing. So this is all about shared decision making. Rather than us sitting on one side of the desk telling people what they should be doing about tackling their kidney disease, we are all looking at the same information and data and empowering people to share the responsibility of how best to manage their condition. This makes for a much more dynamic relationship. There will always be challenges and it is up to us to frame those challenges in a way that the patient feels they can set out a plan of what they themselves want to, or need to achieve in their life and then make the management of their condition fit into these parameters.
How well are we doing in the move to facilitate dialysis at home where this mode of dialysis is a patient’s choice?
Well there is a lot of work still to be done; we are not going to solve inherited problems in just 7 months. But what I do see happening as a result of improved patient involvement is a move in the right direction but do I think we are anywhere near delivering the right solutions for individuals? No, we have a long way to go. And it is not simply a question of getting people onto home dialysis. It’s about seeing if we have the right people and number of people doing PD (peritoneal dialysis). Do we have enough people having appropriate transplantation – be that pre-emptively or when they have been established on dialysis? Do we have the appropriate people doing conservative care and do we understand what that means? So there is a lot on the medical front and on the caring front for us to understand and around this we also need to understand the organisational and structural supports that allow us to deliver the right things. I like the model of the ‘House of Care’ (see below). This has two pillars side by side. One is the clinical domain and one is the patient
domain and then the commissioning processes as the floor and the roof is the organisation and information. And in the very centre of this is the patient and the care plan; something we have all bought into. So we have moved from a strategic plan to a place where we look at you as an individual and ask ‘what does YOUR care look like?’

What drives you to see this through?
I have been a clinician for 25 years looking after people with kidney disease and this is the bed-rock of what I do. So I see this plan through the eyes of a clinician. Here, (Derby) we have a large percentage of patients on home (dialysis) therapies but there are unexplained variations from centre to centre across the UK.

How do you get to a point at which you can offer the optimum treatment for kidney disease unless this can include the option of a timely transplant as an option to dialysis?
I see this as a case of offering A, B or C. A being: ‘let’s keep your own kidneys going for as long as possible’. So into that option we look at lifestyle – stop smoking, get plenty of exercise and adopt a reasonable diet. And as for medical intervention we need to control high blood pressure, and if you have diabetes that too needs to be brought back under control. Plan B is about the transplantation option. We need to know whether you are suitable for a transplant and are there people around you who are prepared to step up to the plate and offer a kidney? If the answer to both those questions is yes, then we need to evaluate both the donor and the recipient with a view to the transplant taking place before dialysis is needed. But not too soon; there is no point in transplanting too early when there is sufficient function left in a native kidney to last four years. And then plan C is what are
Getting to know you…continued

we going to do about the question of dialysis? Do you want to dialyse? If not then we need to discuss conservative care. If you do want to have dialysis then what is that makes you tick in terms of choice of treatment type and location of treatment. That is a shared decision process. I might tell you about the mortality risk of doing X, Y or Z in terms of mode of dialysis but you might need to be at home to ferry the children to school and to pick them up again, or you might have a job and dialysis needs to fit in around that. So the whole of the clinical team need to get out of this habit of thinking simply around the ‘dialysis box’ and more about how do we fit the dialysis need or transplantation need to the life of this person? This is a two way dialogue and doesn’t happen in just one meeting.

How do you make this happen for patients?
I have been working with Tim Kelsey who heads up Patient Participation and Information Technology for NHS England on a big project that is designed to tease out the answer to the question ‘how do we get more people activated and involved in their care?’ How will we do this? By using modern information technology where appropriate; by understanding the work that has already taken place; by understanding shared decision making and understanding shared care and home therapies and how do we communicate the risks and benefits of these therapies in an unbiased way.

What patient experience would you like to see evolve?
Well, we need to get those people with early CKD who may not see a nephrologist, into a care plan that gets them into the mind-set that they actually have control over their life and have a degree of responsibility over their care. The majority of people with early CKD do not progress into end stage renal failure, but for those who do you add bits to their own care plan which you simply plug in when things become relevant to them. It’s a long haul to get to this point but the idea is that you get to a point where the patient is the keeper of the medical information; it becomes their product; they own it, they influence it and they bring it to the people who need to support them. And now much of this dialogue can be delivered via digital media for those patients who have embraced this technology. I also want clinical teams to understand that what might be an important outcome for me as a clinician is not necessarily the prime outcome for the patient. So doctors might talk about mortality whilst patients might prefer to know how long they can expect to live but also, and more importantly how this will all intrude on their life. So carrying this forward you could see patients understanding at a very early stage of their CKD that if they go out and start to exercise perhaps and start to take control of their diet, they may very well never require treatment for end stage renal failure. And I know of several cases where this has happened.

What are the three most important messages you would give to a reader of Kidney Life?

Number one: take control. Want to know what is happening to you. Use tools like Renal Patient View and be active in your discussion with your clinical team. Don’t just stick with the medical model of care; tell people what you want out of life.

Number two: I want to see people who are affected by kidney disease (both patients and carers) to be much more involved in the decision making process about how we organise things. So get actively involved in whatever groups support your renal unit locally and take an interest in what is happening regionally and nationally. Find out how to join your local Kidney Patient Association and make yourself known to them. Volunteer to sit on unit steering committees. Groups like the NKF and the BKPA are the people who put pressure on people like me to put changes in place. So this is the place to start. We need new blood!

Number three: Is probably to be an advocate for kidney patients. We need to understand that kidney disease sits alongside other conditions: heart disease, cancer, strokes and a myriad other condition so we need to see patients visibly raising the profile of kidney disease in the public conscious so that the general public gains a better understanding of how our kidneys work and what happens when they go wrong.

And finally… how does Richard Fluck relax?
Well, I run. I started running when I was 48 as a way of relaxing and now I’ve done 8 marathons and I will be running in the London Marathon this year. It is my dream to run a marathon alongside a dialysis patient….and I have somebody in mind.

My son is very musical and so I have recently taken up the guitar also.

….Looks like that’s the entertainment at this year’s NKF conference sorted then!..!

Would you like to ask Dr Fluck a question about kidney disease or kidney care in the UK? Commencing the summer issue we will be selecting one question from a Kidney Life reader to pose to Dr Fluck. The question and his answer will appear in Kidney Life (you, as the questioner may remain anonymous if you prefer). This is a unique opportunity to ‘ask Richard’ a question about your kidney disease or care, or that of someone close to you, and should prove to a very interesting regular feature in Kidney Life. Please send or email your question to NKF Head Office (contact details on page 3) marked for the attention of Kidney Life.
Altruistic kidney donation is when a living person donates a kidney to a stranger who needs one – a procedure that is on the increase in the UK.

