British Transplant Games 2014...

‘Our kidneys are Super Heros’
Class 1, Swiss Valley Primary School, Llanelli

Medicines: to take or not to take. That is the question

Striking a balance; potassium and phosphates – why do they matter?
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 help with 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.

New release: An excellent new leaflet explaining the benefits of exercise for kidney patients, along with exercise suggestions. This leaflet has been produced by the Leicester Kidney Exercise Team and costs £1. Please contact us here at the NKF Helpline to request your copy.
We say farewell to Ray MacKey

It is with great sadness that we have to report the untimely death of Ray MacKey. Ray was a tireless and hardworking member of the North East Kidney Patient Association, the NKF and the European Kidney Patient Association (CEAPR). Talent spotted by Gordon Nicholas (NKF chairman in 2003), Ray immediately became an essential part of the NKF rising to Chairman himself in 2007, a post he held until 2010. Having caught his breath for a year, he returned as my Vice Chair in 2011, a post he held until his decision to ‘jump ship’ and move from the voluntary side of the NKF to that of employee in January 2014. Sadly, Ray was an NKF Advocacy Officer for only one week. He relinquished the post upon hearing that his skin cancer diagnosis was terminal. Ray being Ray, immediately started raising money for the Macmillan nurses by playing gigs (he was a guitarist) with his own band and continued to do this during the period up to his death on the 6th April. Ray’s passion for improving provision for kidney patients shone through everything he did for the NKF for many years. Ray will be missed by many in the renal world and certainly everyone in the NKF, by many in the ‘live band’ world and by many in the football world – above all he will be missed by his family, Rachel, Amy and Stephen and our thoughts are with them.

Kirit Modi - NKF Chairman

Message from the Editor

As usual, the past three months since the last issue of Kidney Life have witnessed the gamut of emotion; tragedy as some of our dear friends depart this life and leave a great void in the lives of those who dialysed alongside them or worked with them to better the lives of kidney patients everywhere, and great achievements and steps forward as we witnessed on World Kidney Day back in March where some fantastic ‘kidney disease’ publicity was generated.

We have to ask the question. Was there anyone left at home in Wales on World Kidney Day?

Looking forward, we have a truly excellent Patients’ Conference to look forward to in October in one of our most popular locations – The Blackpool Hilton. Also, in July it is National Transplant Week (7-13th July) and during this week the British Transplant Games will be held in Bolton (7-10th July), so, plenty of colourful opportunities for anyone handy with a camera, to get pictures of these events to us here in the Kidney Life office. We would really love to see as many pictures as possible. Indeed, if you have anything to contribute to Kidney Life by way of personal journeys, KPA activity, fundraising escapades or advice that you feel may help our readers, the deadline by when we need to receive any of these for the next issue is 11th July.

Enjoy your Kidney Life!

Deborah Duval - Editor

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

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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

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:

Abbvie Fresenius Quinta Sandoz Sanoﬁ
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Jim Higgins - Vice Chairman
Mick Walker - Secretary
Michael (Bud) Abbott - Treasurer
Tim Statham OBE - Chief Executive

NKF Officers: Lister and Area KPA
Northamptonshire KPA
Leicestershire KPA
Gloucestershire KPA
Where last year delegates battled through the snow to attend this event, we are happy to report that delegates at this year’s KPA Day and AGM enjoyed far more clement weather conditions. Aside from the arduous taxi journey from the railway station to the rear of the hotel, the Arden hotel proved to be an excellent central location and so, many KPAs were very well represented at the meeting.

During the morning talks on ‘What my KPA does’ from Dudley KPA (Judith Sidaway and Sharon Orpen) and Guy’s and St Thomas’s KPA (Sonia Appleby) prompted lively debate on a variety of topics ranging from possible shared access to KPA funded holiday caravans to ways in which the NKF can better support the fundraising efforts of individual KPAs.

The 2014 AGM was also held and a new NKF Executive Committee was voted in along with 4 officers.

Kirit Modi Chairman Lister and Area KPA
Jim Higgins Vice Chairman Northampton KPA
Michael Walker Secretary Lincolnshire KPA
Michael (Bud) Abbot Treasurer Gloucestershire KPA

Executive Committee Members voted in (in addition to the four officers listed above) were:
Denise Abbott – Gloucester KPA, Angela Beale – Bristol KPA
William Beale – Bristol KPA, Ann Carter – Leicestershire KPA
David MacDonald – Wessex KPA, David Marshall – SAKA
Tracey Sinclair – Wessex KPA

Pat Vernon then talked about the changes to be made to the organ donation system in Wales (see opposite page for details) in 2015, and enlightening talks on ‘A day in the life of…’ by Mark Davis (NKF/BKPA Advocacy Officer), Tim Statham (on behalf of Pauline Pinkos – NKF Helpline Manager) and Pete Revell (Head of Fundraising) led the meeting into an open forum question time.

For all of us who have known Dennis Crane during his many years in the NKF, his words on his impending retirement were as usual funny, inspiring and a timely reminder that the NKF really is built on the hard work of good people.

Thank you to those of you who attended this important event.

Note: a copy of the NKF Annual Report 2013 may be found on the NKF website at: www.kidney.org.uk and is a very worth while read!

The co-chairman of the Exeter & District KPA, Mel McColm, along with Jill Baines of the EDKPA, have worked tirelessly to get this new service up and running. Thanks to the support, flexibility and innovative thinking of Steve Barnball, Chief Executive of the Exeter Citizen’s Advice Bureau, there is now an annual contract in place between the KPA and the CAB. Steve Barnball said: “We are delighted to be working in partnership with Exeter and District Kidney Patients Association to provide a benefits advice, assistance and information service to patients and carers and patients’ families. It is understandable that patients and their families are concerned about financial issues; this service allows them to focus on their treatment and recovery, whilst we help with money worries”. Early signs are that this is going to be a very well-used and valuable service. Thanks must also go to the renal department at the Royal Devon & Exeter Trust for their support in providing the accommodation for this service.

Kate Cresswell, South West Region Advocacy Officer for the NKF is delighted to stand alongside this service, giving her support, and taking up the reins for appeals and tribunals as and when necessary. In effect this means that if an application for a benefit is turned down, there is an appeals procedure which can be followed. Kate will, if needed, step in to support the client through this process, accompanying them at their appeals hearing as well.

A new advice service for renal patients in Exeter and District

If the benefits system seems a jumble of words amidst a sea of forms, then help is at hand for folk down in Devon! A new initiative has just been launched between the Exeter and District KPA and the Exeter Citizens Advice Bureau (CAB). The CAB benefits adviser, Freya Searle, will be on hand fortnightly – on alternate Mondays and Thursdays – at the Renal Unit, Exeter, to give expert one-to-one advice. Appointments are bookable, either for a telephone consultation or a personal face to face meeting, depending on the needs and complexities of the situation. Each appointment slot is for an hour, allowing plenty of time to go through each individual’s query in depth, and is a free, independent advice service.
Organ donation saves and improves life for countless people across the UK. In Wales, we have introduced new legislation that will over time revolutionise consent to donation.

