

KIDNEY Life

The magazine of the National Kidney Federation



Summer issue 2010



LIVING KIDNEY DONATION *'With Love'*



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WHO'S WHO

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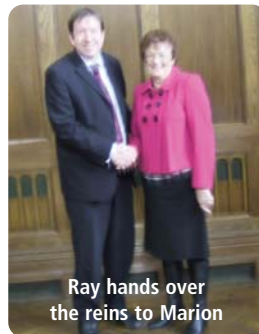
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Charity No. 1106735
Company No. 5272349 Registered in England & Wales
Give as You Earn contributions No. CAF. GY511

NKF AGM

The AGM, held in London on Saturday 27 March saw the handover by Ray Mackey and his supporting executive committee, to Marion Higgins and a newly elected team of officers and executive committee members. At the handover Ray gave a heartfelt speech thanking those committee and NKF staff members who had supported his enjoyable and very rewarding Chairmanship for the past three years, and reiterated his personal commitment to support Marion and the newly elected team during their period of office. Dick Cooke in turn thanked Ray on everyone's behalf, acknowledging the excellent contribution Ray has made to the NKF during his Chairmanship; a sentiment shared by everyone present at the AGM. A council meeting followed the AGM.



Ray hands over the reins to Marion



Newly elected NKF Officers: (left to right) David MacDonald - Treasurer, Kirit Modi - Vice Chairman, Marion Higgins - Chairman, Michael Abbott - Secretary

NKF Annual Draw

Enclosed with this issue are three books of tickets for the 2010 NKF Annual Draw. This is a superb way to help the NKF and we ask you to make every effort to sell the £1 tickets to your friends, relatives, work colleagues and neighbours. Great cash prizes and a free place at the 2010 NKF Roadshow Conference will also go to the winner of the first prize. If you find you are able to sell more books please call the NKF headquarters and we will arrange for more to be sent to you. Please return all counterfoils in the envelopes provided. *Thank YOU in advance of a really successful raffle!* **Tim Statham**

Pay the NKF by Credit/Debit Card



The NKF is now able to accept payment by credit/debit card via the NKF website. So far we are able to offer Friends' Membership, diaries and soon, NKF Conference booking payments. Early indications show very clearly that this is a much sought after facility and we are working hard to broaden its current scope.

Whilst we are not yet able to take card payments over the 'phone or by using the manual papers coupon machines, we are able to accept card payment online at www.kidney.org.uk for the services listed above.

Do You Twitter?

NKF activity can now be followed on Twitter - just go to twitter.com/NKF.UK

Tell the NKF SURVEY ZONE - Use it, don't lose it!

The NKF Survey Zone is YOUR opportunity to let us know how we can best represent YOU. Make a note to check the link www.kidney.org.uk/surveys (or click the 'Tell the NKF' button at the top of the home page) every week to ensure you have contributed to every survey listed. New surveys are listed regularly so checking the site regularly is the only way to make sure you have contributed to them all. One voice is important and might be heard - but 1000s cannot be ignored! This is how we maintain pressure on those who can make a difference to our treatment. The NKF will use the information YOU have provided in the Survey Zone to help formulate policy and assist the pharmaceutical industry and Government plan the future care of all kidney patients in the UK. So, to make your opinion count, make sure we have it!!!

How to contribute to Kidney Life

If you have an interesting story to contribute to *Kidney Life* there are many ways you can do this. You can either contact us by emailing the NKF on nkf@kidney.org.uk making sure your email subject line indicates it is for *Kidney Life*, or you can write a letter and send it in to the NKF HQ. If you have any ideas for *Kidney Life* and would like to speak to the editor about them, please let us have your contact details. Deborah will call you back to discuss them. If you are sending in photographs, please make sure they are sent as an attachment to email in jpeg format (hard copy photos can also be used and of course will be returned once used).

Deadline for Autumn 2010 issue is 9 July 2010.

We'd love to hear from you!

Sponsor or donate to the NKF

Donating to the NKF, or raising money by sponsorship could not be more simple. Just go to www.kidney.org.uk and click 'More' on the 'Membership and Fundraising clipboard'. It is really easy to organise an event without even needing to collect the money! If you need NKF merchandise to help you, click on 'organisation' then 'merchandise' from the NKF Home page.

The NKF Helpline

The NKF Helpline provides information to patients, carers, family, friends and medical professionals. Seek advice, obtain literature, get help - all from the one Helpline number (open for calls from 9.00 am to 5.00 pm, Monday to Friday): **0845 601 02 09** (charged local call rate, UK only) or e-mail: helpline@kidney.org.uk



Kidney Life is sponsored by:

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Anyone with access to the Internet can find the latest information from the NKF at www.kidney.org.uk

A black and white larger print or audio version of this issue is available by ringing 0845 601 02 09

Kidney Life is published by The National Kidney Federation, The Point, Coach Road, Shireoaks, Worksop, Nottinghamshire S81 8BW. The views and opinions expressed by contributors are not necessarily the view of The National Kidney Federation.

A VICTORY FOR KIDNEY PATIENTS

By Tim Statham

I am very pleased to announce that on 16 March 2010, in Europe, a consolidated amendment was passed which effectively removes 90% of the threat that amendment 31 would have posed to Living Donation in the UK and other member states. The actual wording of the agreed amendment is as follows:

'Living donation should be seen as complementary to post-mortem donation and may be carried out where there is no suitable organ available from a deceased person.'

Living donations are predominantly carried out among family members and close relatives and/or for the benefit of a recipient with whom the donor has a close relationship, or where it can be proven that the donor is not acting for the purpose of financial gain in order to prevent commercialization. Particularly, in the absence of such a close relationship, adequate provisions in national law of the Member States shall be made, thus assuring the highest possible protection of living donors.'

We will never know whether it was the submission made by the NKF, the paid for advertisement placed by the NKF, the very many letters sent by individual patients and KPAs, the interventions by the Department of Health (requested by the NKF), the submission made by the Kidney Alliance, or the efforts of the Irish Kidney Patient Association on behalf of CEAPIR that tipped the balance, but something worked despite the outlook appearing very bleak at times. Thank you all for your efforts.

This is an example of how powerful patients can be when they take action jointly. This really is a job well done.

Note: if you would like to read more on what prompted the NKF action and the level of concern alluded to in this letter go to www.kidney.org.uk/news/victory_eu-directive10.html

DRUG WARNING - SECOND REMINDER

The recent cases in the UK (2008/2009) of patients being offered ADVAGRAF instead of PROGRAF, or vice versa - in error by GPs and pharmacists - highlight the very **REAL** danger patients face if they accept a change to their medication made by anyone other than their Transplant Surgeon or Consultant Nephrologist. These days drugs are very complex and even though one make of a drug appears to contain the same or a similar drug to another (in the given example the drug is tacrolimus) the formulations can be very different and very harmful if taken by mistake.

The lesson is clear, if the drug you are being prescribed, or handed, is not identical to the drug you are used to taking – **DON'T TAKE IT** without getting advice from your own renal consultant. This applies even if the person is your GP, chemist, nurse or other physician.

Requested allocation of deceased donor organs

NHS Kidney Care has welcomed the announcement by the Department of Health to change UK-wide policy to enable organ donors and families to request the allocation of a deceased donor organ to a family member or close friend in certain exceptional circumstances. Guidance on the new framework has been prepared for donor transplant coordinators. This will give transplant teams greater flexibility in the allocation of organ donations, particularly in cases where a family member intended to donate a kidney to a person but sadly died before they could.

Beverley Matthews, director of NHS Kidney Care said:

"The guidance helps to clarify important concerns that can arise for bereaved families when faced with difficult decisions about organ donation. Nearly 7,000 people with end stage kidney disease are currently awaiting a kidney transplant, many of whom are supported by family members each and every day while they receive dialysis. This change in policy will undoubtedly provide a more supportive framework for both patient and potential donor."

Taken from *Kidney Care Matters Online*.
If you would like to read more on this topic please go to:
www.dh.gov.uk/en/MediaCentre/Pressreleasesarchive/DH_114864

IT'S A DATE

for the 2010

NKF Roadshow

at The Hinckley Island Hotel,
Hinckley, Leicestershire!

Friday 8th - Sunday 10th

October 2010



GOT A ROADSHOW POSTER IN YOU??

This year the NKF Roadshow has many new ideas to whet your appetite. One new feature is a POSTER COMPETITION, open to all KPAs and individuals (full details will be put onto the NKF website and sent to KPAs and renal units shortly). All you need is a 'renal idea' or a 'renal grouse' or something 'you wish would happen' to improve the renal experience.

The poster categories are:

1. New ideas to benefit Kidney Patients
2. Examples of best practice
3. Patient wishes
4. Message to renal providers - from the heart

Just create a poster that best describes or illustrates your concept and submit it to the NKF office. It can be A4 or larger, on plain or glossy paper, typed, drawn or printed, colour or black and white, with or without graphics or pictures.