Until 2006 all living donors were either relatives or friends of people who received a kidney transplant but in 2006 guidance under the new Human Tissue Act stated that altruistic kidney donation was permitted. Altruistic donation, sometimes also known as non-directed altruistic donation, is the term that describes a donation that is given without knowledge of who is going to receive the kidney. An altruistic donor simply volunteers to give away a kidney to someone who needs it. NHS Blood and Transplant finds a suitable recipient and the transplantation is arranged by the local kidney transplant centres of the donor and recipient.

Although at first this may seem an odd idea, it is the same system that we use for blood donations. Blood donors simple decide to give a pint of blood – they don’t know who is going to receive their blood. They donate their blood altruistically because they want to help someone else who needs a blood transfusion.

The number of altruistic kidney donors is still small, but it is increasing every year as more and more people discover it is something they could consider.

Why I decided to give away one of my kidneys to a complete stranger

By Claire Ramsden

In 2007-8 when the first altruistic donations started to happen, these resulted in six successful transplants. In 2012-13 76 altruistic donors gifted a kidney and the number in 2013-14 will be even greater.

With around 6000 people in need of a kidney transplant and around 300 people in need of a kidney dying each year, the case for altruistic donation is a powerful one.

- Only a small proportion of people on the organ donor register die in circumstances that make their organs suitable for transplant, meaning there are far more people needing a transplant than there are organs available
- Data suggest that a donation from a living donor rather than a deceased one lasts longer
- Donations from live donors can be planned under the very best circumstances, with the surgery taking place at a time when both donor and recipient are in good health and recovery support can be pre-arranged
- The cost-saving to the NHS for a successful kidney transplant over keeping a patient on dialysis is estimated at more than £20,000 per annum after year one. So, over a ten year period, this amounts to more than £200,000. Transplanted kidneys can last for decades. Recently a woman celebrated forty years of a functioning transplanted kidney.
- Recipients may be more comfortable receiving a kidney from a stranger than from a friend or family member

In 2011, national charity Give a Kidney, was set up by a group of people committed to promoting and raising awareness of altruistic living kidney donation. The founding members include 10 people who each gave a kidney to a stranger under the NHS altruistic living kidney donor scheme.

Note from the Editor: Thank you Claire – you are an inspiration to us!
Let’s celebrate the Renal Registry

By Sue Lyon

It has been hard to miss the headlines about standards of care in the NHS, or the publicity when information on outcomes for individual surgeons began to be published last summer. But all this noise drowned out the fact that this kind of information is very old news indeed for kidney patients, who can find out exactly how their dialysis or transplant unit is performing through the UK Renal Registry’s annual reports.

The Renal Registry issued its first report in 1998, and information on all adult and paediatric renal units has been freely available since 2007. The latest report is now online and analyses data on the 54,824 adults and 861 children and young people who were on dialysis or living with a kidney transplant at the end of December 2012 (see diagram). There are chapters on—among many other things—adequacy of haemodialysis, infections, levels of haemoglobin, calcium, phosphate, bicarbonate and cholesterol, and transplant listing—all analysed by renal unit.

At present, although there is a summary at the beginning of each chapter, the Registry does not post a version of its annual report aimed at patients and the general public. This is a pity because there is, not surprisingly, a lot of detail to wade through and some of the information and language are quite technical. The Registry is also very focused on the results of all our regular blood tests. It is of course really important that we ‘know our numbers’, but these can miss important outcomes like the effects of our treatment on our quality of life.

So it’s very welcome news that the Registry is now conducting pilot studies on collecting feedback from kidney patients. The Registry is also looking at measuring how far patients with kidney failure are really able to share decision making with their doctor about their choice of initial treatment. Both are essential next steps for the Registry. As our National Clinical Director, Dr Richard Fluck, writes in his introduction to the latest Renal Registry report:

“[Patient experience and outcome measures] must be embedded into clinical practice in the way that systematic data collection has been achieved for laboratory data. These need to then develop into patient-centred outcome measures that provide system level markers for both the users and the commissioners of the service to understand the quality of care.”

Perhaps when patient feedback is eventually included in annual reports, the Renal Registry will also consider giving us a less technical summary of its results. In the meantime, it’s well worthwhile visiting the Registry’s website if you want to find out more about the standards of kidney care and how your unit compares.

More information

To find out more about the Renal Registry and read the latest report, go to: www.renalreg.com
For information on surgical outcomes:
www.nhs.uk/choiceintheNHS/Yourchoices/consultant-choice/Pages/consultant-data.aspx

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John Mascerenhus, Haemodialysis Patient

Treatments for kidney failure 2012
Behind the TV character we all feel we know, is a woman who, like many readers of Kidney Life, has supported her mother through kidney failure, dialysis and a transplant.
Nina explains, ‘I was quite young when my mother began to feel unwell. I was at school and we lived as a family in Hong Kong. The medical team around her at that time just did not know what was wrong and so her diagnosis of polycystic kidney disease (PKD) was a surprise to us all. We wish now that we could have had the diagnosis earlier so that we could all, as a family help her to get to grips with what had to be done to extend the time she had before she would need to dialyse, and make her life more comfortable. But she coped very well and even started to write up recipes that adapted the way we ate to suit her new dietary restrictions. Her attitude was so positive. She hated taking tablets but just did whatever she needed to with such humour. I think I was too young to fully appreciate her diagnosis and what she would have to face in terms of future treatment.

‘We moved back to the UK and she started treatment for her PKD at Hammersmith Hospital. Everything was so much better organised there and when mum’s fingers and ankles really started to swell up, we all knew that it was time for her to start dialysis. She would not hear of one of us being tested for live donation so was placed on the transplant waiting list. She always said that her call into hospital for her transplant would happen on an important day in the family. And so it was... the phone rang telling her that a potential donor had been found and that she should go into hospital immediately, on the very same day that my brother Kris announced that he was engaged to be married.

‘Her transplant did not work immediately but after a couple of days it did kick in and she came home a much healthier woman, ready to embrace life to the full once again. Her good humour never left her and we would always see her chatting to the youngsters in clinic appointments.