In less than two years time, the way in which people choose to be an organ donor in Wales will be changing when the Human Transplantation (Wales) Act 2013 comes into force.

From 1 December 2015 Wales will have a “soft opt-out” system of consent to organ donation. An opt-out system is one where people are regarded as having consented to organ donation unless they have said otherwise – this is known in the new law as “deemed consent”. Soft opt-out means that families will still be involved, and will be able to say whether they know their loved one did not want to be a donor.

The new system marks an important change, and one which will help address the chronic shortage of organs available for transplant. It is a very sad fact that last year, 36 people died in Wales waiting for an organ transplant and over 200 more were on the active waiting list. Of course the numbers are even greater at a UK-wide level. We believe that changing to a soft opt-out system will result in a 25 per cent increase over time in the number of donors in Wales which will save or transform the lives of many people. Across Europe many countries with opt-out type systems have higher donation rates. We want to mirror this in Wales.

Many people are surprised how rare it actually is to be an organ donor. Of all the people who die in Wales in a single year – some 30,000 on average – only a very small proportion will ever be in the position of becoming an organ donor. This is because most people do not die in the circumstances which makes organ donation possible. However, for those who do, many potential donations are lost because when approached, families are often unsure of what their loved one would have wanted. As a result, in many cases they choose not to go down the route of organ donation. A soft opt-out system makes the position much clearer. People will know the law in Wales means individuals will be regarded as having consented to donation unless they have said otherwise. Families will know that their loved one had the chance to opt out if they’d wanted to.

A new system like soft opt-out relies on a lot of publicity and on people understanding how it works, the choices they can make, when they can make them, and how to go about it.

The choices facing people living in Wales are quite straightforward.

• Those of us who do not want to be a donor will have two choices – either, as now, register a decision to be a donor or do nothing and have our consent deemed.

Important safeguards are built into the law. Deemed consent will apply to the same organs and tissues which are currently covered by the organ donor register (e.g. heart, lung, kidney, liver, etc.) and will not cover unusual types of organ transplant. It will only affect adults living in Wales for 12 months or more, and who also die in Wales. It will not apply to children and young people, those who lack capacity, or to people who die in Wales but do not live there. Similarly, Welsh residents who die in England or elsewhere in the UK cannot have their consent to donation deemed. In addition, if a person had not opted out but their family or friends know they would have objected, then they can provide information about that.

So that the Welsh public is well informed, we have already started one of the most extensive communications programmes ever undertaken by the Welsh Government. The countdown clock shown above is one of the most recognisable elements of the mass media campaign, and it has already featured in adverts. These set out the choices mentioned above, encourage people to think about them and invite the public to visit our website www.OrganDonationWales.org which contains information about the new system and organ donation in general, or to call the donor helpline on 0300 123 23 23.

Over the coming months there will be more TV and other adverts, household door drops, and specific engagement with communities across Wales who may not always get to see messages in the traditional media. We will also work with our stakeholders to publicise the new system through their events and networks.

Most people, when asked, say they would donate their organs, but the majority of us never talk about it or record our decision. The new law in Wales will make everyone’s position clearer and achieve more transplants for those who need them.

Note from the editor:
The bill, in its entirety may be read on the National Assembly for Wales website at http://www.assemblywales.org/ use search criteria ‘Human Transplantation (Wales) Act 2013’.
Thank you for buying NKF Draw tickets in our Spring Draw. The lucky winner of the £2000 first prize will be announced in the Autumn issue of Kidney Life.

2014 is already shaping up to becoming a very busy year with many of you already enrolled in some of our fantastic NKF fundraising events this year. Thank you very very much! If you would like to join in any of these events too or know of someone who may like to help us please go to www.kidney.org.uk/fundraising and have a look at the vast range of events we can offer you – from events that can take place in one afternoon to competing once in a lifetime ambitions whilst raising invaluable funds for the NKF. Alternatively just call Pete Revell on 01480 389791. He will be happy to guide you.

What about joining us for one of the following?

Ben Nevis
3rd October – 5th October 2014
‘A challenging trek in the heart of Scotland’s Western Highland to the highest point in the British Isles – 1,343 metres!’

Your trekking challenge...
This exciting challenge will see us conquering Ben Nevis, the highest mountain in Scotland, Wales, England and Northern Ireland. We begin our adventure in the heart of the breath-taking Western Highlands of Scotland at Fort William.
The mountain attracts many trekkers, climbers and mountaineers, as the 700 metre high cliffs of the north face are among the highest in the United Kingdom and are one of the principal locations for ice climbing.
Our trail to the summit is not technically difficult, but trekking will be strenuous – stamina and determination are a must. The stunning views of the highlands will be with us all the way and provide a fantastic backdrop to this epic weekend adventure.

Don your boots and let’s get trekking

NKF FUNDRAISING
‘The 700 metre high cliffs of the north face are among the highest in the United Kingdom’

Fright Hike 2014
The spookiest charity challenge around
Don’t be fooled, these walks are not for the faint hearted – the ‘Hike’ in Fright Hike is a challenging 30km trek and definitely not just a walk in the park.
If the challenge of walking 30km, setting off at dusk and walking into the pitch blackness of the dark around Halloween isn’t enough to make the hairs on the back of your neck stand up, we’ll hooooowl! We’ve picked the scariest forest locations we could find in the UK to host Fright Hike.

The Fright Hike Village
All the Fright Hike routes will start and finish at a Fright Hike Village where a whole host of facilities will be available for everyone taking part in all four event locations – toilets, hot food and refreshments available to buy, car parking and a great atmosphere pre and post hike!

Sign up as a team – support each other on your Halloween hike!
Sign up as an individual – our Fright Hike crew will support you…and we’d love to meet you!

Sites for Fright Hike:
Sherwood Forest – 25th Oct
Forest of Dean - 1st Nov
Epping Forest - 1st Nov
Queen Elizabeth Forest Stirling – 25th Oct

For more details on either of these two events contact pete.revell@kidneyknf.com

Or

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We return to one of the most popular locations in the past 10 years, Blackpool, for our 2014 Patients’ Conference. If you have not yet taken the plunge and joined us for this annual event, this is surely the year to choose to come along and join in.

The Hilton Hotel on Blackpool’s famous promenade overlooks the sea and is just a few minutes’ walk – or a short tram ride - from the pier. So wake up to the exhilarating sea view, take advantage of the indoor pool for an early morning swim before joining us for what is going to be a packed conference agenda.

Audience participation in a popular debate, informative talks from professionals and patients will set you up for the cooking demonstration during the afternoon, by celebrity TV Chef – and kidney patient – Lawrence Keogh. His recipes are all adapted to offer the kidney patient the best nutritionally balanced eating plan packaged up in exciting meal choices. This demonstration really is a must for anyone feeling disheartened at the prospect of following a renal diet.