All the posters will be on display throughout the Roadshow (8-10 October), for inspection and consideration by all attending delegates. They will be judged on their merits and prizes will be awarded for each category. Please note every poster must have a nominated 'representative' who will be present at the Roadshow who will be able to answer the judges' questions, if necessary. The NKF will disqualify any submission that is not clearly marked with name and contact details of person/KPA submitting the entry and name and contact details of Roadshow nominated representative - who in turn will have full knowledge and understanding of the poster message and content.

Come on - thinking caps on. Coloured pencils at the ready....Andy Warhol started somewhere....!

Yes you've read it correctly - this year the Annual NKF Conference has undergone a face-lift and become a ROADSHOW, moved to The Midlands, and there's definitely a buzz of anticipation in the air.

Not only have we found a new first class venue - with excellent leisure facilities including a high tech gym, a swimming pool and sauna, but the whole event is running to a new and exciting format. So our conference, where some fascinating and sometimes controversial topics will be explored, along with your opportunity to put your questions to the panel of speakers will occupy the morning session only. Then, after lunch, workshops will run concurrently throughout the afternoon.

Do you want to learn how to cook exciting, tasty food that ticks all the renal diet boxes (oh yes it IS possible) - well you can take a class with TV chef **Lawrence Keogh**! And you can learn how to take care of your feet and understand the potential benefits of reflexology, or get to grips with the buttonhole technique in preparation for dialysis at home. This year it is not a case of doing one workshop OR another...**you could do them all!**



We want **YOU** to join in this year. Lots of us turn up alone but go home having made a load of new friends. If you've never joined in before, make this the year you do. You will be made truly welcome. Flick right to the back page now and get your booking form completed and sent into us in plenty of time.

Remember - you can book online too via the NKF website at www.kidney.org.uk/roadshow10/ and pay using your credit or debit card.



CHARING CROSS HOLIDAY DIALYSIS TRUST

ST. ANNE'S

St Anne's provides self catering holiday accommodation for renal patients. Dialysis is undertaken in a purpose built dialysis unit situated in the garden of St Anne's and supervised by a renal trained nurse.

St Anne's, with its beautiful garden, is just a short walk from the centre of Emsworth, a picturesque village in the upper reaches of Chichester Harbour, full of charm and character with its numerous tea shops and pubs. Non-residents are welcome to use the dialysis and garden facilities.



Open all year round - why not take a Winter or early Spring break - or even a long weekend break

For further information contact:

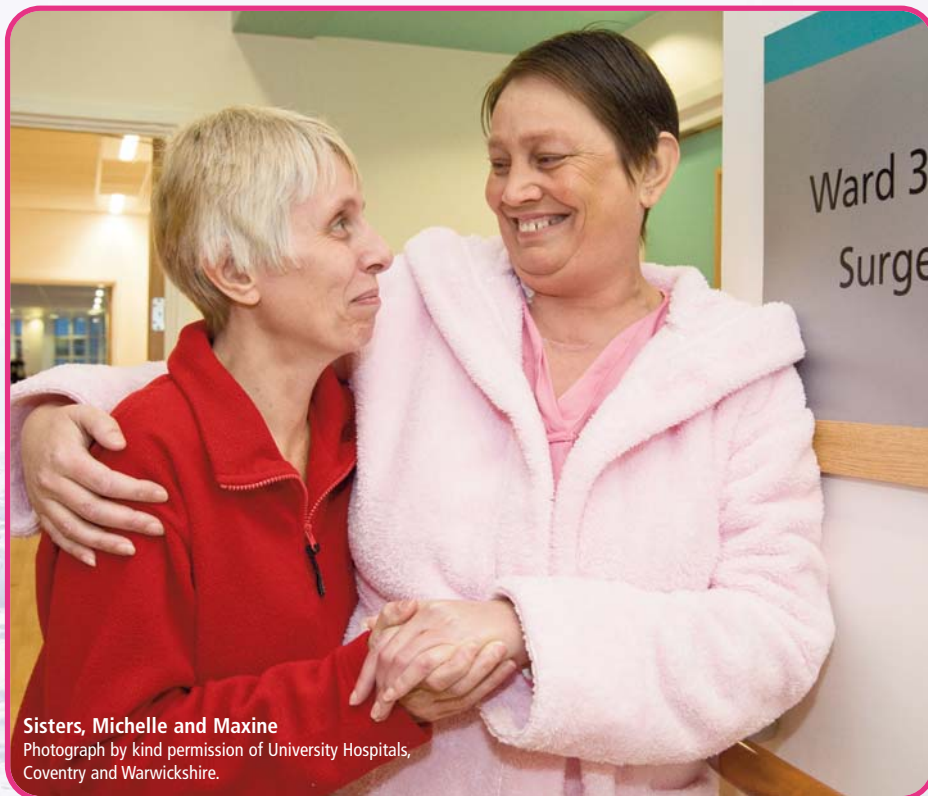
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leave a message and we will return your call
e-mail: e.faber123@tiscali.co.uk
www.communicate.co.uk/london/cxhdt

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University Hospitals, Coventry and Warwickshire reports *'World first technique used to help sister save her sibling from kidney failure'*

TWO Cool SISTERS

A freezing technique has been used for the first time at University Hospital in Coventry so that a sister could save her sibling from kidney failure. **Maxine Bath**, aged 41 from Wolverhampton, developed kidney failure when she was 20 and has been on kidney dialysis for the last 15 years.



Sisters, Michelle and Maxine

Photograph by kind permission of University Hospitals, Coventry and Warwickshire.

Ten years ago her family was tested to see if any were suitable donors but none were compatible because Maxine had antibodies against their kidneys. Then Maxine took a turn for the worse in the last 12 months when she developed the added serious complication of continuous low blood pressure.

Because of this, the Trust could not use its normal machine to remove antibodies as it can lower blood pressure further. Instead renal consultant, **Rob Higgins**, and his team, used a cryofiltration system where the plasma is removed from the blood and chilled to 0°C. At this temperature a lot of antibodies turn into a gel which can be filtered off. The plasma is then warmed back up and returned to the blood. It is believed that this is the first time the technique has been used in a tissue type antibody incompatible transplant.

Out of her mum, two sisters and partner, it was younger sister **Michelle** who was the closest match. Both sisters had five sessions of cryofiltration before Maxine was able to receive a kidney from **Michelle Titmus**, on November 20, last year.

Michelle said: *"It's been very difficult to see Maxine getting slowly worse over the last few years, knowing there wasn't anything we could do to help her."*

"I had a lot of tests and scans done to check I was healthy enough to donate and that was when it started to sink in that I was actually going to be able to do this for my sister. I was so excited."

"It may sound silly but it really hits home when I can watch her eat food, like a jacket potato, that could have killed her before,"

"I just keep thinking that she doesn't have to have dialysis anymore – how great is that?"

Maxine said: *"Six months ago I was contacted by Rob Higgins to see if my family would be tested again as they said they now had a machine which could get rid of the antibodies for me."*

"Although it's not been long since I had the operation, I'm already feeling healthier. I am looking forward to being able to eat food I couldn't have at all before, like nuts and chocolate. I just want to get back to a normal life."

"Rob told me I was the first kidney patient in the world to try this technique which I thought was really exciting. It hasn't quite sunk in yet."

Rob Higgins, kidney consultant at University Hospitals Coventry and Warwickshire NHS Trust said: *"Maxine would have gone blind within two years because of her low blood pressure if she had not received a new kidney."*

"Cryofiltration is not suitable for everyone but, in Maxine's case, it meant that she did not have to spend 10 days in the Intensive Care Therapy ward to give her adrenaline, so it was better for her."

"This is another innovative measure we have implemented at the Trust which opens the doors of donation for more kidney patients awaiting transplants."

After three months recuperation Michelle will return to her job as an office worker. Maxine has been told she will need six months rehabilitation but, after this, she is hoping to start working as a cleaner, as she already has a job lined up.

Advertisement

AFTER ITS WELL PUBLICISED LAUNCH LAST YEAR, WE WERE DELIGHTED TO RECEIVE THE FOLLOWING SUBMISSION TO *KIDNEY LIFE* FROM KIRIT MODI - WHO WAS ALSO RECENTLY ELECTED NKF VICE CHAIRMAN - ON HOW HE TAILORED HIS PERSONAL *KIDNEY CARE PLAN* TO WORK FOR HIM.

I received a pre-emptive kidney transplant in December 2001 and have been attending Lister Hospital to monitor my kidney function. I was very pleased when the Kidney Care Plan was sent with *Kidney Life* last year and I was keen to use the plan.

I started off with a minor problem in that the plan I received did not have the insert which is the key document, but I finally managed to get a copy from **Dr Paul Warwicker**, who is in charge of renal services at the Lister Hospital. I discussed the plan with him and he agreed to use me as a pilot patient. As an out-patient, my results are monitored every three months and I then see a nephrologist to discuss my health. I do not always see the same person because of the rota used by the hospital. I requested that I would like to work on my plan with a nephrologist who knows me well and I suggested **Dr Sarah Fluck**. Both Paul and Sarah agreed with this.