‘Mum had 8 very good and healthy years with her transplant but about 8 years on her health started to deteriorate quite rapidly and eventually her transplant failed. I know now that this can be part of having PKD. I was acting on stage in London in a comedy ‘Goodness Gracious Me’, and it was so difficult walking on stage every night where I had to make the audience laugh, knowing that as soon as I came off stage I was a member of a close knit family trying to look after our mum who was, by this time, very poorly indeed and whose long term prognosis was not at all good. We, as a family knew we did not have long left with her.

‘Mum died in 1999. She was just 62 years old. I am sad that she did not get to meet my son and my daughter: her grandchildren. But we all have such wonderful memories of this strong, funny and charismatic woman. And it is because of her that I now want to offer my support to the NKF in their work towards getting better treatment and outcomes for kidney patients in the UK.

Nina Wadia joins the NKF as Patron

For those watchers of the BBC1’s Eastenders, Nina Wadia will be a familiar face. And if you caught the Christmas special ‘Open all hours’ with David Jason you will have caught sight of Nina in that too. Such is the demand on Nina’s high profile as a character actress on our screen and on stage in the West End of London.
Study highlights benefits of cutting salt in CKD

Limiting sodium (salt) intake seems to lower the risk of heart attack and protect the kidneys in chronic kidney disease (CKD), according to the LowSALT CKD study.

The Australian researchers randomly assigned 20 adults with high blood pressure and stage 3-4 CKD to either high (180-200 mmol/l day) or low (60-80 mmol/l day) sodium intake. (One teaspoon table salt contains about 100 mmol/sodium.)

At the end of two weeks, compared with high sodium, low sodium:

- Lowered blood pressure by 10 mmHg systolic and 4 mmHg diastolic—similar to results of adding another antihypertensive drug
- Halved the protein in the urine
- Reduced volume of fluid outside the cells by 1 litre.

People with CKD are advised to limit dietary salt, but LowSALT CKD is the first blinded, randomised controlled trial comparing high versus low sodium intake. The study is continuing for a further 20 weeks to assess participants’ quality of life and adherence to salt restriction.

Journal of the American Society of Nephrology 2013;24:2096-2103

Ocreotide LAR: a treatment for PKD?

Ocreotide long-acting release (LAR) may help protect the kidneys in autosomal dominant polycystic kidney disease (ADPKD).

The randomised ALADIN study included 79 Italian adults with ADPKD and estimated glomerular filtration rate (eGFR) of 40 or higher. Participants were randomised to either two 20 mg intramuscular injections of ocreotide LAR or placebo injections every 28 days.

After one year, increase in mean total kidney volume was significantly less in the ocreotide group than in the placebo group. This difference was no longer significant after three years, but eGFR remained stable in the ocreotide group while worsening in placebo patients. The authors believe their research may justify larger studies to test ocreotide as a treatment for ADPKD.

Lancet 2013;382:1485-95

Proteinuria prompts concern for kidneys

More severe proteinuria (protein in the urine) is linked with a faster rate of decline in kidney function, regardless of estimated glomerular filtration rate (eGFR).

In nearly 640,000 adults in Alberta, Canada:

- Kidney function declined more slowly in people with mild proteinuria and lower eGFR (30-44) than in those with heavy proteinuria and higher eGFR (45-59.9)
- Normal protein levels and low eGFR (15-29.9) correlated with stable or improved kidney function
- These findings were not affected by gender, age and diabetes status.

Journal of the American Society of Nephrology 2013;24:1661-7

Stem-cell study fails for kidney transplants

Infusing donor stem cells does not improve outcomes after living-donor kidney transplantation, according to a small study of nine patients. All received alemtuzumab induction, followed by tacrolimus and mycophenolate, a switch to sirolimus and then planned withdrawal of immunosuppression over two years.

Chronic transplant injury or recurrence of kidney disease affected all four patients given stem cells from their donor. Two lost their transplants, and neither of the two remaining patients was able to give up their immunosuppressive drugs.

Transplantation 2013;96:800-6

Weekend warning: avoid hospital

Adult haemodialysis patients admitted to hospital over the weekend have longer lengths of stay and a slightly higher risk of death than those admitted on weekdays.

This conclusion is based on an analysis of over 3,250,000 non-elective (i.e. emergency) admissions of haemodialysis patients in the USA. Compared with patients admitted during weekdays, those admitted between midnight on Friday and midnight on Sunday:

- Had 6% higher risk of death from any cause
- Had 18% higher risk of death during the first three days of admission
- Were less likely to be discharged home and had longer hospital stays.

Although this is a US study, its findings reflect general concerns about weekend admissions that have prompted calls for seven-day services in the NHS.

American Journal of Kidney Diseases 2013;62:763-70

No BEACON for bardoxolone

Bardoxolone methyl is no better than placebo at protecting kidney function in people with type 2 diabetes and stage 4 chronic kidney disease (CKD).

In fact, the large BEACON study was ended early after nine months due to a higher risk of heart failure or death in bardoxolone-treated patients.


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.

12 Spring 2014 www.kidney.org.uk HELPLINE 0845 601 02 09

Don’t try this at home!

Any changes to treatment reported in Medical Matters were carried out under medical supervision. Never make changes to your medication by yourself. If you are worried about your treatment, talk to your renal unit team.
Good progress on BAME matters  By Kirit Modi, NKF Chairman and Co-Chairman NBTA

I am delighted to report that good progress has been made on dealing with issues facing Black, Asian and Minority Ethnic (BAME) patients waiting for an organ transplant, although more still needs to be done. The NKF supported the publication of the Manifesto by the All Party Parliamentary Kidney Group (APPKG) in March 2012. Since then a new national group National BAME Transplant Alliance (NBTA) was established in July 2012. NBTA provides leadership and co-ordination on both organ and stem cell transplantation and involves BAME groups, charities, academics, clinicians, NHSBT and the Department of Health. Its new web-site is at www.nbta-uk.org.uk. NBTA has recently published a paper on the Big Wins to improve organ transplantation to support the implementation of the national strategy on Taking Organ Transplantation to 2020 and is requesting all four countries to consider their plans to address BAME issues.

NHSBT (www.nhsbt.nhs.uk) has recently published a Faith Action Plan which sets out, for the first time, a national strategy for working in partnership with all the major faith communities. The Renal Registry has, after many years, published analysis on BAME kidney patients in December 2013. NKF has taken a leading role in these national developments and will report progress to the APPKG at its next meeting on 21 January 2014. These developments at a national level have been supported by local initiatives in the last year such as the following.