Saturday evening’s Gala dinner will culminate in entertainment by comedian, Bobby Dazzler and a disco for those of you wishing to strut your stuff on the dance-floor. And for those of you really young NKFers, Blackpool’s late night-life is legendary and you are free to party on into the wee small hours. Very early wake up calls will be booked on your behalf.

On Sunday we will be running an open forum discussion addressing some of the problems we face as kidney patients. This is your opportunity to spend time with your contemporaries and associated professionals to learn about what options you have, and is always a very popular aspect of our annual get together.

For those planning to arrive on Friday evening, many will be attending the Chairman’s meeting where a more general debate on what is going on in our kidney world will take place. And later, Pete Revell will be hosting a Quiz Night in the bar.

If you are one of our new Kidney Life readers make THIS year the year you join us at this great weekend event. You will make friends, enjoy the Hilton’s hospitality and learn a lot. If funding the weekend is a worry for you please get in touch with your hospital’s Kidney Patient Association (KPA) as they may well be able to offer you some financial assistance.

To book your place at this event please use the booking form on page 24 of this issue of Kidney Life. Alternatively you may book and pay securely via our website at www.kidney.org.uk

See you there!
Throughout my life I have always wanted to help others have a better quality of life, and have been involved with projects as diverse as working with AIDS orphans in Rwanda after the genocide war to helping the elderly in Islington with their weekly shopping.

In 2011 my brother, Tayo was diagnosed with end stage kidney failure and needed a transplant and, as his only sibling I offered to be his living kidney donor. Nothing could have prepared me for the journey ahead. It was an emotional time and after months of medical tests I was told I could not donate as my health may be put at risk. I was absolutely heartbroken as I desperately wanted to help him. My two daughters Bimmi and Mo also went forward to be tested to see if they could donate, but unfortunately were not compatible. For months I wallowed in my grief but as my brother began his daily routine of dialysis I knew I needed to use my experience to effect a positive change in my community. I wanted my story to portray the realities of dialysis and the struggles people with kidney failure face. In 2013 I self-published a book called More Than a Match, which narrates a moving account of my family’s experience as potential living kidney donors for a loved one. It takes a light-hearted approach as it walks people through the living donor assessment process.

As a potential kidney donor, I learnt that African Caribbean people have one of the lowest sign ups to the organ donor register and as a result waited much longer for a kidney transplant than the rest of the general population. I set out on a mission to survey African Caribbean people in churches, hair dressers, barber shops and black community groups to find the answer. Many said they were reluctant to sign up to the organ donor register for ‘cultural reasons’, were willing to be a living kidney donor for a loved one but didn’t really understand anything about organ donation. I saw this as a great opportunity to use my experience to inform people about living kidney donation. I decided to use film as a visual form of raising people’s level of understanding and give them a different perspective. I co-wrote, self-funded (no money in the NHS kitty!) and produced a short independent film called We Are Family.

We Are Family is inspirational and thought-provoking story about the Williams; an African Caribbean family struggling to come to terms with one of their own recently diagnosed with kidney failure and who needs a transplant. It has the makings of a daytime TV soap with family quarrels, tense and tearful moments, and also a little romance. The film captures their challenges and fears as they embark on an emotional roller-coaster to overcome this real life situation. However, the most powerful element of the film is not a portrait of a family in crisis, but the illustration of a wonderful message of love and a genuine solution. At the heart of the film is its authenticity as people find themselves identifying with its characters.

The film is a unique and innovative way of engaging with people about the important benefits of being a living kidney donor, although it illustrates the diversity of black family life it is relevant to people from all backgrounds. It is a useful resource that can encourage more kidney patients to ask their family and friends for support and more importantly it can succeed in opening the hearts of relatives and close friends on a subject that is unfamiliar. It’s clear from evidence that the quality of life of their loved one is improved following a transplant in comparison to dialysis.

The film creatively blends information and drama to communicate a social message and connect people in a powerful way whilst offering a solution to increase the number of transplants for black kidney patients. It subtly informs people on dialysis, organ donation and transplantation and will hopefully leave viewers with a desire to become a living donor or to join the organ donor register, and for those living with kidney failure the hope of a better quality of life.

There will be a special screening of WE ARE FAMILY on the 1st of July 2014 at 6pm at the Lexi Cinema, Chamberlayne Road, Kensal Rise, London NW10. For more information email: info@giftoflivingdonation.co.uk or call: 020 8451 1605

Dela Idowu
Co-writer and producer of We Are Family, is the author of More Than a Match - one family’s experience of living kidney donation, Director of Gift of Living Donation, a community Interest company, and a member of the Guy’s & St. Thomas’ Kidney Patients’ Association and Clinical Reference Group for Adult Kidney Transplant service.
I will always remember the first day I was told that I may have Kidney Failure, I had been to my local GP for a blood test and within 3 hours my GP had called me to tell me to go to Lincoln Hospital and report to a ward where I was to spend the night. The next day I was transferred to Leicester, which in itself was eventful as we navigated icy roads in an old ambulance and got lost.

Eventually we arrived and the doctors came to speak to me and told me that they would need to do tests as they suspected I had kidney failure. I remember saying, “Let’s get on with it then.” I had a biopsy and further blood tests. I went home to rest and then returned a few days later to start haemodialysis; at first through the groin, then via a line and eventually via a fistula.

I was transferred to Lincoln Renal Unit where I continued to dialyse 3 days a week for 4 ½ to 5hrs a session, for nearly 5 years. Then one night I got a call telling me that there was a kidney for me. I had dialysis for 3 hours when I got to the hospital but then went into theatre to have my transplant.

When I came around I felt the difference straight away. For those who know me…I do like a nice cup of tea and for the first time my cup was full to the brim and I was allowed to drink the lot! After 7 days in hospital I was discharged and started to walk around the village. It has now been 6½ years since I had my transplant and all is well…it’s just the rest of the body that’s dodgy now.

As a kidney patient on dialysis I had many problems to deal with including too high calcium levels, difficulty controlling fluid intake and dietary restriction, emotional issues, relationship issues and dealing with the knowledge that some friends just did not want to know and telling me to cover up my fistula. Life was not easy at that time and so this transplant means a lot to me.

When I was dialysing at Leicester I joined the Kidney Patient Association (KPA) there but when I was transferred to the Lincolnshire KPA as it was closer to home. But after my transplant I still wanted to help out and so went onto the committee and became the Unit’s representative helping peritoneal dialysis and pre-dialysis patients in Lincolnshire. A year later I became Lincs KPA Secretary. A post I held for 5 years.