Creatinine Ratio (PCR) which is also not used routinely by the hospital. She clearly explained how I was doing and clarified my main results which she had used to determine my current state of health.

Sarah then told me about my potential risks, which are:

- **deterioration in the kidney function**
- **cardiovascular risks**
- **diabetes**
- **skin cancer**

I now have a much clearer understanding of these risks.

Finally, we discussed what I can do to help myself and included in this are a couple of personal aspects of my life which I will continue to monitor. We agreed to review my progress and the plan again, in six months.

I have now completed my *Kidney Care Plan* and all the information is included in the insert. The insert is very useful as a guide and I used it flexibly to suit my needs rather than complete each of the five separate sections. The most important section for me is 'My personal health plan' which includes goals relating to my health.

My Kidney Care Plan and Me

by Kirit Modi

I started by completing as much of the insert to the plan as possible. Sections on the medicines I take and some of my latest results were fairly easy to complete. I then had to set out clearly what topics and goals I wanted to discuss.

I identified three areas:

- **how am I doing at present?**
- **what are the main risks for me in the next five years?**
- **what can I do to help myself?**

I sent my draft to Sarah Fluck and we arranged to meet and discuss these points. The discussion took about 20 minutes. During this meeting Sarah gave me information about my results that I did not previously know. For instance, I did not know my eGFR since this is not used routinely by the hospital. She explained my eGFR and that this is not benchmarked by my ethnicity. She also explained my Protein

Some of my personal observations are:

- **using the Kidney Care Plan involves considerable time, both from the patient and the nephrologist. This has major implications for renal departments as well as for patients**
- **I was surprised at how difficult it was to obtain the insert to the Plan.**
- **the Plan needs regular review and updates and should perhaps be available electronically.**

In summery, I discovered new things about my health through the process and feel I have greater ownership and responsibility for my health as a result. I am grateful to both Paul Warwicker and Sarah Fluck who responded so positively in helping me with the plan.

For further information on the *Kidney Care Plan* and to download your copy, go to www.kidneycare.nhs.uk/_Resourcestodownload-MyKidneyCarePlan.aspx



Kirit Modi

Thank you very much indeed for sending in your amazing photographs and accounts of activities across the UK and internationally on WKD 2010. It has been a job and a half to sift through them and come up with this montage.....to perhaps whet your appetite for 2011?!

Wales



The Ospreys at the LC Leisure Centre in Swansea with living donor co-ordinator at Morrision, Helen Burt, Rhian Thomas, secretary at Morrision and Clare from Shire Pharmaceuticals.

This year in Wales on World Kidney Day we aimed to raise awareness of the link between diabetes and renal disease. Patients and staff in Wales were out in force to encourage members of the public to take care of their kidneys. Patients of the 'Friends of Renal Care Glan Clwyd' were at the White Rose Centre in Rhyl, where nurses and patients gave advice and measured the blood pressure of interested passers-by. Balloons, posters and stickers were handed out.

Patients and staff in Swansea held events at several locations in and around the area. One of which was held at the Swansea LC. Events were held in Boots at Swansea, Mumbles and Fforestfach, Asda at Llanelli, Tesco at Pontardawe, Ystradgynlais Community Hospital and Pen Goraf and Abercraf GP surgeries.

Also

Art on Dialysis

The Art on Dialysis programme supports patients at the Renal Annexe in Morrision Hospital. It has been running since October 2008, funded by the Renal Patients Trust Fund. Whilst undergoing dialysis, using only one hand, patients make pictures with a variety of

materials including pencil, charcoal, pastel and watercolour. They are often inspired by famous works of art, but also use their own imagination. During the summer 2009 we asked patients and staff to complete a questionnaire to evaluate the project and the results were very positive, so continued funding has been approved until July 2010.



Gerald Saunders presenting his painting to Margaret John

An exhibition of the patients' artwork was held at the White Room, The Grand Theatre, Swansea on the 9-19 March. The exhibition was opened by Welsh BAFTA award winning actress, **Margaret John**, who stars in 'Gavin and Stacy' and 'High Hopes'. Margaret was delighted to be presented with a picture painted by patient, **Gerald Saunders**. As World Kidney Day was on 11 March, the press coverage of the exhibition was used to help raise awareness of renal disease.

Lister



(From left to right) Lister Kidney Foundation members Richard Thompson, Marina Ridley (who is also the first person to use the NxStage Home Dialysis machine), Tony Byrne, Sandra Byrne, Kirit Modi and Nick Carver, Chief Executive East and North Herts NHS Trust.

An event was organised in the Lister Hospital on WKD to help raise awareness of kidney

disease and to help support the Lister Kidney Foundation. The message was clear - a large proportion of kidney disease can be prevented, or its seriousness reduced, through simple measures that everyone can take as part of a healthy lifestyle, such as exercise, a healthy diet and regular blood pressure monitoring. We must all do more to prevent the hundreds of deaths of kidney patients who are on the transplant waiting list in this country.

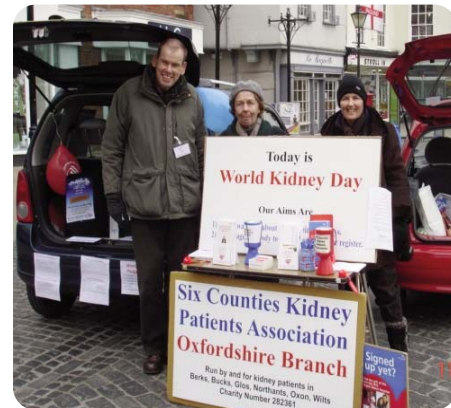
Southend



Shirley Rae and Mary Quek on the WKD stand outside Sainsbury's in Horsham

WKD 2010 in Horsham - Southend KPA had a stand in the access to Sainsbury's, the aim of which was to raise awareness of just how damaging kidney disease is, how it can and does destroy lives - but that it is treatable if caught very early. The aim was to prompt people to consider, "What do my kidneys do for me?" and "Are my kidneys healthy?" and, also extremely importantly for the UK, to promote organ donation and the need for people to sign-up to the Organ Donation Register.

Oxford



Members of the Oxford branch of the Six Counties KPA holding a poster and information display at Abingdon Market Square on WKD.

Hammersmith



Staff on the Auchy Ward in the West London Renal Transplant Centre who always help out on World Kidney day



Bhupinder Manz and assistants on WKD in Southall

Shropshire

by Peter Jones

Beth, my wife and I arrived at the Charles Darwin Shopping Centre in Shrewsbury to set up our tombola stand. **Jeff Auton**, the Vice Chair with wife **Val**, daughter **Rebecca** and **Iffor Roberts**, arrived soon after. The renal staff set up their stands covering diet, blood pressure, fitness and mountains of information on all aspects of renal problems. The renal staff had managed to get the Rowton Castle health centre to agree to participate by bringing along types of exercise equipment and providing a prize in the draw of free health sessions at the centre.

The day was a great success, with many passers-by stopping to take part in the tombola and, more importantly, to gain a better understanding of the renal world. And our fund raising account benefited greatly.

Manchester



Dr Nick Vites with opera singer, Katherine Jenkins, on ITV's 'Popstar to Opera star'

Manchester Primary Care Lead GP for CKD, **Dr Nick Vites**, came up with a magical 'note' to help get the WKD message out to the general public. Dr Nick is a firm believer in the power of celebrity and was soon in touch with **Marcella Detroit** of the popular ITV show 'Popstar to Opera star' to enlist her help.

As a result, all the programme's celebrities, including Marcella, Katherine Jenkins (who is also Patron of 'Kidney Wales'), **Kym Marsh** and judge, **Meatloaf**, signed a letter to Dr Nick extending their best wishes, through his work, to all patients who have been affected by kidney disease. Marcella dedicated one of her performances to WKD and invited Dr Nick to join her as a guest on the show.

Addenbrooke's



All the renal services staff at Addenbrooke's getting into the spirit of WKD!

Staff from all parts of the renal service at Addenbrooke's took part and can be seen here wearing their World Kidney Day T-shirts. All who took part enjoyed the celebrations and the day was a great success.

St Lucia



WKD at Soufriere in St Lucia

My Name is Louis Toussaint

I recently visited St Lucia, which is in the Caribbean, for a two-week break in the sun. Whilst I was out there it happened to be World Kidney Day and I was approached by my cousin, who encouraged me to attend a local procession led by the Soufriere Primary School.

The main reason for being approached was that she knew I had been a renal patient and thought that it would be a great place to attend whilst on my trip. The school children leading the procession were chanting and saying encouraging words such as protect your kidneys, drink lots of water etc.