• Campaign in Leicester among the Hindu Community organised by Leicestershire KPA, BAPS Charities and the NKF.
• Awareness raising event at Watford mosque organised by the Lister Kidney Foundation and the Watford Hospital Organ Donation Committee.
• Awareness raising event in Derby organised by the Royal Derby Hospital Organ Donation Committee with the support of the NKF and others.
• Awareness rising session organised by the Jain Samaj in Manchester, supported by the NKF.
• A major project aimed at the Pakistani communities in Birmingham led by KRLIK and supported by the Department of Health, NBTA, NKF and others.

These events are enabling us to produce resources (leaflets and DVDs) aimed at supporting work with the Hindu, Muslim and Jain communities in this country and are available from the NKF Helpline. Clearly we need to do more to cover all major BAME communities throughout the country.

I hope more KPAs will consider addressing issues facing BAME kidney patients in their area. We now have national strategies and action plans in place and have considerable experience and expertise at a local level. Please do not hesitate to contact me if I can help in any way.

By Kirit Modi, NKF Chairman and Co-Chairman NBTA

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.

Name of Giver:.................................................................
Amount to be given:...........................................................
I wish to make a bequest to the NKF as shown below.
Signed:..............................................................................
Date:..................................................................................

Many Thanks - NKF The Point, Coach Road, Shireoaks, Worksop, Nottinghamshire S81 8BW • Charity Number 1106735
Please send or hand this coupon to your solicitor together with any specific instructions in order that your wishes can be incorporated into your will.
Rare diseases are common. There are several thousand conditions overall, and it has been estimated that 5-10% of the population suffer from a rare disease. However, these are often complex in nature, as well as difficult to understand and treat, so the Renal Association has introduced a rare disease strategy, at the centre of which sits the Registry for Rare Kidney Diseases (RaDaR).

You have been diagnosed with a disease that is described as ‘rare’. A rare disease is defined as having such a low incidence (rate of occurrence) that it cannot be effectively managed on experience drawn from one or even a few medical centres. Most doctors are unlikely to have much experience of it, and will rely heavily on external information to offer advice or treatment. The problem is amplified because good quality clinical and scientific information is difficult to capture, or may not exist. Many rare diseases are complex and have genetic or metabolic causes. Treatment is less likely to be developed and tested than in more common disorders.

Being diagnosed with a rare disease often brings a sense of isolation. Sometimes, the diagnosis is slow to be recognised and this may reduce your confidence in the healthcare system. Standards of care can vary depending on local expertise. You may scan the internet for scraps of information or contact with other patients. This can be demoralising if the information is misleading as is sometimes the case. There is a dearth of sound literature for specific patient groups, largely because of the scarcity of reliable clinical scientific publications on which to base it. For some of these conditions there are already patient support groups but for many there are not.

What is the solution? We need better co-ordination of rare diseases at a national level. As a principle, there should be integration of diagnostic and treatment services, audit and research, and patient information and empowerment. For individual patients, the best outcomes are obtained when you are well informed and take an active interest in your own management – in partnership with well-prepared, proactive teams of caregivers.

What is RaDaR?
An essential first step towards understanding and optimising management of any rare disease is the collection of informative clinical data. This has been difficult to do in the past in a co-ordinated manner across all renal centres in the UK and has, therefore, led to the creation of RaDaR.

RaDaR is a web-based portal that any healthcare professional or patient can access at any time, with centralised key information. The idea is that this benefits everyone involved in your care.

- The Patient – you can see your clinical information, enter your own data (where permitted) and access information about your disease that is written by experts and kept constantly up to date.
- Clinicians – can easily access and update information about any patient in their centre with a rare disease. They can access disease management protocols, diagnostic tests and the latest research.
- The Researcher – has (anonymised) access to clinical and, when appropriate, biological data on all patients in the UK with the rare disease they specialise in. This allows sufficiently powered studies to be carried out, thereby maximising the potential of that information, and also gives the ability to identify and approach patients in the UK who may be suitable for future trials and studies. RaDaR operates within the UK Renal Registry, a highly sophisticated database for patients with end stage renal failure. Here, the existing technical expertise, management and governance structure will help to ensure success.

Research for this project was funded by grants from Kidney Research UK and the British Kidney Patients Association.

Current renal rare disease groups
- Alport’s syndrome
- Adenine phosphoribosyltransferase deficiency
- Bardet-Biedel syndrome (UK nationally commissioned service)
- Bartter syndrome (Types 1, 2 and 4)
- Bartter syndrome (Type 3)
- Cystinuria
- Dense deposit disease
- Dent’s disease
- EAST (Epilepsy, ataxia sensorineural deafness and tubulopathy) syndrome
- Familial uromadulin-associated nephropathy (hyperuricaemic nephropathy and medullary cystic kidney disease)
- Giteima syndrome
- Haemolytic uraemic syndrome atypical
- Haemolytic uraemic syndrome (shiga toxin-associated)
- Hepatocyte nuclear factor-1-beta mutation
- Hyperoxaluria (primary hyperoxaluria, oxalosis)
- Liddle’s syndrome
- Lowe syndrome
- Membranoproliferative glomerulonephritis
- Membranous nephropathy
- Nephrotic syndrome (steroid-resistant, congenital or associated with primary focal segmental glomerulosclerosis)
- Autosomal recessive polycystic kidney disease
- Pregnancy and chronic kidney disease
- Vasculitis

By Moin Saleem FRCP PhD, Professor of Paediatric Medicine, University of Bristol and Children’s Renal Unit, Bristol Royal Hospital for Children.
‘Happy New Year to you from the Advocacy Team. We hope 2014 is a good one for you in every way.’

As the year begins many of you will hopefully be turning your thoughts to holidays and planning breaks away; with this in mind NHS England are expected to publish Dialysis Away From Base (DAFB) Guidance in 2014 aimed at patients/carers, commissioners and providers of dialysis in England. This aims to be a clear guidance, acting as policy, to hopefully demystify some of the arrangements around DAFB and follows a presentation to the All Party Parliamentary Kidney Group (APPKG) meeting in October 2013 – the NKF still hope that issues around DAFB such as capacity can get an airing in a Westminster debate, as many of you raise very important issues, not least about capacity at some of the popular locations in the UK and the difficulties that you have experienced on the continent.