I have now gone back to Leicester KPA and joined the committee there to help pre-dialysis, dialysis and transplant patients. I am also keen to help young patients, BAME (patients from black, Asian and minority ethnic backgrounds), fundraising, and anything else that comes my way. If I only help one person a day, I know I have done something. I have done some daft things for KPs too though. Being Father Christmas springs to mind…and no, I am not taking bookings!! Also, I was given a puppet with pyjamas on as a gift and I decided to use him as an aid to explain what it was like to have kidney failure in the hospital. Children loved him, as did the nurses and even the doctors came around to like him too.

During this time I was asked if I wanted to join the NKF Executive Committee, and thought, like many of you might think, that I did not know enough to be of any use. But some friends on the KPA said I did and so I decided to have a go and get a nomination form and send it in. At the NKF AGM I was accepted onto the Executive Committee. I was shocked but chuffed to bits at this. It means I can really help people who have kidney failure everywhere now.

I was elected for a second and third year, and I have been involved now in so many diverse things such as going to Parliament to APPKG (All Party Parliamentary Kidney Group) meetings, the BAME Manifesto, surveys, fundraising, raising the profile of NKF and NKF website improvements. I have enjoyed every moment. Then, in my third year I became co-lead of Young@nkf. Young@nkf keeps all those under the age of 30 in touch with what is going on in the kidney world via all means of social media.

In 2013 someone suggested that I stand for the post of Secretary of the NKF. After thinking about this for a while I submitted a nomination form and once again at the AGM I was voted in as Secretary to the NKF. I thought WOW, I’ve done it! Now I am involved in all sorts of NKF official business which means I go into the NKF HQ regularly. The year started off seeing me attend sub-committee meetings for the NKF, attending NHS England meetings amongst a host of meetings where we address all manner of aspects of kidney failure such as APPKG, PKD, Phosphate issues, BAME updates and Young@nkf matters. The Young@nkf is great fun too. Last year we attended a ‘Young Adults with CKD’ weekend away. This was a fantastic event that focused on young adults with CKD and gave them all a chance to join in group outdoor activities and talk about what their kidney failure means to them. It was a very worthwhile and valuable event for everyone.

‘It has now been 6 ½ years since I had my transplant and all is well…it’s just the rest of the body that’s dodgy now’

On the 29th March 2014 the NKF held its second KPA Day in Birmingham. At the AGM on this day I was re-elected to the post of Secretary for the NKF for the year 2014/15. Let’s see what this year brings for us. There is a future for kidney patients; we’ve just got to keep working at it.

I never imagined my experience would see me helping kidney patients all over the UK in this way and I would encourage anyone who feels they have something to offer kidney patients, to step forward and join the NKF on the Executive Committee. If I can do it, you can too.
Medicines: to take or not to take.

By Andrea Devaney, Consultant Pharmacist – Transplantation and Renal Services, Oxford Transplant Centre, Oxford University Hospitals NHS Trust. BPharm, MRPharmS (IPresc), FFRPS, DipClinPharm, MSc

Medicines are considered the most common therapeutic intervention in healthcare and as such there is a national drive to help patients, public and society in general achieve best outcomes from medicines. More recently the term ‘medicines optimisation’ has been borne. Medicine optimisation is a multi-disciplinary and patient-focussed approach to getting the best use of medicines and it is central to ensuring that the right patient gets the right choice of medicines at the right time. There are four important principles of medicines optimisation: aim to understand the patient’s experience, evidence based choice of medicines, make medicines optimisation part of routine practice and ensure medicines use is as safe as possible. Ultimately medicines optimisation can help encourage patients to take ownership of their treatment, and an improved focus on outcomes for patients will help ensure patients and the NHS get better value from the investment in medicines.

Medicines are the second biggest spend for the NHS, second only to staff costs. Over the past few years all organisations across the entire NHS have been working to develop service plans, including for Kidney care, to deliver Quality, Innovation, Productivity and Prevention (QIPP) initiatives, and to generate efficiency savings which can then be reinvested back into services. Given the significant spend on medicines, it is not surprising that medicine waste reduction is also a national target and as such it is everyone’s responsibility to tackle this problem. It is estimated that up to £300 million is wasted every year on unused or partially used medication and a national Medicine Waste campaign was set up in 2012 to highlight this issue. Medicine waste is not a new problem and back in 2003 the World Health Organisation established that in developed countries, up to 30-50% of patients with long term conditions did not take their medicines as recommended.
“Medicines will not work if you do not take them” and medicines will not be effective if the prescribed treatment is not followed. However, medicine non-adherence should not be considered as just the patient’s problem. Healthcare professionals have a duty to support patients to take their medicines and achieve best outcomes, and in so doing this starts with ensuring full agreement with the patient at the time of prescribing and maintaining support to the patient once the medicine has been dispensed.

Medicine non-adherence is categorised into two types—intentional (the patient decides not to follow the treatment recommendations) and unintentional (the patient wants to follow the treatment recommendations but has practical problems). Figure 1 describes a practical guideline for missed doses when taking a medicine on a once or twice daily basis. It is perfectly normal in everyday busy lifestyles to miss a dose of medicines, however, repeated missed doses can affect your health and if you have a transplant then this can lead to rejection. It is well reported in transplantation that medicine non-adherence leads to a threefold increased risk of late acute graft rejection and a seven-fold increased risk of graft failure. If you are missing doses regularly then you should speak to a healthcare professional as there may be a simple alternative or a medicine adjustment that could be made to help you to take your medicines more consistently.

It is important to be open and honest with the healthcare professionals involved in your care so that in turn they can offer appropriate supportive advice/suggestions to assist with the overall goal of achieving best use of medicines and optimum treatment outcomes. Multi-compartment compliance aids or dosette boxes are a very helpful way of supporting medicine taking. Many different types are available to purchase via community pharmacies or the internet, some even have an in-built alarm to alert you to take your medicines, but in the end it is a personal choice as to what will work best for you. Another advantage to a compliance aid is you can easily see if the dosing box is full or empty, therefore confirming whether or not you have taken your daily dose can be extremely beneficial. Double dosing should be avoided wherever possible. Where there is medical need e.g. visual impairment or language difficulties, multi-compartment compliance aid which are pre-filled with your medicines can be requested and supplied via your doctor. Confusion around why a medicine has been prescribed and at what dose is another common reason for non-adherence. This situation can arise for various reasons and it is important clarification is sought as soon as possible from a healthcare professional e.g. GP surgery, community pharmacist. The prescribing process is a multi-principle process and includes a two-way negotiation between prescriber and patient, during which the patient’s views, experiences and expectations should be considered in order to achieve adherence and best outcome. A visit to the renal centre also provides an opportunity for medicine review, either during a routine out-patient clinic or an in-patient admission, and this is an ideal time to raise any medicine concerns or queries. As part of this review process patients may be given or can request a personalised medication record card which details their current medication, medication strengths, quantity to take throughout the day, reason for taking, common side-effects and additional information including specific information e.g. planned stop dates. This card provides an informative overview of the current medicines.