To my surprise, I was invited to say a few words at the Soufriere stadium to explain my experiences as a renal patient, how it was for me when I was on dialysis, how my transplant has now changed my life today and, finally, I was asked to highlight how kidney disease affects a high amount of minority ethnic groups and what we can do to try and help prevent kidney failure.

The speech went well and it was a very good turnout, the weather was extremely hot with the sun beaming down on us and, of course, this helped as well.

It did not end at the stadium. I was also invited to the local school and hospital to do another speech. I was told that St Lucia has got the highest rate of diabetes and hyper tension in the eastern Caribbean. My work never ends, but I enjoyed my time.



Christine and Sam

Reaching out across the Atlantic on World Kidney Day

by Christine Crampton

Hello,
I would like to contribute my story to your *Kidney Life* World Kidney Day article.

Thirty-five of my 37 years of married life has been affected by Polycystic Kidney Disease (PKD). The first I knew of this disease was when my mother-in-law needed treatment for this when she was 44. It was never spoken of in the family and consequently it wasn't nice to have to learn about it and how to deal with it without prior knowledge. But that was back in the early 1970s and very different to now.

When I was expecting my first child I was questioned about my family medical history and I mentioned PKD. This prompted my husband Alan to be sent for tests which showed that he too had the disease. My husband eventually went into end stage renal failure in 1996 when he was 47, and dialysed by CAPD for two years. He then received a kidney in November 1998, and I am happy to say that 11 years later he is fit and well, still running a business and is rarely poorly.

Sadly, my son Sam also has the disease, but in a more aggressive form. We knew about it when he was 15 and taking his GCSEs. However, knowing this seemed to make him more determined, and he sailed through his exams and later, university. During the five years he was at university he was battling with his blood pressure and gradual kidney function deterioration. Also, at this time his dad started dialysis and then had his transplant. Sam had to cope with all this while still working to achieve amazing academic results.

Whilst at University my son met the girl who was later to become his wife. Christine (my namesake) is from Atlanta, Georgia in the USA, and was doing a three-month course in England. They carried out a long distance romance until his graduation in 2001 when he went to the US and managed to get the job of his dreams. Sam and Christine got married in 2003.

Sam's health started to deteriorate more rapidly than his dad's had, and five years ago when he was 27, he was told that he would need a transplant within three months. He was told also that if he followed a low protein diet he may manage to improve his health in the interim. He did this and managed to delay dialysis for another three years.

Sam started dialysis in 2008. In February 2008 Christine underwent an emergency appendectomy. Not long afterwards she began to think that as she had managed to deal with that experience without a problem she could probably cope with donating a kidney. I had already been tested and was not able to donate for other reasons. So she was tested, and was found to be as good a match as a sibling or parent, so plans for the two operations to take place on 26th June 2008, went ahead.

We happened to be with them in May 2008 for our annual visit when Christine got the good news that she was compatible and they told us what they were going to do. We returned to USA a month later to be there to help with their recovery. Live donation meant that we had a definite date for the surgery.

Together with Christine's parents we paced the floors at the Piedmont Hospital in Atlanta, until the news came that all had gone well and the operations were a success. Christine's parents were amazing because, after all, their daughter was volunteering for this operation and the benefit of her own health did not depend on it. They both recovered remarkably quickly and were soon back to their normal lives; running, playing golf, tennis, fishing; everything they had done before.

Christine is a tennis player and had entered the Wimbledon lottery for many years without luck. But for the 2009 season she was lucky and got two tickets for the matches on 26th June, the anniversary of their surgery. We were also able to celebrate my husband's 60th birthday with them while they were here in England over this period, which was wonderful as my husband never thought he would celebrate even his 50th! It was wall to wall joy.

So, now as the second anniversary of the transplants approaches, all is well with my family. Not a day goes by that we are not grateful and thankful, and we never take life for granted. Dialysis never kept my boys down. Sam is certainly a chip of the old block and they have both been made more determined and stronger by these events. We all know we are lucky, but much of that luck has to come from within, together with a positive attitude and a strong will to overcome this disease.

I am attaching my favourite photo of Sam and Christine in the T-shirts that the hospital gave them. I think it tells the whole story.....
.....one of many real 'Love Stories'.

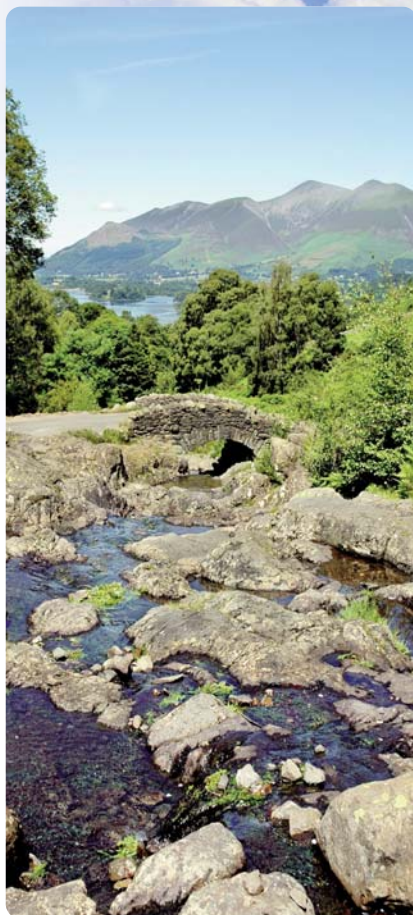
Note from the Editor: If you would like to know more about living kidney donation please speak to your Renal Unit's Transplant Coordinator who will be happy to discuss options with you.

Louise, Kevin and Karen at Lakeland Dialysis welcome you back to the Lake District

We would like to say thank you to all the many patients, old and new who have supported us since we opened in 2004. This was especially heartfelt over the November and December 2009 and the first few months of 2010 as we were overwhelmed with cards, e-mails and general concern as to the state of both our business and of the Cockermouth area in general following the awful flooding at the end of November.

Fortunately we are situated quite a little way higher than the Main Street in Cockermouth, which bore the brunt of the flooding and, consequently, our clinic was not affected directly.

Happily, the area is recovering well with much of the Main Street functioning as normal. Many of the shops have had major facelifts and the bridges and roads that were worst affected have been inspected and are now all open as normal. Some visitor accommodation places were affected, but the general feeling in the area is that most of these will be fully open again by spring. Although we encourage people to holiday in Cockermouth itself, most of the surrounding areas have not been as affected and also offer great places to stay.



The Lake District offers a wide range of wonderful attractions for all the family. In the gem town of Cockermouth you will discover Wordsworth House, the birthplace of the poet, as well as galleries, potteries and gift shops, a leisure pool and parks. Within 15 minutes drive

from us is Keswick which offers shopping for the more serious shoppers, a trip on the steamer around Derwent Water - a must do trip to appreciate the spectacular scenery here. You can also take in a performance at The Theatre by the Lake or visit one of the many National Trust houses and gardens close by. Alternatively you could try a bit of bird watching at the Whinlatter visitor centre where there are Osprey viewing points.

Lakeland Dialysis prides itself on offering personal, quality haemodialysis treatment in a modern and very friendly clinic. Each patient is given an individual appointment time, the morning sessions starting at 7.30am, 7.45am and 8.00am. The afternoon sessions run from 1.00pm, 1.15pm and 1.30pm. Your care will be provided by a qualified nurse with many years of renal experience, and an assistant. All staff take great pride in ensuring your needs are met at all times with a professional service in relaxed surroundings.

Patients are treated using modern machines and seated in comfortable reclining chairs. A Freeview TV set, including DVD and headphones are provided together with a daily newspaper, magazines and a book swapping facility. Wireless internet connection is also available. Refreshments include tea and toast, biscuits and cold drinks.

We all look forward to welcoming you to our dialysis facility so that you along with your family and friends may enjoy a break here in the Lake District. **See you soon!**

Louise, Kevin and Karen

Advertisement

KPA DATE

St James KPA

The renal unit at St James' Hospital in Leeds has benefited from the amazing mountaineering adventures of friends **James Connell**, a medical research associate at Cambridge University, and **Phillip Rushfirth**. James' mother, **Bridgett**, was diagnosed with Nephritis in 1970 and when her first transplant failed, in 2004, the generous gift of a kidney from a living anonymous stranger (altruistic donation) last year freed her once again from the rigours of dialysis, and inspired James and Phillip to attempt the ascent of 4,810m Mont Blanc in the Alps. Their efforts were sponsored and the £2500 money raised was donated towards the purchase of a bioimpedance machine for the renal unit.

James, 37, said: *"The unique challenges that we faced on the slopes of Mont Blanc highlighted the difficult everyday challenges that patients face while on kidney dialysis, awaiting a life changing kidney transplant."*

Mrs Connell's husband, **Bill**, a Freemason, then enlisted the help of the organisation. A 1960s night raised a further £4,500 while the West Riding Masonic Charities matched that amount and the Leeds Masonic Charities gave a further £500 enabling the purchase of not one bioimpedance machine, but three! These machines analyse fluid levels in dialysing kidney patients.