Further to the APPKG meeting last October where we presented on the ‘Bedroom Tax’ with the kind help of three patient attendees, we also submitted an evidence paper to the Work & Pensions Select Committee who were looking into the ‘Welfare Reforms’; further pressure has been placed on decision makers by our friends at the BKPA and combined with Channel 4 through their Dispatches programme highlighting the effects of Bedroom Tax on renal patients in particular, we hope that pressure increasingly mounts this year for the Government to recognise the effect the benefits cuts are having on our kidney community? The NKF’s stance is very clear on this – patients in receipt of housing benefit who have or will be having home dialysis should be exempt from the ‘bedroom tax’ and should not have to go through the hoops of applying for discretionary housing payments (DHP).

For others amongst you the start of the year may be a time to undertake a new challenge, set yourself a goal or perhaps identify components of your lifestyle that could be changed to encourage a healthier you. Whatever it might be do consider getting in touch with your regional advocacy officer who would be more than happy to provide practical advice and suggestions to support you in your decisions – making changes is never easy but we are here to support you in any way we can and having access to a supportive ear can be very beneficial, as many will testify who have contacted us over the last 12 months. I have taken up a personal challenge and will be running the Virgin London Marathon in April for my local Kidney Patient Association at Guys Hospital!

Over the last year the Advocacy Service continued to work hard, striving to meet the needs of our kidney community, providing practical, compassionate, confidential support and assistance on a range of issues, which included: providing patient representation at regional network meetings; support at tribunal hearings for benefits; assistance with conflict resolution; one-to-one support and guidance over the phone; supportive visits to dialysis units; sign-posting to professional services including welfare advisers; and valuable patient education – we have also been addressing local transport issues, resolving holiday problems and advising on live donation and transplant concerns.

Furthermore, members of the advocacy team have been involved in Public Patient Involvement (PPI) on Clinical Reference Groups for Dialysis (A06) and Transplantation (A07) having helped to produce service specifications. These can be viewed on line www.england.nhs.uk/resources/spec-comm-resources/npc-crg/group-a/ and will shortly have far more patient friendly versions available from which you can judge if the service you get is that specified.

The report Kidney Health: Delivering Excellence was published in October last year and we consider it an important report for all patients/carers to familiarise themselves with, and either individually or with your KPA make sure that your local Hospital is working towards the ambitions contained within. The report can be viewed online www.britishkidneypa.co.uk/images/stories/downloads/Kidney-Health-Report.pdf

Having a link with a Kidney Patient Association (KPA) can be a real support for many patients and provides access to local information and help, and importantly provides a social hub from which many patients get a sense of community. For those of you who feel that you would like to be part of your KPA or more involved, details of your nearest KPA can be found on our website. Alternatively ask at your local unit.

Should you need to contact your regional advocacy officer please do not hesitate to use the Freephone Helpline number in the first instance 0845 601 02 09 or contact them directly via email. We are here to assist and support with the challenges that come your way.

Best wishes for the year ahead.

Nick Palmer
Mary and Peter say thank you to the NKF

On Saturday 19th October, Mary (70) and Peter Grimshaw (71) celebrated their Golden Wedding Anniversary with their family and friends at Oldham Golf Club, Oldham. Not only was this a celebration of 50 fantastic years together, it was also a proclamation of their total dedication and commitment to each other. Many years ago Peter was diagnosed with kidney failure which was controlled by medication for approximately 8 years. Peter then spent 2 years on dialysis at home which involved 3 x 4 to 6 hour sessions. During this time Mary decided to undergo tests to see if her kidneys would be compatible to enable her to be a live donor.

Amazingly they were and so on 19 January 2011 both underwent back to back surgery during which Mary became a live kidney donor for Peter at Manchester Royal Infirmary.

Almost 3 years on and both are in good health and living each day to the full.

To thank all those involved and for the information and support that was given to Mary & Peter during this worrying time they requested that any guests who were minded to buy a present for their 50th wedding anniversary, instead to make a donation to the NKF; which many did and at today’s date they have managed to raise over £500.

Note from the editor: Mary and Peter thank you so very much for this wonderful account of your reasons to celebrate. We can assure you every single penny sent in will be used to help kidney patients here in the UK. Thank you!

Let’s do it in 2014 for the NKF

By Pete Revell, NKF Head of Fundraising

Last year we saw people jump out of planes, climb Ben Nevis, walk along Hadrian’s Wall, drive huskies to Lapland, run a marathon and even cycle from Vietnam to Cambodia. The best bit is that every single one of these people did these amazing things to raise funds for the NKF.

So here we are at the very start of a brand new year looking forward to the summer. Now is the ideal time to start planning your own 2014 event or challenge and we can help you do this. If you visit our website at www.kidney.org.uk/fundraising you will find a whole host of different fundraising events and challenges planned with you at the very centre of them. We can help you with whatever information or support you need, so if you want to talk to us to outline your own plans for an event just call me on 01480 389791 or email pete.revell@kidneynkf.com. Once your event is booked you will receive an information pack which will include sponsorship forms and a guide on how to set up your own fundraising page at www.justgiving.com. Still stuck for ideas? Request one of our A-Z lists of FUNdraising ideas.

Thank you if you have helped us in any way over the past year. Without your help the NKF would not be able to help support the 2 million people with kidney disease in the UK. Let’s make 2014 the best year ever so that we can give even more kidney patients a better future.

NKF Christmas Draw winners are announced

Thank you if you bought tickets for our NKF Christmas Draw and congratulations to the winners. As the draw took place just before Christmas, Pete Revell, NKF Head of Fundraising decided it might just bring a smile to the faces of the winners of the first and second prizes if the cheques were hand delivered. Mrs Allen is just celebrating her first year with a successful kidney transplant and said that she and Mr Allen would be using the money to fund a great Christmas and buy a new computer. 2nd prize winner Mr Chalmers had a transplant in 2008..and both were very happy indeed with their NKF unexpected prizes!