Through adoption of the medicine optimisation approach safety, adherence to treatment and reduction of medicine waste can be achieved by supporting patient’s to get the best outcome from their medicines. Do always ask if you are unsure about your medicines, have any concerns or are repeatedly missing doses as there is always a healthcare professional willing to help and there may be an easy solution available.

References:


3. Medicine Waste campaign
www.medicinewaste.com

On World Kidney Day the SKF had a table in the entrance of the Southport and Formby district hospital to publicise the importance of looking after your kidneys. They had information leaflets and also gave out bottles of water, kindly supplied by Tesco.

Ann and Omid Khoshbin held a fundraising event at The Verve 37 in Uplands, Swansea to raise awareness of WKD. Ann donated a kidney to her husband, Omid.

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Visiting Dyffryn Comprehensive School are celebrity TV driver, The STYK with Morriston Renal Unit Dietician and Chris Brown, Lead Renal Pharmacist talking to pupils from the science class where they learned about each form of dialysis.

Living Donor co-ordinator at Morriston Renal Unit, Helen Burt offers ladies at Castle Bingo in Swansea, a cup of water and a blood pressure check.

At the LC2 Leisure Centre in Swansea, Osprey Rugby players with two pairs of living donors: mums, Fran George and Rae Jones each donated a kidney to their daughters, Kathryn and Elinor.

Southport Kidney Fund

Lancashire & South Cumbria KPA

KPA members joined staff at the Royal Preston Hospital on a stall in the Main Outpatient waiting area handing out WKD information. A KPA member, who is about to join the committee also had a letter about her sister from whom she received a live kidney read out by Alan Titchmarsh on his afternoon show on ITV1.

John Sagar, who chairs the L&SC KPA spoke to the Imam at Nelson’s main mosque and, as a result, he has put a WKD poster & leaflet on the main entrance notice board, which should be seen by 500 attending a funeral on World Kidney Day and 1500 who attend Friday prayers.

John also gave the Imam information concerning the ratio of Asian to white donors and ‘requiring recipients’.

Stoke on Trent

University Hospital of North Staffordshire

Mark Davis along with CKD Consultant, Dr Sat Reddy and Renal Matron, Pam Towe gave an interview to BBC Radio Stoke on what it means to be a kidney patient and highlighted the important role our kidneys play.

Afterwards, along with many of the nurses from the renal unit an event was held in the main atrium of the hospital in Stoke-on-Trent. The event took the form of chatting to passers-by as they entered the hospital, about kidney failure and the need to be aware of the role our kidneys play. Nurses took blood pressure and handed out leaflets. For anyone advised to do so a further (urine dip stick) test was available in one of two private rooms allocated for the purpose. In all around 100 members of the public attended the stand.
North West Region

The HOPE KPA

The Hope KPA celebrated World Kidney Day by Tweeting messages of encouragement around the world highlighting the importance of getting more live donors on the transplantation register. Hosted by Cristina Vasilica, Rob Finnigan and Stuart Powell over a 16 hour session of keyboard and smart phone bashing, the team of twits were all tweeted out after a busy day tweeting and re-tweeting over 1000 messages from around the Globe via @GMKiNet #KidneyKIN.

Meanwhile at Salford Royal Hospital, members of the Hope KPA committee were on standby at a table set up to promote the importance of signing up to the NHSBT Organ Donor Register.

Mersey Region

Kidney Patients Support Group

Members of the MRKPSG handed out WKD information to members of the public at the Royal Liverpool Hospital, and organized a raffle and tombola to raise funds for the group’s activities.

Bolton KPA

The Bolton KPA has held various events for WKD including a Trinidad and Tobago Day and India Day. The idea was to have a day of food and culture at the unit from the different countries that people on the unit originate from, both staff and patients. People would bring food in and decorate the waiting area, even dressing up. It was a good way of bringing everyone closer together and with the great food we have had, makes a welcome change from the cardboard sandwiches!

Other events they have put on in the past include Summer Fayres and Christmas parties, which gave a chance for patients, staff and families to have a great time and get to know one another outside the hospital environment.

The amazing thing about the Bolton group is that it has just 25 members, including a couple of people who are not patients or staff at the unit! This really brings home the mantra of ‘if we each do a little, we’ll all do a lot’ and does wonders too for building patient partnerships with staff.

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Rituximab is safe and effective in nephrotic syndrome

One or two doses of rituximab prevented recurrences and reduced the need for immunosuppression in people with steroid-dependent or frequently relapsing nephrotic syndrome included in a clinical trial.

The study included 10 children and 20 adults with minimal change disease (MCD), mesangial proliferative glomerulonephritis (MPGN) or focal segmental glomerulosclerosis (FSGS), who had all been in remission for more than one month after steroid treatment. Participants received one or two doses of rituximab intravenously. One year later:

- Every patient remained in remission; 18 were treatment-free and 15 never relapsed
- Compared with the year before rituximab treatment, total relapses fell from 88 to 22 and median number of relapses per patient decreased from 2.5 to 0.5
- These effects were seen across all types of disease and in both adults and children
- Mean estimated glomerular filtration rate also rose significantly, with the largest increases seen in children and in FSGS patients
- Treatment with rituximab was also well tolerated.


Does living donation increase the risk of kidney failure?

Researchers from the USA report that, compared with healthy non-donors, living kidney donors have a slightly higher risk of kidney failure. However, this increased risk is extremely small:

- After 15 years, the living donors had an estimated risk of kidney failure about 3 in 1000 compared to 0.3 in 1000 for healthy non-donors.
- The estimated lifetime risk of kidney failure was 9 in 1000 for the donors, compared with 1.4 in 1000 for healthy non-donors and 32.6 in 1000 for unscreened non-donors.

While this study is at first sight worrying, its results are in fact reassuring. The increased risk for donors was very small and much less than in unscreened people in the general population. The risk of kidney failure is also unlikely to be due solely to donation, since this study does not differentiate between unrelated living donors and family members who may share some health risks with the kidney recipient.

Journal of the American Medical Association 2014; 311:579-86

Kidney transplantation is feasible for HIV-positive adults

This study reports outcomes in 35 HIV-positive people, who underwent kidney transplantation up to December 2010:

- At one and three years, patient survival was 91.3% and graft survival 91.3% and 84.7% respectively
- At one year, the cumulative incidence of acute rejection was 48% and median estimated glomerular filtration rate was 64.

HIV-positive people are at increased risk of kidney failure, and this study confirms the feasibility of transplantation. But kidney complications were frequent, even though HIV virus levels were under control and HIV disease progression was uncommon.

The authors add that the highest rates of acute rejection indicate that immunosuppression needs to be further refined in HIV-positive transplant recipients.


Statins improve heart surgery outcomes for CKD patients

Clinical trials have shown that statins reduce the risk of death and disability after heart surgery in the general population, but there is little information on use of these drugs in people with chronic kidney disease (CKD).