St James' KPA members supporting the 60s night



James and Phil on Mont Blanc

North East KPA

Kidney patients travelling to The James Cook University Hospital for dialysis three times a week can now receive their treatment in a much more welcoming environment.

The renal unit at the Middlesbrough hospital recently re-opened after a £1.3million refurbishment and offers a much more relaxed atmosphere for patients while also addressing their privacy and dignity needs.

The clinical team has also been lucky to have the support of the North East Kidney Patients Association (NEKPA) which will hand over a £16,000 cheque to pay for personal ceiling mounted televisions in the treatment rooms and new seating.



NEKPA cheque for £16,000 (photograph taken by Amanda Marksby)

Ooops!

In the last issue of *Kidney Life* we covered the amalgamation of the KPAs associated with London hospitals, Charing Cross, Hammersmith and St Mary's. In this piece we called this newly formed KPA 'The West London KPA' and to date this KPA has not been formally renamed. As soon as we have notice of its new name you will read it here, pressed firmly into the pages of *Kidney Life*! Many apologies for any offence this error may have caused KPA members.

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.

The Law Society has a website at www.solicitors-online.com and you can get more information on wills on www.make-a-will.org.uk. The **NKF Helpline** on **0845 601 02 09** can also 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

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. **Many Thanks - NKF**



DONAL'S *Question* TIME

Question

'As the number of dialysis patients increases year on year with some patients now dialysing for many years, what plans are afoot to tackle the resulting complications, both physical and mental?'

Bob Price

Answer

Dear Bob

Thank you for raising the issue of the health and mental wellbeing of people on dialysis. You are quite right about the numbers of people on dialysis continuing to rise year on year. Most people on dialysis are not currently transplant listed and they will therefore be on long term dialysis for the rest of their lives. Such patients often have a number of additional medical problems over and above the fact that their kidneys have failed. Indeed, co-existing heart disease or blood vessel disease is often the reason individuals are deemed unsuitable for transplantation.

The quality of life for people on dialysis is influenced by a range of factors including physical health, mental wellbeing, dietary and fluid restrictions, psycho-social issues, transport and the ability to dialyse away from their base unit or home. The Renal National Service Framework describes a vision for the empowerment, support, care and treatment of children, young people and adults with kidney disease to optimise patient experience and outcomes. It has a set of standards, quality indicators and good practice markers that must be achieved to make world class kidney care a reality.

For people on dialysis, the experience often is the outcome and if we are to optimise patient experience and outcomes, attention to all the needs of those with advanced kidney disease should start long before dialysis is required. The year before renal replacement therapy is likely to be needed is a crucial time to address medical, both physical and mental, psychological and social issues so that the transplant, dialysis and conservative care options can be fully explored and informed choices can be made. This should take into account individual decision making styles and people's preferences, needs, desires and lifestyles as well as their physical, mental, psychological and social situation. Shared decision making is the way in which the multi-disciplinary kidney care team communicates to the patient personalised information about the options, outcomes, probabilities and scientific uncertainties of the various treatments and the patient communicates his or her values and relative importance he or she places on the potential benefits and harms. Shared decision making is a fundamental part of care planning and promotes the best choice in what otherwise can be a complex and overwhelming situation. Every kidney patient is entitled to receive care planning and have their own individual care plan addressing all these needs.

But not everybody who needs dialysis receives this multiprofessional preparation and choice to achieve the best outcome for their own wishes and circumstances.

In each issue of *Kidney Life*, we ask Dr Donal O'Donoghue (UK Director of Kidney Care) to respond to a question sent in by a reader. For this issue we have selected a question sent in by Bob Price of the Oxford Branch of the Six Counties KPA.

We have however seen substantial improvements over the last five years. The number of people with end stage kidney disease arriving at kidney units requiring immediate emergency dialysis has fallen by about a third since the introduction of strategies to identify kidney disease earlier by the NSF. Those that do arrive without adequate preparation should receive intensive input from the renal team so they too have an opportunity to choose the type of dialysis, consider transplantation or, where appropriate, choose conservative kidney care. Timing of such discussions when patients have been very unwell can be tricky and I think that we can do better both in identifying more people early so fewer "crash land" and also in ensuring that sufficient attention is paid to consideration of benefits and risks of different choices made by patients when they start dialysis in this unplanned way.

People who are on dialysis come in all shapes and sizes – some are young, some are old, some want the freedom of managing their own condition at home, others require the support of the kidney team to optimise care so the care plan has to be personalised – we will fail if it's a tick-box exercise. We do, however, know what complications to expect and both patients and staff need to be looking out for the early warning signs so the complications of dialysis can be minimised. For those on haemodialysis, having an arterial venous fistula is the key to good outcomes and reduced complications including infections and vascular events which are major medical problems for people receiving dialysis. There have been significant improvements in vascular access over the past 5 years as evidenced by a reduction in more than half of the number of MRSA blood stream infections now seen. There is still big variability between units and the targets set by the Renal Association have not been achieved in most units yet; the fact that in some units 95% of people receive dialysis use a fistula is very encouraging, it means that units where only 65% of people have a fistula, or worse still only 50%, can do considerably better. One of the national Kidney Care Audits that I am sponsoring focuses on vascular access with the aim of being able to regularly measure this quality marker and achieve year on year improvement in every kidney unit.

One of the many challenges in kidney care is that most things are not as clear cut as the need for good vascular access for long term wellbeing for people on haemodialysis. The evidence base for clinical practice in dialysis is much less than in many other conditions such as heart disease or cancer because historically there hasn't been as much research in kidney care as other areas. However, Kidney Research UK, the Renal Association and the British Renal Society are starting to plug that evidence gap. We can also draw parallels from other areas, particularly heart disease and until proven otherwise, it makes sense that people on dialysis, because they have such high rates of heart disease, should receive the same sort of treatments as people without kidney disease who have had heart attacks where we have much more research and know more clearly what should be done.

There can be no health without mental health. This has been a neglected area in kidney care. We know that up to 30% of people on dialysis will experience a period of depression. Being on dialysis is often a psychological as well as a physical strain for families as well as patients. Guidelines on the identification and treatment of depression in people who already have an established physical illness has recently been produced by the National Institute for Health and Clinical Excellence (NICE), these guidelines are very relevant to kidney services. There are now good tools to screen for depression in the pre-dialysis and dialysis population and there are pharmacological, behavioural and cognitive treatments that can help alleviate depression in people receiving dialysis. This should not be neglected.

The social and psychological support workforce play a fundamental role in renal care, helping patients and carers address the practical, economic, social and psychological problems associated with chronic disease, disability and eventually death and bereavement. It is a concern that social workers and psychologists are in such short supply on dialysis units. The Renal Special Interest Group of the British Association of Social Work carried out a study of renal social work provision in 2007 and disappointingly found that the number of renal social workers had fallen by 11% since 2002. The Kidney Alliance has also highlighted that social work appears to be one of the most severely under-resourced areas of renal services, with staffing at levels falling far short of those required to provide an adequate service. Yet some places are successfully addressing this problem. In 2008 Wirral University Teaching Hospital analysed the requirements for their patients. Their review found that anxiety and depression were common and with the support of the Hospital Trust the team have now employed a full time psychologist and are training members of the nursing staff in counselling. It's a false economy not to treat depression, not to provide psychologist support for people with advanced kidney disease and not to address the social care needs of those on dialysis. Mental illness, psychological distress and unresolved social care issues result in an increased need for hospital admissions and much longer lengths of stay than in people who have these needs well supported. Unnecessary admissions and long length of stay waste money that could be used in improving the quality of care for people with kidney disease.

So Bob, in summary, progress has been made in some areas but there's much to be done – particularly in terms of mental wellbeing, psychological and social care. That is the reason that care planning remains high on the agenda of NHS Kidney Care and why we are support a move to a chronic disease management model of care where the patient is at the centre, where education, empowerment and encouragement for the patient on dialysis are given as much importance as some of the physical measurements we make to assess quality, and where care is delivered in a true partnership with the patient. There is good data to show that the more a person is involved in their own treatment decisions and management plans, the better the outcomes.

Potassium Watch

by John Rippon

In common with most of your readers, I am forced to follow a low potassium diet. As if this were not difficult enough, I have recently become aware of an additional problem. In response to the government drive to reduce the amount of sodium in processed food, some manufacturers are replacing some of the salt (sodium chloride) in certain products with potassium chloride. I have discovered that foods which I formerly considered 'safe' now contain added potassium. When I asked the Food Standards Agency about this practice, I received the following reply;

The FSA's current position on salt replacers is that we do not recommend substitutes used solely to maintain a high salt flavour. The Agency's long-term aim is to adjust the population's palate to foods with lower salt levels and the use of replacers does not meet this aim. In addition we are fully aware that potassium based salt replacers in manufactured foods as a whole may not be suitable for individuals with immature kidneys such as children and individuals with renal insufficiencies and this is another reason why we do not advocate the use of these replacers.