1st Prize £2000 was won by Mr Allen from Wisbeck
2nd Prize £1000 was won by Mrs Chalmers from St Albans
3rd Prize of an iPad was won by Mrs O’Neil from Harrow
4th Prize iPad mini was won by Mrs Salter from Colyton

3rd Norwich Advent Service

By Sandy Lines MBE

In early December Norwich Cathedral played host to the 3rd Norwich Advent Service. The event was organised by the United Norwich KPA and the NKF. The service lasted for an hour and the congregation sang along to traditional carols. The service also gave thanks to the people who work in the renal world and highlighted the plight of kidney patients and the need for more transplants to take place. Free mince pies and hot drinks were served after the service. Pre-service donations from people who wanted to come but were unable to, amount to over £500 and we await news of how much was collected during the service. The Cathedral is booked for the 2014 Advent Service and we hope to see as many people there as possible. The date will be published in a later issue of Kidney Life. Many thanks to everyone who made this event such a success.
Kidney Community calls for action

New report warns of tens of thousands of lives at risk as Government strategy expires

The report, entitled Kidney Health: Delivering Excellence, highlights major inequalities in access to high quality care, poor diagnosis of kidney disease and alarming levels of avoidable harm. This is all at a time when the Government’s 10-year Renal National Service Frameworks come to an end.

The National Service Frameworks (NSF), published in 2004 and 2005, have led to many notable successes in renal care, including:

- raising the profile of patient-centred care
- setting clear standards for delivery of care
- promoting patient choice
- improving quality of care
- improving identification of kidney disease in general practice
- reducing the number of late referrals (‘crash landing’)

The hard work of NHS staff has driven these changes and improvements over the course of the past ten years. However, in spite the progress that has been made, in many areas improvements are now levelling off.

Kidney Health: Delivering Excellence was co-written on an equal footing by kidney patients and healthcare professionals. It represents the most comprehensive review of NHS kidney services for more than a decade. The report concludes that there are sixteen priority areas in which the NHS should aspire to make improvements. These include:

- reducing the wide variation in access to home dialysis therapies and self-care
- increasing the number of transplants and delivering more equitable provision
- better identification of patients with kidney disease by GPs
- promoting person-centred care and self-management
- and increasing public awareness of kidney disease.

Can you help spread the word about the report?

There is now an opportunity for all patients and carers to get involved and make their voices heard. You can help to raise public awareness of kidney disease and the ambitions of this report by:

- Considering which of the 16 ‘ambitions’ applies to your own care
- Talking to family and friends about what struck you the most?
- Talking to your GP, your kidney specialists and nurses about the report and ensuring that they are aware of its existence.
- Finding out what your local Kidney Patients’ Association is doing to promote the report and its ambitions

This introduction is an extract from a longer article for patients written by the Kidney Health Partnership Board. A link to the media information announcing this important report may be found currently (February 2014) on the front page of the NKF website at www.kidney.org.uk, or directly at the following link: http://www.kidney.org.uk/home/news-2/kidney-care-at-serious-risk-according-to-renal-experts/
Anyone for Dialysis Olympic Games?

Could we have our very own Games specifically for those of us on dialysis?

I was watching the athletes at the Paralympic Games and I wondered….could we have our very own Games specifically for those of us on dialysis? We have the Transplant Games but nothing for patients on any form of dialysis – and I am one of them! The UK dialysis Games would see dialysis units compete against each other. And the benefit to us of competing and achieving would be enormous.

In York we have a fitness group run by Vicky and Miriam and some volunteers. Miriam goes to the other renal units to encourage patients to exercise. And as we patients start to exercise and start to feel stronger, some of us may like to put ourselves to this ultimate test and compete in a sports event.

So, if you are on any form of dialysis and would like your unit to take part in a National Dialysis Olympics or if you are a charity who could help us organise this please get in touch. Mark Hallam 07918 670645. Together we CAN!

Taking a walk for the NKF

Pete Halsall and Rob Sale walked 16 miles along the River Wey Navigation from Weybridge to Guildford in October to raise funds for the NKF. The walk raised a total of £1493.35.

Pete, whose partner Monica Nelson is a patient at King’s College Hospital, Camberwell in South London said “We’ve been thinking about doing something like this for a long time. Now we’ve done it and managed to raise a really amazing amount of cash for the NKF! Monica has been on home dialysis for over 5 years whilst waiting for a transplant and the NKF has been a source of real support. We’d like to thank everyone for being so generous!”

Rob said, “It’s been great to be able to raise so much money for such a worthy organisation, particularly because the NKF has helped so many people I know who are affected by kidney disease. Hopefully, we’ll do another walk next year!”

Bob and Pete – thanks so much for doing this walk and raising so much money for the NKF. At the end of that day we bet those well-deserved beers tasted even better than usual. As you know every penny raised at events like this is used to improve the lives of kidney patients in the UK.

KC Dialysis Centre

This friendly, family run unit is situated about 100 yards from the beautiful sandy beaches of Southbourne. Bournemouth town and its famous pier are approximately 2 miles away.

The unit’s recent refurbished facilities offer:

- Eight station unit with reclining chairs.
- Dialysis facilities all year round.
- Opening times 9am to 7pm.
- Direct online booking so patients can check availability and book at a pace that suits them.
- Arrangements made with local hotels situated within a few minutes walk of the unit to offer a discount on accommodation. Alternatively, we offer a ground floor self-catered flat directly next door to the unit at very competitive rates.
- The unit is staffed by well trained nurses and the Director, having over 30 years experience in this area of care, ensures a warm and friendly atmosphere is maintained at all times.

For further information telephone 01202 422311.
Website: www.kcdialysiscentre.com
Email: admin@kcdialysiscentre.com
35 Southwood Avenue, Southbourne, Bournemouth, Dorset BH6 3QB
Participants needed for research into experiences of kidney checks in primary care

Doctors are now expected to check for changes in how the kidneys are working at an early stage. If early potential problems with kidney performance are detected, patients are monitored by their GP through regular blood tests to check how the kidneys are working. However, doctors disagree about the value of identifying potential kidney problems early when it may not affect a person’s day-to-day health.

We are interested in talking to people from all over the UK, who have been told they are having their kidneys monitored by their GP, about their views and experiences of having kidney performance checks, and what information they would like to know about their kidneys. As we are interested in early potential problems with kidney performance, our project does not include people with specific conditions such as polycystic kidney disease or those with advanced kidney problems who have been treated by dialysis or transplant or those whose condition is monitored solely by a hospital specialist, although we are interested in hearing the reflections of some people who have only recently been referred to a specialist after having been monitored by their GP for a while. The results will be used to help doctors manage this issue and inform future health policy, as well as informing other patients about kidney health.