This study looked at outcomes in 2306 people with CKD (estimated glomerular filtration rate less than 60) who underwent angiography and stenting between July 2004 and December 2007 in the USA. At discharge from hospital, 79% of the patients were receiving statins. One year after discharge:

- Death from any cause occurred in 5.7% in statin group compared to 8.7% in the no-statin group
- The risk of heart attack or repeat heart surgery was also lower in the statin group

American Journal of Cardiology 2014;113:621-5

Good blood glucose control worthwhile for young diabetic dialysis patients

A study from the UK Renal Registry concludes that lower HbA1c levels before and during dialysis improve survival in people with diabetes aged under 60 years.

In 3,157 people with diabetes followed up for a median of 2.7 years:

- Compared with HbA1c 6.5-7.4% (48-57 mmol/mol), HbA1c 7.5-8.4% (58–68 mmol/mol) reduced the likelihood of survival by 20% and HbA1c over 8.5% (over 69 mmol/mol) reduced survival by 50% in people aged under 60 years.
- There was no association between HbA1c and survival in people aged over 60 years and above.

The researchers add that the highest HbA1c is likely to decrease survival by one year. They conclude that their findings support current guidelines advocating tight blood glucose in younger patients before and during dialysis.

Adler A, et al. Diabetes Care 2014; epub 26 February

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.
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.
Here is my gift to help the work of the National Kidney Federation

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.

Yes Please
Date: ........................................

Name of account holder: ............................................................................................................
Bank sort code: ........................................... My account no: ................................................................
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
British Transplant Games
This year the British Transplant Games will be held in Bolton
Thursday 7th August - 10th August 2014

The British Transplant Games are organised on behalf of Transplant Sport. The Games were inaugurated in 1978 in Portsmouth by Maurice Slapak, who at the time was a Consultant Transplant Surgeon. About 100 participants took part in the first Games in a one day event.

Over the past 35 years the Games have grown to a four day annual event with over 600 transplant recipients aged from 2 - 70+ taking part in over 20 different sports with over 1000 supporters watching on.

Some members come to win medals, training for their specialist events, hoping to be selected for Team GB & NI competing at the World Transplant Games. Most come to meet new friends; catch up with old friends; enjoy new sports at their own pace and relax for a few days with others who have also faced debilitating illness but are now fit and well as a result of a successful transplant.

Qualification criteria are simple: if you've had a life-saving organ or bone marrow transplant or are a living donor you qualify to join in the fun at the British Transplant Games. Here's your opportunity to meet others who have shared similar experiences, try out new sports, compete for gold medals and, of course, remember your donor. All are welcome, regardless of sporting ability. Hopefully, taking part in the Games will encourage you to regularly take part in activities!

There is still time to register but look smart – the closing date for entries is 30th June 2014.

And please do not forget to send copies of your photographs in to Kidney Life – we promise to publish as many as possible!

For more information on the UK Transplant Games 2014 please go to: www.transplantsport.org.uk or, for those wishing to enter: www.britishtransplantgames.co.uk

GOOD LUCK EVERYONE!
Striking a balance; potassium & why do they matter?

Following a renal diet can seem frustrating and if you also have other medical conditions requiring special diets such as diabetes or coeliac disease, making further adjustments can appear very daunting and confusing. Renal dietitians are used to banter on the units and regularly hear “don’t let the dietitian see you eating that banana” or “I won’t tell the dietitian about the fish and chips you ate last night” and we are aware of those that fake sleep when the dietitian arrives on the unit! However, we are there to help...

Diet is something that you have control of in your treatment and it can make a huge difference to your health and future outcomes. Your dietitian can work with you to still include many of the foods you previously enjoyed. So, if you want those fish and chips or a little banana, this is not impossible: just chat to your dietitian to discuss how these can occasionally be included.

Most people need to restrict potassium and phosphate on dialysis; however the level of restriction is very individual, depending on blood results. Salt and fluid restrictions are important for almost all renal patients. I aim to discuss dietary restriction of potassium in this month’s article.

Potassium

Potassium is important for the normal function of all nerves and muscles, including the heart. Levels are normally controlled by the kidneys, however in renal failure, blood potassium levels often increase as the kidneys are unable to excrete enough excess potassium in the urine. Target range for potassium is 3.5 – 6.0 mmol/l and levels above the normal range can increase your risk of heart attack.

Potassium usually needs to be restricted to 1.0 mmol potassium per Kg body weight; therefore a large man can often manage a higher potassium allowance compared to a small-framed lady. However, there are many factors that can influence the level of potassium restriction needed that also need to be considered. Little or no urine output, missing dialysis sessions, reducing time on dialysis, poor diabetic control and certain medications can also increase potassium levels and may increase the need for tighter dietary restriction.

So….. you are told you need to restrict potassium and are then provided with a list of foods to include and those to avoid. It seems like all the food you enjoy is on the avoid list and all you have left to survive on is dust. However, there are plenty of foods to still enjoy, so try to be positive and work with your dietitian to discuss suitable meals and snacks to include in your diet.

The foods on the avoid list are the highest sources of potassium and too many of these foods will increase your risk of potassium levels increasing above 6.0 mmol/l. However, nothing needs to be avoided completely, it’s about eating in moderation, thinking...
phosphates

By Nicola Walpole, Dietician

about your overall day’s intake of potassium and working with your dietitian to plan how you can still include foods you enjoy.

Potatoes are high in potassium. Soaking potatoes overnight, chopping small and boiling all help to reduce the potassium content. However, an average portion of boiled potatoes are generally around 13.0 mmol/l potassium, around a fifth of most people’s potassium allowance. Baked potatoes, chips and roast potatoes are very high sources and can contribute three quarters of your daily potassium intake in an average serving. If you miss roast potatoes and chips, your dietitian will usually be happy for you to boil a potato and then roast it or have a small handful of chips, however it is all about portion control and planning meals with your dietitian to see how these can occasionally be included.

A small tin of baked beans (150g) is around 12.0 mmol/l potassium, an average banana 11.0 mmol/l potassium and 8 fried button mushrooms around 7.0 mmol/l potassium. Therefore, you can see that if potatoes are avoided, there is flexibility to include small portions of these high potassium foods occasionally. If you use other sources of carbohydrate such as rice, pasta, noodles, couscous or bread and avoid potatoes on the day you wish to include one small portion of high potassium foods, this can normally allow you more flexibility with your diet e.g. you may be able to have a few slices of banana on your cereal, a small tin of baked beans on toast, chilli con carne with rice or a few mushrooms with a fried breakfast for example on the days potatoes are avoided.