However, there was little sign in their response that they would be taking effective action to discourage the practice in the near future.

The problem is compounded by the fact that the presence of potassium in a product is not always obvious from the list of ingredients. Some manufacturers do explicitly use the term 'potassium chloride' in the list of ingredients but it can also appear as:

- **LoSalt**
- **Low sodium sea salt**
- **Low sodium mineral salt**
- **Low sodium salt, or**
- **E508**



Tesco, for example, informed me that their 'low potassium sea salt' consists of; sodium chloride 41%, potassium chloride 41%, magnesium sulphate 17% and water 1%. I have asked the Food Standards Agency whether these terms are in accordance with labelling regulations and await their response with interest.

Some manufacturers/retailers add a warning on the label that the product is not suitable for people on a restricted or low potassium diet, but this is certainly not universal. Even when the presence of potassium is mentioned explicitly, labels are often extremely difficult to read due to the tiny size of the print and dense packing of words. In order to assist those who need to be aware of the presence of added potassium in products, I have set up a web-site where I list products I have personally identified as containing potassium.

The address of the site is www.potassiumwatch.org.uk. The list is currently fairly short as I have only recently begun looking at labels. As this is a very onerous task, I would be very grateful to receive further sightings of products by my fellow renal patients, especially those with very good eyesight!! I have not included products which people on a low potassium diet would avoid anyway such as potato crisps.

Note from the Editor:

John, thank you very much for highlighting this problem. You have explained it to us very well. Even if we all contribute just one item to the list on your website we could have a comprehensive 'danger' list in a very short time. We all wish you the very best of luck with this. Come on - let's all check the labels together!

Processing error at NHS Blood and Transplant - EXPLAINED

by Sally Johnson of NHSBT

As a key organisation that works closely with NHS Blood and Transplant (NHSBT) to encourage more people to sign up as organ donors, I am writing to you regarding an issue related to the Organ Donor Register (ODR) that has been covered in the media this weekend.

You may have heard that NHS Blood and Transplant is investigating a processing error that has led to a number of ODR registrations being incorrectly recorded, where registrants had registered through the Driver and Vehicle Licensing Agency (DVLA) and where they indicated a preference to donate specific organs. The error has occurred within our system and therefore responsibility for correcting it lies with NHSBT and not the DVLA.

Firstly I would like to reassure you that nobody has been registered as an organ donor against their wishes, no data has been lost at any stage, and no other routes to join the NHS Organ Donor Register have been affected. We are taking this error extremely seriously and have completed a thorough investigation to identify the source of the problem. It has now been corrected to ensure that future registrations are accurately recorded.

We have identified that approximately 812,000 records may have been affected, representing just under five per cent of the 17 million records on the ODR. Of these, 444,000 are in the process of being corrected electronically, and a carefully controlled process has begun to do this. However, there remain 368,000 people whose preferences are not clear. We will therefore be writing to all of these donors, asking them to confirm their preferences.

Our investigation has also revealed that since this error occurred a small number of these affected registrants did donate after their death. Our first priority is to contact their families as a matter of urgency to explain that there may have been a discrepancy with the information we were holding in relation to their preference and to apologise for any distress this causes.

There is clearly a risk that as a result of this issue, public confidence in the NHS ODR as means of recording wishes about organ donation may be affected. It is therefore extremely important to us that that key individuals and organisations who share our goal of increasing the number of organs for patients have access to clear and accurate information, and are confident in the action we have taken.

I very much hope that we can rely on your continuing support in promoting the vital message that organ donation saves lives. As you know, patients rely on the generosity of organ donors, and it is incredibly important that people continue to sign up as donors and discuss their wishes with their families.



MEDICAL *Matters*

The endothelin antagonist drug avosentan substantially reduces loss of protein in the urine (proteinuria) in people with type-2 diabetes and kidney disease, but can cause serious side effects, according to a study from Germany. The Avosentan ASCEND study included 1392 patients with diabetic kidney disease, who were randomly assigned to treatment with either avosentan 25 mg, avosentan 50 mg, or a dummy pill (placebo).

Avosentan at either dose lowered urinary protein output by 40%-50% compared with less than 10% in patients taking placebo. But patients receiving the drug were at higher risk of serious side effects, including problems due to fluid overload. The researchers conclude that lower doses of avosentan may have a more favourable risk-benefit balance for people with diabetic kidney disease.

Despite treatment, people with kidney disease often experience proteinuria, which further damages the kidney. Endothelin is a key factor in the development of proteinuria, since it constricts blood vessels and raises blood pressure, causes the kidney's filtering function to deteriorate. Researchers suspect that blocking endothelin could be a promising new treatment strategy for patients who develop proteinuria. Endothelin antagonists such as oral avosentan are already available and are prescribed for patients with heart conditions.

Journal of the American Society for Nephrology 2010;21:527-35

Transplant recipient are known to be at increased risk of certain cancers because they take immunosuppressant drugs to prevent rejection of the transplanted organ. An Australian study has found that, after a return to dialysis, this higher risk is rapidly reversed for some, but not all, cancer types.

This nationwide, retrospective study included 8173 Australian kidney transplant patients registered on the Australia and New Zealand Dialysis and Transplant Registry, who first received a transplant during 1982-2003. All cases of Kaposi's sarcoma (a form of skin cancer) occurred during treatment with immunosuppressant drugs. The risk of new cancer was significant lower during dialysis after transplant failure for non-Hodgkin's lymphoma, lip cancer,

and melanoma. In contrast, the risk of leukaemia, lung, kidney, urinary tract cancer and thyroid cancer remained high after a return to dialysis. Transplantation or dialysis had no effect on the risk of other cancers. The researchers comment that their findings may help to formulate policies for cancer surveillance after kidney transplantation.

British Medical Journal 2010;340:c570

Mupirocin ointment appears to reduce the risk of catheter-related bacterial infections in haemodialysis patients, according to this review of studies by the well-respected Cochrane Library. The analysis included 10 randomised controlled studies involving 786 patients. Mupirocin ointment reduced the risk of catheter-related infections, with a significant effect on infections caused by *Staphylococcus aureus*. The risk of catheter-related bacteraemia was also reduced by polysporin ointment and povidone-iodine ointment. However, none of the three ointments reduce the risk of death related to infection. Researchers also found that topical honey does not reduce infection at the site of the catheter or catheter-related infection. Compared to dry gauze dressing, transparent polyurethane dressing does not reduce the risk of catheter-related infection. UK guidelines recommend that haemodialysis patients should use an arterio-venous fistula for dialysis, but catheters continue to be widely used. The risk of infection is higher with a dialysis catheter than with a fistula.

Cochrane Database of Systematic Reviews 2010; 1

Measuring certain types of immune cells may help identify people at high risk of skin cancer after kidney transplantation, according to a study from Oxford. Researchers measured levels of key immune cells in 116 transplant patients, 65 of whom had developed squamous cell skin cancers. Patients were matched for gender, age, length of immunosuppression and other risk factors for skin cancer. High levels of T-regulatory cells ('Tregs') and lower levels of natural killer cells, together with previous squamous cell skin cancer, increased the risk of this skin cancer by more than five times. The authors believe that, if their results

are repeated in other groups of kidney transplant recipients, measuring levels of these immune cells could help identify people who need especially careful monitoring because of their higher risk. Equally, there would be less need to reduce immunosuppression for patients at lower risk of skin cancer.

Journal of the American Society for Nephrology 2010 [epub ahead of print]

A study has found that repair of a blocked artificial haemodialysis fistula is more likely to be successful if the fistula is kept open with a stent. A stent is a tube made from a special fabric supported by a metal mesh. In their prospective study, the researchers randomly assigned 190 haemodialysis patients, whose artificial fistulas had become blocked, to either balloon angioplasty alone or balloon angioplasty plus the stent. In balloon angioplasty, a thin tube with a tiny balloon at the end is threaded through the blocked blood vessel. When the tube is in place, the balloon is inflated to clear the blockage and restore blood flow. Six months after surgery, fistulas were significantly more likely to remain unblocked in the stent-group than in the balloon-angioplasty alone group (51% compared with 23%). The stent group was also less likely to need further surgery (16% compared with 32% in the balloon angioplasty group). The risk of adverse events was similar in the two treatment groups, apart from recurrent blockage, which was significantly more common in the balloon-angioplasty group.

New England Journal of Medicine 2010;362:494-503

Poor quality sleep is common in Stages 3-5 chronic kidney disease (CKD), according to a prospective patient questionnaire study from four kidney centres in the USA. Significant predictors of poorer quality sleep included younger age, breathlessness, self-reported depression, pain and itchiness. In this study, self-reported daytime sleepiness was also significantly associated with higher risk of death before the start of dialysis. The researchers strongly recommend that more attention should be paid to the issue of poor sleep in CKD, especially as some of the risk factors associated with the problem can be treated.