Taking part would involve being interviewed in your own home (or elsewhere if you prefer). The interviews will be used to develop a new section on the award-winning website www.healthtalkonline.org. On the website you can watch video clips, listen to the voices or read the accounts of people relating their experiences of a wide range of health issues. Health professionals can also learn from people’s stories on the website and use them to improve the way they interact with and care for patients. www.healthtalkonline.org is accredited with the Department of Health’s ‘Information Standard’ and our research is approved by Berkshire Research Ethics Committee 12/SC/0495.

If you are interested in taking part in our research, or you are a GP who could recruit participants for us, please contact Julie Evans at Oxford University (email: julie.evans@phc.ox.ac.uk; phone: 01865 289335 [answerphone 24 hours]).

Would you like to advertise in Kidney Life?

We have a select few places available for the right companies within our magazine

As Kidney Life nears its 25,000 target audience this year, we see its adverts hitting a far greater audience than ever before. If you have a kidney patient centred product or service that you feel would benefit from reaching a wider audience, then we would like to hear from you. The NKF offers extremely competitive rates to advertise in Kidney Life and a choice of: Quarter page (portrait), Half page (landscape) or full page (portrait) sized advertising spaces.

For full details of costs and how to book your Kidney Life advert please contact the Helpline on 0845 601 02 09
(Freephone from all UK landlines)

GET NOTICED: BY OVER 22,000 READERS

We made an error in the Winter 2013 issue of Kidney Life and we would like to set the record straight! On page 6 we renamed Roger Greenwood. Well done if you spotted it… sorry Roger!
Mat, a CKD patient suffers from focal segmental glomerulosclerosis, but is not wasting a moment of his wait for a transplant.

‘Although my kidney function has deteriorated I’ve carried on cycling all year’. Mat says. ‘The weather last summer was fantastic for riding and I did quite a lot throughout the whole summer. Not specific events but I did go to the Isle of Man to do some mountain biking, which was awesome. There are some great mountain biking trails over there with stunning views of the coast wherever you are up on the mountain.

‘But I am starting to feel the steady decline in energy levels when I ride now. I have undergone tissue tests so that I may go on the transplant waiting list, in the hope of getting a transplant in the not too distant future.

‘My brother-in-law has stepped forward to be considered for live donation which is exciting too because he is also a cyclist so I know he is fit and doesn’t drink or smoke. It’s a long work up to a transplant for us both but we’re both keeping our fingers crossed.

‘Now that my energy levels have depleted to this extent I now have to consider my general health each time I go out on a ride. Before a ride I have to take a look at how I’m feeling that day or that week. I have to consider things like the temperature outside, and try to be sensible about what I can take on.

‘The cold saps anyone’s energy but it seems to be even worse for me at the moment. I’m also more prone to colds and chest infections because my immune system is impaired because of the steroids I have been prescribed. So all these things will determine the length of ride and route I will take on any given day.

‘So these are the negative aspects of riding whilst in kidney failure, but there are many positive ones too. I am still exercising and I know I am very lucky to be able to when so many kidney patients just can’t. So I drag myself out whether I feel like it or not because I feel so much better afterwards.

‘When my energy levels began to wane noticeably, I got in touch with a fantastic company called 50cycles.com. I bumped into the company director, Scott Smith on their stand at the NEC Cycle Show and told him about the challenge I was facing.

Astonishingly they have allowed me the use of one of their electrically powered bikes - an ‘e-bike’. This means I can use my own energy to power the bike when I am up to it but when my energy starts to fail me, I can switch to whatever level of ‘electrical assistance’ I feel I need. I think these e-bikes are fantastic. For me, pre-transplant they mean I can still exercise to my own physical limit and then ease back a bit and let the bike take the strain until I am able to regain some energy and take over completely again. I think these bikes would also be great post-transplant when regaining physical strength with gentle exercise is so important to graft survival and general wellbeing. E-biking ticks all these boxes.

‘With my e-bike I can still cycle to and from work - a distance of approximately 12.5 miles each way. As we do not have a shower at work I take advantage of maximum assistance on the e-bike on the way to work, but take over the physical work and cycle myself all the way home...where I can get washed properly afterwards. And I go out most weekends on my e-bike in complete confidence that however tired I might get I can always fall back on the bike’s power to get me home if needed.

I have some BIG plans for this year and I will keep you posted on their progress in Kidney Life. If you would like to follow my progress in the interim you can go to my Facebook page DibbFet or on Twitter at @ KalkhoffEbiker

Note from the editor: Go Mat!! Rest assured Kidney Life will be covering Mat’s 2014 exploits on his amazing e-bike. The bulk of this interview first appeared in Cycling Weekly. Original interview by Matt Lamy. For any units interested in looking into the prospect of suggesting an e-bike for their patients please go to www.50cycles.com for further information.
During 2014 the NKF will strive to continue to provide vital services so that no one has to face kidney disease alone. Getting vital information out to you in our series of Kidney Matters Leaflets or in Kidney Life magazine is free of charge and that’s how we want it to remain. But doing this comes at a great cost to the NKF at a time that our services are increasingly in demand and our income is stretched.

We rely entirely on public support. A small donation from you (if you can afford it) will help the NKF reach every kidney patient in the UK and enable us to continue to get Kidney Life and important information relating to their health, out to them. Can you help us do this?

**How your donation could help:**

**A donation of £20 a month**
Will help with the ever increasing production costs incurred in producing and distributing patient information leaflets. There are currently 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.

**A donation of £10 a month**
Will help towards with escalating postage costs incurred in sending out Kidney Life and patient information to patients and renal units nationwide.

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

**A donation of £2 a month**
pays for your Kidney Life magazine

**How do I set up a standing order to make a regular monthly payment to the NKF?**

Call the girls on the NKF Helpline and they will take your contact details and send you a form.

*Thank you for helping us help kidney patients in the UK!*

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**NKF Payment Form**

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 telephone on 01909 544999

**Option 3**
Send this form together with your cheque (payable to National Kidney Federation) to NKF The Point, Coach Road, Shireoaks, Worksop, Nottinghamshire S81 8BW

Please itemise your order and each amount

1: .................................................. £
2: .................................................. £
3: .................................................. £
Total order  £ .........................

Don’t forget to enclose any relevant order forms (where necessary)

For further assistance dial NKF at 01909 544 999
In early 2009, my dad was diagnosed with HSP (Henoch-Schönlein purpura). HSP, also known as anaphylactoid purpura, purpura rheumatica and Schönlein-Henoch purpura, is a disease of the skin and other organs. It was monitored but after a few months test results proved that our fear that my Dad’s kidneys had been damaged because of this illness, were well founded. It is unsure why HSP occurs, only that it is an immune response usually to infection.