Fruit and vegetables are often limited to 4 portions a day on standard lists; however your dietitian may be able to provide you with more detailed lists of potassium content, such as the Renal Nutrition Group low potassium diet sheet, to allow you more flexibility to include more portions of the lowest sources. Remember to watch portion sizes though! It is easy to look at a low potassium list and ignore the portion guidance. A low potassium food can easily become high if portions are too high e.g. 3 tablespoons peas contain 3.3 mmol/l potassium (low) and 9 tablespoons 9.9 mmol/l potassium (high).

Eating out can often increase potassium levels. Sometimes this is due to no control over the cooking methods used to prepare vegetables. However, often is it due to too many high potassium foods being eaten on the same day; wrong choices of food and large portion sizes. I have often heard “I don’t go out much, I am going to eat what I like”, however a high potassium feast of potato wedges for starter followed by steak, chips and beans and then chocolate pudding risks dangerously high potassium levels.

Try to choose lower potassium choices and if you would like to include a high potassium course, ask for a small portion and try to make sure the rest of your meal is low in potassium e.g. have a pasta dish followed by a small portion of chocolate pudding or ask for the steak to be served with boiled potatoes or rice or couscous and have pavlova or treacle sponge or trifle for dessert. Good choices for starters could include a few olives, garlic bread, a small prawn cocktail or a small slice of water or galia melon. Main meals could include pasta or rice or noodle based dishes: lasagne with a small salad and Ciabatta, risotto, burger with a few corn crisps, salmon with boiled potatoes and vegetables, meat curry and rice or chicken fajitas are all good choices.

State-of-the-art renal unit opens in Merthyr Tydfil, South Wales

On 8th April Health and Social Services Minister Mark Drakeford was joined by Welsh legend Max Boyce to open a state-of-the-art renal unit, in which the Welsh Government had invested over £2m.

Built to replace the old unit in Prince Charles Hospital, the new facility will improve the patient experience in a number of significant ways.

The new unit has an additional 17 stations, allowing all suitable patients to be treated locally rather than face the need to travel, and can provide local treatment for a wider range of patients than the original unit.

The new unit also contains a self-care area which, once in use, will further encourage greater independence; a key factor in managing long term conditions such as chronic kidney disease. It also contains a training area for home dialysis, providing a helpful transition between unit and home.

Health and Social Services Minister Mark Drakeford said:

“Even in these financially challenging times, we are serious about investing in infrastructure, technologies and services to help support the NHS in Wales to deliver essential services to patients. At a time of such perceived uncertainty, we are committed to improving services in Wales to make them safe and sustainable for now and into the future.

We want to continue to modernise facilities and increase capacity for dialysis in a number of sites across Wales as part of a programme of development in renal dialysis care”.

Mark Drakeford, Minister for Health and Social Services unveiling the plaque. Photo: courtesy of John Owens, WKPA

HELPLINE 0845 601 02 09 www.kidney.org.uk Summer 2014 19
As I write, the Work & Pensions Select Committee is due to report back on the ‘support for housing costs in the reformed welfare system’, to which I submitted evidence on behalf of the NKF back in October 2013 with regard to the ‘bedroom tax’ (or referred to by the DWP as the Social Sector Size Criteria or SSSC).

In summary, they report “the ‘bedroom tax’ is having a particular impact on people with disabilities, especially those living in adapted accommodation, or who need an extra room as a result of their disability, and who are unlikely to be able to move house or enter work. There is evidence that many of these people are suffering financial hardship’. This much we know already but furthermore in homes which have been significantly adapted for them should impact of the SSSC on disabled people. Disabled people living they ask that ‘the Government should take steps to mitigate the be exempt from the SSSC. The Government should also exempt from the SSSC all adults on the higher rate mobility or care component of Disability Living Allowance, or equivalent in Personal Independence Payment’. The report also looks at Discretionary Housing Payment (DHP) and asks that the Government ‘issue clear guidance that disability benefits should be disregarded in any means tests for DHP’……and make explicit that it supports long-term DHP awards for specific categories of claimant’.

As more information becomes available we will update our website (www.kidney.org.uk) as we expect a response from the Government in due course, before any update or amendment to current procedure. Watch this space!

With a number of requests for assistance when it comes to supportive letters for tribunal hearings or to local authorities in terms of applying for DHP in ‘bedroom tax’ issues. It has been widely reported that ATOS will not have their contract renewed for and furthermore will finish before the end of 2015. Many of you their work on capability assessments or on benefit assessments, However, who will replace them remains to be seen! As a service The NKF is pleased to acknowledge the substantial financial support that the BKPA provides to fund five of the eight NKF Advocacy officers in the UK.

Earlier this year the NKF wrote to our network of KPAs, and highlighted on the website the issue of Repatriation of patients receiving immunosuppressive drugs post-transplant to specialist centres, raised by NHS England. As an organisation we are conscious of the need to raise awareness of chronic kidney disease (CKD) as well as Dialysis and Transplantation and so it would be useful to hear about any positive or negative stories from you about being employed. I am sure there are many stories out there so please get in touch with your local advocacy officer.

I wish you a happy and healthy summer and ask you to look out for further information over the coming months on our website regarding new guidance for Dialysis Away From Base, patient friendly versions of Dialysis and Transplant service specifications, and information about the Dialysis Games planned for the summer.

Nick Palmer, Head of NKF/BKPA Advocacy Team
Dennis Crane retires

Long-standing volunteer and employee of the NKF Dennis Crane, will be retiring in August. Dennis leaves a proud record working tirelessly on behalf of kidney patients in his role as Regional Advocacy Officer for the North of England since 2004, and latterly the North West of England when, in 2012 the service grew from three to eight officers as a result of generous sponsorship and ongoing support from the BKPA.

Dennis started life with the NKF in the mid-1990s, as a National Executive member and secretary. In football terms Dennis would be long overdue a testimonial - a sell-out it would be – perhaps the Colin Bell of the team!

Today Dennis remains a transplant recipient of over 30 years. He was an ‘original’ home dialysis patient in the years of D.I.Y. machine building; this experience and insight together with a blend of humour and professionalism has made him a perfect patient champion, ambassador and leader, helping to shape the kidney community and reflect our diverse needs. It came as no surprise that Dennis was awarded the MBE in 2002 for his service to people with kidney disease.

Admired and respected by colleagues, patients, clinicians, academics and managers within the NHS, Dennis has directly helped patients through advocacy but also through involvement in research projects, publications, and membership of most recent note the ‘Dialysis and Transplant Clinical Reference Groups’ and the ‘Yorkshire Dialysis Decision Aid steering group’.

The Advocacy Team hold Dennis in high regard and have endeavoured to absorb his wisdom to the maximum. His sharp wit and questioning mind will be missed as will his friendship and support and it goes without saying that everyone associated with the NKF past and present wish Dennis a thoroughly enjoyable and most healthy retirement, knowing full well he will be keeping his finger on the pulse of local issues but, we hope enjoying the benefit of some down time!

‘Good luck Dennis and thank you, from all of us at the NKF for your hard work. You will be missed!’