Clinical Nephrology 2010;73:104-14

The side effects related to long-term steroid therapy have led to continued interest in steroid avoidance or withdrawal (SAW) after kidney transplantation. Based on their analysis of 34 randomised studies including 5637 patients, these researchers from the Royal College of Surgeons in London concluded that, although SAW immunosuppressant regimens significantly increase the risk of acute rejection compared with continuing steroids, there is no significant effect on patient or kidney survival. Both creatinine and creatinine clearance improve with SAW, as do cardiovascular risk factors including high blood pressure, new-onset diabetes and high cholesterol. The authors conclude that SAW seems justified in low-risk kidney transplant recipients.

Transplantation 2010;89:1-14

Treatment of gum disease (periodontitis) results in at least three months of improved blood glucose control in people with type-2 diabetes. This is the finding of an analysis of five randomised controlled studies including a total of 371 patients and lasting three to nine months. The authors comment that the association between better oral health and improvements in HbA1c (the best measurement of blood glucose control) should be interpreted with caution. However, gum disease is known to affect general health, possibly due to the spread of bacteria from the mouth to the rest of the body.

Diabetes Care 2010;33:421-7

Want to know more?

The source of the studies is listed as the title of the journal, year of publication, volume, and page numbers. For more details on an individual study, go to www.ncbi.nlm.nih.gov/sites/entrez Under the 'PubMed Tools' menu, click on 'Single Citation Matcher', complete the boxes ('Journal', 'Date', 'Volume' and 'First page') and click the Search button.

There may be a link to enable you to download the complete article, but this may involve payment of a fee.

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.

NOTICEBOARD

The NKF Policy statement on the provision of dedicated renal social worker

Renal Social Workers

The National Kidney Federation believes that all kidney patients should have access to a dedicated renal social worker paid for by the National Health Service (NHS) or other NHS approved body.

It has come to our attention recently that there remain a few renal units across the UK where patients have no access to a social worker with specialist knowledge of renal patient needs, or where this provision is on a part time basis and is proving woefully inadequate for renal patients and their families.

If you are a patient who has needed to use the vital support provided by your unit's renal social worker in the past twelve months we would dearly like to hear from you. Your experience will help us highlight the importance of this service, to the few Trusts still unwilling to free up the funding required to provide their renal unit with a dedicated renal social worker.

Just one or two paragraphs outlining your experience will be wonderful and we will print as many as possible in the next issue of Kidney Life. Watch this space!

Give me sunshine....!

As welcome as it most certainly is after one of the longest and coldest winters on record, the sun also represents a serious threat to those of us who have compromised immune systems.

'Advances in transplantation medicine, as reflected in improved post-transplant patient and graft survival, have also meant prolonged duration on immunosuppressive therapy. This has resulted in an increased incidence of long-term transplant related complications, including metastatic skin cancers.' *British Journal of Renal Medicine (Winter 2009/2010 page12)*

So, don't forget to slap on the factor 50 and



dig out that flower-power sun hat - even if you're out in the sun for only a few minutes! It WILL be worth it in the long term.

NKF Survey Zone

If you haven't already done so, please go to www.kidney.org.uk/surveys/home-dialysis-working-group/ and complete this survey on home dialysis options. With the information you provide by completing this survey we can help to ensure that Trusts work towards providing a fully supported range of dialysis options to their renal patients. **Thank you!**



Advertisement

Cancer Risks in Transplanted Patients



Michael Gates

At three months old, Michael was rushed to hospital with failing kidneys and received his first transplant at one. Sadly, it was rejected and another had to be found. By the time he was six, Michael had received his fourth and final kidney, which was successful and is still working well.

Michael competed in his first British Transplant Games when he was seven years old, and he went on to come fourth in the backstroke when he was just 10 years old. This early success inspired him go on to the World Transplant Games, training three times a week to compete in the 50m backstroke and 50m breaststroke. To date, Michael has a clutch of medals, including four golds, from the British Transplant Games, the Australian National and the Chinese National Games.

Anyone who has already given consent to organ donation from a loved one will already appreciate the remarkable opportunity it can give to someone who so badly needs a new organ. Sometimes Michael thinks about the children whose kidneys he received and words can never express how grateful he is to them. But he urges people to also make their wishes known to their family so that should the worst happen, a transplant is allowed to go ahead.



Michael Gates - Four Transplants by the age of 6!

Michael Gates has been spared a lifetime on dialysis, having been fortunate enough to undergo four kidney transplants all before he reached his sixth birthday. Now 26, Michael has constantly defied doctors by fighting back and is currently training to compete in the swimming at the British Transplant Games, in Bath.

It's not too late to become involved in this year's British Transplant Games in Bath 19 -21 August. Every year we receive accounts and photographs of amazing personal goals being well and truly exceeded, and triumphant teams' successes at the British Transplant Games. Now is the time to get in touch with your renal unit's team manager to see what talent you can add to your team this year. We look forward to seeing the photographs!

PEOPLE PAGE

NKF United



NKF United out in force on World Kidney Day

A report on our progress - by NKF United Team Chairman, Rigel

NKF United FC gave a good account of themselves on World Kidney Day when they attended North Warwickshire College to raise awareness of the National Kidney Federation and CKD. The team arrived in vast numbers with 24 players, management staff, family, friends and supporters. All members of NKF United were dressed in full team kit that showed off our very proud NKF United colours.

The students and staff of the college were treated to a talk from **Timothy F Statham OBE** (NKF Chief Executive), highlighting the issues surrounding Chronic Kidney Disease and the aims of the National Kidney Federation and of the team, NKF United FC, before it was time for the kick off. The talk went incredibly well, and there was a lot of interest afterwards with people wanting posters and information.

The football match itself was a tough challenge for the NKF team, who were punching well above their weight, and playing a very experienced opposition. This showed in the first half, with NKF United falling behind through sloppy errors in defence and in goal, but the team did not drop their heads and fought back very well. NKF United were considered the better side in the second half, constantly flooding the college's half of the pitch and attacking relentlessly. Despite this gallant effort and registering their second defeat, the players kept their spirits high throughout and felt as though they had a lot of positives to take away from the experience.

For further information on our team, and a list of NKF United fixtures go to: www.nkfunitied.com/nkfunitied_website_069.htm

Birthday Surprise for Trust's Oldest Dialysis Patient

The James Cook University Hospital's renal unit celebrated a very special milestone in February - its first nonagenarian patient.

It's a double celebration for dialysis patient, **Richard Snowden** - it was his birthday and he is also the Middlesbrough hospital's first 90 year old dialysis patient.

Richard from Easington - who started dialysis when he was a mere 80 year old in August 2000 - celebrated his 90th birthday on Wednesday 17 February. He has been on dialysis for nine and a half years, attending the James Cook renal unit until February 2004, before transferring to the Stockton Dialysis Centre in the grounds of The University Hospital of North Tees.

Staff from the centre made his dialysis day extra special when he came in for his regular three times a week, three and a quarter hour dialysis session, with a special party in his honour. **David Reich**, consultant nephrologist, said: "Richard has done really well on dialysis, it is a major part of a kidney patient's life and managing this successfully for ten years, at his age, is a real credit to him. We were delighted to celebrate his birthday with him and wish him all the very best."



Richard with Dr David Reich, consultant nephrologist



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However, whilst the NKF represents the most significant UK kidney patient voice both nationally and internationally, it does not offer grants to patients. The BKPA, on the other hand, is able to offer grants to kidney patients and their family for a variety of different things: travel expenses to and from hospital, holidays, to help with domestic bills and for a host of miscellaneous expenses such as a garden shed for the storage of dialysis equipment.

If you are a kidney patient or a carer of a kidney patient and find yourself in a situation where financial pressure is mounting and you are not sure how to go about asking for help, there ARE options open to you.

All UK Kidney Patient Associations (KPAs - not to be confused with the BKPA) come under the umbrella of the NKF and whilst the NKF itself does not provide grants you will find that your local KPA may be able to help both financially and with very useful information on how to apply for any State benefits.

Your renal unit should also have a dedicated renal social worker who will have access to up-to-date State benefit qualification criteria - please DO NOT be embarrassed to ask him/her for help. Your local KPAs can also help you deal with any local renal hospital/dialysis unit concerns.

The BKPA also assists with funding to expand dialysis facilities and pays key kidney staff salaries where no funding is available. Over the past few years the BKPA has helped fund four *Ronald McDonald* houses which offer free accommodation to families with children in hospital.

If you would like to make contact with the BKPA please go to: www.britishkidney-pa.co.uk or call **01420 541424**.