Dad was referred to Salford Royal where biopsies were taken and he was diagnosed with early stage chronic kidney disease (CKD). At that time, there were no obvious symptoms that my dad was suffering with CKD. But as the months went by Dad became severely anaemic and was referred for various tests. He received iron treatments and blood transfusions. Then suddenly in early 2010, Dad became ill with an infection and was admitted to the renal ward at Salford Royal. There he was an inpatient for a long period and as days turned to weeks then to months, we wondered if he would ever recover.

After two severe infections, Dad was lucky to pull through but these infections fast-tracked him into end stage kidney failure and he had to start dialysis. Some unusual good news came our way at the end of 2010/early 2011 though. Dad’s kidney function improved temporarily and so dialysis was discontinued. Unfortunately, months later, Dads condition worsened and so has been on dialysis ever since and is now registered on transplant waiting list.

This rollercoaster ride opened my eyes to how a renal patient and their loved ones are affected by CKD. There was no way I was going sit back and do nothing, especially when dad refused living donation from family. I researched kidney charities and when I came across the NKF I knew I had found the one I wanted to support. I admired and was amazed by the work they do. Not only was this a remarkable charity, but it is run by renal patients so they have their own personal experiences that make the charity so successful.

Patient services are the one area that is so important and yet gets overlooked easily. I believe that force to drive renal charities on is needed and that is why I support the NKF 100%. I support them with a group made up of family members and friends through various fundraising activities.

Our children’s parties are very popular. These are organised throughout the year and are themed to certain seasons such as Christmas parties, Easter ‘eggstravaganzas’, and teddy bears’ picnics. Our most popular event is the Swishing Night where ladies gather together at our local church hall for one big clothes swap evening!! There are stalls of women’s interest such as jewellery, cupcakes, make up and candles. There’s entertainment, a bar and a raffle. We have volunteers modelling the clothes in a fashion show before there is a mad dash to the rails. We usually organise the swishing event around World Kidney Day to raise awareness of the impact of kidney disease. We have done various one off events too such as bake sales, table top sales, and local fayres. And we have some amazing ideas in the pipeline for 2014.

I am so lucky to have fantastic friends and family who give up their time to support me in these events. We are looking forward to continuing our journey together. So far we have raised just under £4000 for the NKF.

Zoe McGuirk (Keith’s Blue Moons www.justgiving.com/nkf-keithmiller)

I researched kidney charities and when I came across the NKF I knew I had found the one I wanted to support…

Note from the NKF. Zoe what a star! We would all like to say a huge thank you to you and your team of volunteers who do so much for the NKF. Every single penny raised goes to help us improve the lives of kidney patients in the UK so the money you raise is spent wisely.
Ten years ago, Jains from across the world, celebrated the opening of the Jain Community Centre and Temple in Manchester, with great joy. The Centre was a dream for promoting Ahimsa, which symbolises love, genuine care, and compassion towards all living beings.

To commemorate its 10th Anniversary the community decided to celebrate this wonderful occasion with different events and dedicate the year 2013 to two charities selected by members. The two chosen charities were St Ann’s Hospice and The NKF (National Kidney Federation).

Events started with more than 15 members participated in the MIDNIGHT WALK. And celebrations started with the President’s Launch where tributes were paid to members who were no longer with us.

To celebrate the birth of Lord Mahavir, who has attained enlightenment, the second event was held in the auspicious presence of Sadhvi Shree Shilapiji from Veerayatan in India. The members performed a drama ‘Walk with me’ based on the life of Lord Mahavir. Later the community also celebrated the annual flag raising ceremony.

To promote different cultures and religion ‘A cultural fusion’ was held, where various communities gathered to perform an item representing their culture or religion. Some 22 acts were performed. This was followed by a weekend filled with sports and games, many of which have never been played before.

The 10-year celebration came to an end, when the “Grand Finale” was celebrated with over 400 members present. An interesting presentation of the past and present Jain Community was beautifully presented. This was followed by a cultural show where more than 70 members participated.

Another highlight of the evening was superb presentation of the Souvenir. It depicts the journey of JCC from a formation in a hired school hall in 1973 to the wonderful Centre of the present.

With Lord Mahavir Swami’s blessing, our 10th Anniversary celebration ended very well with a total over £7,000 donated equally to our nominated charities.

The Executive Committee and the Board of Trustee’s, want to express our sincerest gratitude to St. Ann’s Hospice and the NKF for giving us this opportunity and their help in raising the funds.

On behalf of everyone here at the NKF may we say a huge thank you to the hard work and generosity of the Jain Community Centre and Temple and the wonderful people who worked so hard to use the 10th Anniversary celebrations to raise funds for two very worthwhile charities.

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Become a Friend for Life of the NKF

Tel: 01909 544999

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 this form) and post it, together with your donation to the NKF at: The NKF (National Kidney Federation), The Point, Coach Road, Shireoaks, Worksop, Nottinghamshire S81 8BW

An annual subscription of £20 or more will entitle you to receive 4 issues of Kidney Life Magazine. All donations will be acknowledged.

Cheques should be made payable to National Kidney Federation

The section below is optional - please ignore if you do not want the NKF to re-claim tax. If you are a UK taxpayer, and complete the following Gift Aid Declaration, as well as the form above, the NKF will be able to reclaim the tax on all donations you make to the NKF Declaration: I am a UK taxpayer and want the NKF to reclaim the tax on all donations I make on or after the date of this declaration. My tax bill this year will be more than this donation. Please tick as appropriate

I am: a patient  carer  friend  . If patient, please tell us the name of your renal unit or nearest KPA

Signed, sealed and delivered on: Date ________________________________ Signature ________________________________

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)
Calling all younger renal patients!

If you are under 35 and have problems with your kidneys, get in touch with young@NKF now. We can put you in touch with other people just like you to discuss whatever is on your mind or just keep up to date with us on Facebook or Twitter.

If you need to talk to someone about your kidney problems, or those of someone close to you, call us here at the NKF Helpline. We have over 150 individually titled leaflets on every aspect of kidney disease and caring for people with kidney problems, from with help with applying for benefits to medical information for parents of children with kidney disease. Our service is friendly, confidential and personal to YOU. And your call is free from all UK landlines. Call us now and let us help you…..it may be the best thing you do today.