Super Kidneys are Super Heros

Teacher, Lisa Morgan (sitting in the middle) who has received a kidney in a living donor transplant from her brother, was the inspiration behind the School Assembly at Swiss Valley Primary School in Llanelli, Wales on World Kidney Day. Pupils in Miss Morgan’s Class 1 dressed up as their favourite super hero to illustrate the role of the super hero kidney. All of us here at the NKF think all of you children in Class 1 are true SUPER HEROES!
Scottish kidney patients’ nightmare in the snow

by Ewan Maclean, NKF/BKPA Advocacy Officer for Scotland

Those of us who have experienced kidney failure know that for many of us thrice weekly dialysis sessions are an essential part of our treatment. This treatment alone takes a toll on our systems and on our family life and can play havoc with work and leisure. Add this to the mix of daily medications, clinic visits, travel and transport issues to and from hospital - and we must surely sometimes wonder how we cope.

However, if you are feeling sorry for yourself, remember Aesop’s fable – ‘there’s always someone worse off than yourself’. And in the case of some Scottish patients, nothing could be more accurate.

Imagine their thrice weekly journey. They rise at 7.00 am, have a light breakfast in preparation for pick up at 8.15 in a Red Cross minibus and then begin the journey to their dialysis unit. The first 50 miles is on a rough country road then continues onto one of Scotland’s most dangerous roads; one which gets them to hospital in Vale of Leven some 3 hours 30 minutes later….and even then, only if road and weather conditions are favourable.

Sometimes there is a wait before a machine becomes available and then they dialyse for 4 or 5 hours before getting back into the Red Cross van to undertake the return trip of 3+ hours back home. As we have all witnessed, this winter has seen extremely adverse weather conditions and during this, journey time was extended by an extra hour each way. On more than one occasion recently, during heavy snow they were unable to complete their journey at all, with one particular weekend where they were on the road to the hospital for seven hours, only to return home without having received any dialysis at all.

On average, they are home by 8pm, sometimes much later, so tired that even the thought of cooking a meal is abhorrent. Most dialysis days, these patients go without a hot meal at all. Even in the winter, the hospital provides only a sandwich and cup of tea.

As one of the patients said: “we have a light breakfast, because the road is so bumpy and winding that to have anything substantial makes us feel queasy. We thought the hospital would at least supply us with a hot meal but all we get is a sandwich and tea. As a result I spend three days of every week without a hot meal as I am always too tired to start preparing food when I get home. In summer this is just bearable but in the worst of Scottish winters when our journey is even slower, it is intolerable”.

These patients are tired of the journeys and fear that it is the very journey itself that could cause them harm. They drive past two hospitals, both of which have space for a dialysis unit and the hope is that NHS Highland will move quickly to establish a dialysis facility closer to their homes.

The NKF, through their Advocacy Service is actively involved in pursuing a long-term solution for these patients and believe that a local dialysis service could be provided quickly and cost-effectively within the two existing facilities in this part of Argyll bringing an end of these nightmare journeys.
The new fast-track kidney allocation scheme (FTKAS) for declined kidneys has led to more transplants, according to a survey of UK centres.

FTKAS is designed to optimise use of donor kidneys by simultaneously offering previously declined, difficult-to-place organs to the centres in the scheme. Between November 2012 and April 2013, 68% of 124 kidneys offered through the new scheme were transplanted, compared with 39% of 166 kidneys offered under the previous arrangements in 2006-11. In the Leeds researchers’ experience, outcomes in terms of graft and patient survival are comparable for FTKAS and standard-allocation kidneys.

Nearly three quarters of kidney transplant patients were unhappy or uncertain, and three fifths did not feel fully consulted when they were switched to generic immunosuppression.

These findings come from a small online survey conducted by the ESPRIT group and supported by the NKF. Reasons given for the switch were financial (76%) and medical benefit (40%), while 15% of patients were given no reason. Two fifths of patients needed a change in their immunosuppressant dosage, and 11 reported new or worse side effects. The ESPRIT group (www.esprit.org.uk) hopes to build on this survey to carry out more detailed research in a larger group of transplant recipients who have undergone switching.

Living kidney donation is safe for people with high blood pressure as long as the condition is treated effectively. Researchers from London analysed information from annual follow-up visits for 555 consecutive live donors from 2000-2012. In the 50 donors with high blood pressure, there was no evidence of proteinuria (protein in the urine) five years after donation. Their blood pressure also remained well controlled and was no different from blood pressure of other donors.

Eculizumab improves kidney function in people with atypical haemolytic uraemic syndrome (aHUS), both before and after transplantation. This finding comes from follow-up of two international clinical trials including 37 aHUS patients. The benefits of treatment were seen both in progressive aHUS and in long-standing disease, and improvement was likely to be greater the earlier that eculizumab was started.

Altruistic kidney donors who withdraw their offer can be expensive for transplant centres, report Bristol researchers. In the last six years, 105 people contacted the unit offering to donate a kidney altruistically. To date, 11 people have successfully donated and 49 are progressing towards donation. Twenty-one people were medically unsuitable and 17 decided not to go ahead with donation. The total cost of investigating the latter group until they pulled out was £19,864, but this does not take into account the amount of time spent by transplant co-ordinators. To reduce the likelihood of dropouts, the researchers recommend further studies to find out why people withdraw their offer.

Obese patients should not be denied kidney transplantation purely on the basis of their body mass index (BMI). This is the conclusion of an analysis of the records of people who received a kidney-only transplant between 2002 and 2012 in Cambridge. After five years, patient and graft survival was comparable for people with a healthy BMI and those classed as overweight or obese. The risk of wound infections rose with BMI, but obesity did not increase the likelihood of urinary, vascular or lymphatic complications.

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, historical estates and much more all on your doorstep.

For more information contact us on 01328 711996 Or email us on mermaid.dialysis@welshhospital.org.uk Please take a look at our web site www.norfolkdialysis.com Charity Reg No: 1154540CQC No: 1-302936793

HELPLINE 0845 601 02 09 www.kidney.org.uk Summer 2014 23
## Annual Patients’ Conference 2014

**TAKING CONTROL: NKF CONFERENCE 2014**

Hilton Blackpool
10 – 12 October 2014

**Please cut out the Booking Form and enclose it with a cheque made payable to National Kidney Federation and return to The Point, Coach Road, Shireoaks, Worksop Nottinghamshire, S81 8BW. You can also book by credit/debit card by calling: 01909 544999**

**Bookings may also be made online at: www.kidney.org.uk**

**Cancellation:** Any conference booking cancellation must be confirmed in writing. The NKF is unable to offer refunds on bookings cancelled after 29th August 2014 and recommends cancellation insurance is purchased.

### BOOKING DETAILS AND COSTS

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* this price is based on 2 people sharing.

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For any other dietary requirements please contact the office on 01909 544999.

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