Tucked inside this issue of *Kidney Life* you will find a leaflet from the **British Kidney Patient Association (BKPA)**. There are many charities in the UK and internationally that are dedicated to supporting kidney patients, and whilst all charities 'support kidney patients' this support comes in many different forms. Over the course of the next few issues of *Kidney Life* we aim to highlight some of these charities and the ways in which they differ from the NKF. First on the list is the BKPA which, in recent years, has seen **Elizabeth Ward** hand over the reins to Chairman, **Sally Taber MA, RGN** and her experienced management committee. **Tracey Sinclair**, NKF Committee Member and editor of the Wessex KPA newsletter tells us more about the BKPA.

The NKF and the BKPA

by Tracey Sinclair

The BKPA was set up by Elizabeth Ward in 1975 after her 13 year old son was diagnosed with kidney failure. Since Mrs Ward's retirement the BKPA is now run by a small and highly dedicated team of experienced people. Both the NKF and the BKPA are able to offer advice and support information by way of leaflets and by telephone.

Advertisement

Letters Page



It has been great to read the many WKD contributions and sift through the accompanying photographs sent into Kidney Life. They are a real testament to the hard work put in all year by KPA members and their families and friends. Each year, in the KL office, we can see the WKD message gathering momentum as more and more people become involved in the drive to raise awareness of our condition and the need to meet the shortfall in organ donation.

So when we received this letter from Jim Rae informing us of the 'not so compassionate public on its way into Sainsbury's on WKD' we were all caught by surprise and it made us take a moment to reflect on what is always going to be an uphill struggle for all of us. Jim's (edited) words capture this struggle eloquently.

Dear Editor,

Thursday March 11th saw the people of the world celebrating World Kidney Day. The day was marked by events in Horsham, throughout the UK and all over this planet. The aim was to raise awareness of just how damaging kidney disease can be; how it can and does destroy lives. But that it is treatable if caught very early. The aim was to promote the thoughts in people's minds 'what do my kidneys do for me?' and 'are my kidneys healthy?' Also to promote organ donation and the need for people to sign-up to the Organ Donation Register.

For this opportunity we say a very big thank you to Sainsbury's in Horsham.

For what seemed forever but in fact was five hours, we stood in the wind tunnel that is Sainsbury's foyer attempting to engage the public. Given the millions of

pounds spent on TV and radio adverts in the last three months, promoting organ donation, we were sure we would be swamped with questions and requests for the 500 or so organ donor register sign-up forms we had with us.

Oh dear how wrong we were. During the five long, long hours we estimate that over 5,000 people passed through the foyer. Despite our best attempts we handed out less than 100 forms and less than 10 people stopped to fill-out and mail the form in the post box just two yards from our table. Is this the total affect of all those millions of pounds of taxpayers' money spent with TV and radio companies?

During those five long, cold hours we saw the two faces of Britain in the 21st century. On the table we had a collecting box. It was fairly inconspicuous. Rather than engage with us on renal matters and fill-out a form, 98% of people either rushed past us looking in any direction but ours, or gave us a donation but did not take a form and then exited with amazing speed.

Though my wife's friend Mary and I were dispirited at the end of the shift, the person I feel for most is my wife Shirley, who was devastated. Shirley lost her own kidneys through no fault of her own, 38 years ago. She has been back on dialysis and the transplant list since November 2003 but still no call more than six years later. In the light of the massive TV and radio campaign of recent months, Shirley had high hopes for the day. In just five hours that expectation was shattered. She came home and kept asking over and over again, "When and how am I ever going to get a transplant?"

The money raised during WKD will enable KPAs all over the country to try and cope with the devastating affects of renal disease. Money never will be able to buy life.

Jim Rae

On the move - but cheaper!

Dear Editor,

First let me say how much I love to receive the *Kidney Life* through my letter box but I would like to mention something with regards to one of your articles 'Dialysis In my Caravan' in your Spring issue 2010.

I think that it is fantastic that **Barney Howlett** is not letting anything get in his way with regards to Peritoneal Dialysis and as a massive traveller myself he should still feel free to see the world if he wishes as there are so many places that you can travel to even when you are on dialysis.

But there is a lot of people in this current climate who cannot afford the portable bag for warning up the fluid at a cost of £249 plus vat which is a total of £292.58. When a hot water bottle, a flask and a baby's changing bag only cost about £25 in total.

I am an extremely lucky person as I was only on dialysis for about six months before a wonderful family made what must have been a very hard decision to donate a loved one's organs. I have now had my transplant for five months and I feel on top of the world.

During my time on PD I was also doing four exchanges a day, but it never stopped me going off for weekends or even longer, I could go camping out in the wilds of Wales or anywhere and not need to worry about plugging a machine in to a socket.

All I did was buy a hot water bottle and a baby changing bag and a flask.

For example: When going out for a weekend, or a week or a month it would not matter.

I would do my first exchange at home before leaving to whatever destination I wanted to go to but, before I left the house, I would fill a hot water bottle, I then used a towel to wrap the hot water bottle up with my bag of fluid and place them in the baby changing bag which would be nice and warm by the time I needed to do my second exchange. At the same time, I had filled the hot water bottle I would fill a flask of hot water for my evening exchange. So once the hot water bottle started to cool down, all I had to do was replace the water with the water from the flask.

The baby changing bag does a lot of things. I used it to carry all my dialysis needs as there are loads of pockets. The bag and the changing mat which is part of the bag is hygienic and once sprayed with cleaning fluid can be used as the surface to prepare for your exchange.

All this for a very small cost!

I wish everyone out there on dialysis or anyone who is waiting for that 'phone call, all the very best of luck. And keep travelling.

Even though I will never know who you are, I would like to give my never ending thanks to all the families who have donated their loved one's organs.

Tina Denton

Note from the Editor:

Tina, what a lovely letter! Thank you very much indeed for sharing your ingenious travel tips. We are all delighted to hear that your transplant is working well!



National Kidney Federation

NKF Roadshow

at The Hinckley Island Hotel, Hinckley, Leicestershire!
Friday 8th-Sunday 10th • October 2010

THE ALL NEW...




With thanks for support from **genzyme**

Thanks to the generosity of this year's NKF Roadshow sponsor, Genzyme, the cost to each attending delegate has been subsidised by 25%

Delegate	
Title	<input type="text"/>
First Name(s)	<input type="text"/>
Surname	<input type="text"/>
Address	<input type="text"/>
Postcode	<input type="text"/>
Telephone	<input type="text"/>
Second Delegate	
Title	<input type="text"/>
First Name(s)	<input type="text"/>
Surname	<input type="text"/>
Member(s) of	<input type="checkbox"/> KPA <input type="checkbox"/> YPG <small>Tick as appropriate</small>
Special Requirements	
CAPD, Vegetarian (V), Wheelchair bound (WB), Impaired Mobility (IM) Please tick appropriate boxes	
<input type="checkbox"/> CAPD <input type="checkbox"/> V <input type="checkbox"/> WB <input type="checkbox"/> IM	<input type="checkbox"/> CAPD <input type="checkbox"/> V <input type="checkbox"/> WB <input type="checkbox"/> IM

The Programme includes:

- Transplantation
 - Vascular Access
 - Transonic monitoring
 - Dialysis - Home therapies
 - Dialysis therapies patient perspective
 - Cooking demonstration incorporating diet – Lawrence Keogh 
 - Podiatry and reflexology
 - Patient Education and buttonhole technique
- Friday: A meeting with the Chairman
Sunday event: Council meeting at 9.30 followed by two workshops
a) holidays b) advocacy

SPECIAL PACKAGE: Sat/Sun 9-10 October *Includes:*

- Saturday:** Saturday Roadshow fee, morning coffee, lunch, afternoon tea, evening dinner and entertainment, B&B
- Sunday:** Council meeting and workshops
- Saturday only: Includes:** Saturday Roadshow fee, morning coffee, lunch, afternoon tea.
(Gala dinner may be booked separately see booking table below)

Booking table:

Options	Roadshow Fee	Late Surcharge Fee Payable from 6 August	Number of Delegates	Total Cost
Special Package double/twin	115	135		
Special Package single	135	155		
Saturday Roadshow only	56	64		
Saturday Roadshow & Gala Dinner	83	91		
Friday B&B double/twin	50	50		
Friday B&B single	80	80		
Friday evening Buffet	16.50			
My donation towards the work of the NKF				
Total Sum enclosed with booking				
I would like to attend the KPA Chairman's meeting				
No of tickets required				

ALL BOOKINGS ARE ACCEPTED ON FIRST COME FIRST SERVED BASIS.

CANCELLATION

Any Roadshow booking cancellation made must be confirmed in writing. The NKF is unable to offer refunds on bookings cancelled after 6th September 2010 and so recommends that you take out cancellation insurance.

HOW TO BOOK

Detach and complete this booking form, and return along with a cheque made payable to National Kidney Federation for the **FULL AMOUNT PAYABLE**, to:

**National Kidney Federation,
The Point, Coach Road, Shireoaks, Worksop,
Nottinghamshire S81 8BW**

or go to the online booking form at www.kidney.org.uk/roadshow10/ and either print off the form, complete and send in with your payment as above, or pay online using your credit or debit card.

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