



kidneytalk

Guy's & St Thomas' Kidney Patients' Association Newsletter

Welcome

There have been some big changes at the top of the Association and welcome Henry Kimbell as the vice chair and Trudy Page as the Treasurer. Over the coming months we will continue to make the KPA more relevant to people with kidney disease and continue to explore ways of enhancing the quality of life for all. Much of this work is being undertaken in partnership with other organisations such as local libraries, other charities and large organisations such as Sainsbury's.

There are lots of new things for the Spring – our KPA website will be launched on World Kidney Day (10 March), a laboratory visit on 16 April, charity golf on 8 April and many other smaller local events.

Last I wish to acknowledge those who contribute their time to the KPA and those who take part in events or sponsor our work in some way. Thank you.

DEVELOPING DIALYSIS SERVICES

Many of you will be familiar with our community dialysis units in Camberwell, New Cross Gate, Forest Hill and Tunbridge Wells. The Sidcup dialysis unit opened last year on the Queen Mary's Hospital site. The current dialysis unit is a temporary facility and a permanent kidney treatment centre is being planned in partnership with South London Healthcare NHS Trust.

Earlier this year planning permission was granted for a dialysis unit in Long Lane SE1. This will provide a modern, spacious, pleasant dialysis facility for people living or working in Southwark.



'A nurse born not made'

The Trust Annual Awards Ceremony was held on 24 November. These awards are to recognise individuals and teams that have gone that extra mile to deliver the best possible patient care.

Staff, patients and carers are invited to nominate people for the awards. This year the People's Award went to Liz George, who many of you will know as Sister in the Kidney Transplant Clinic. One of the patients who nominated Liz said 'she was a nurse born not made'. The award was presented by Trevor Cook, Chair of GSTTKPA.

The home dialysis training units will also move into this facility and there will be designated areas for people wishing to self care. The unit has been designed in collaboration with patients and is due to open at the end of 2011.

MINISTERIAL VISIT

Guy's has one of the largest home dialysis services in the UK and in November Health Minister, Simon Burns visited to find out more about it.

Two patients who dialyse at home, Andrew Samuel and Peter Hill, met the Minister and explained how home dialysis can offer greater independence, flexibility and convenience.

GETTING INVOLVED IN IMPROVING AND PLANNING SERVICES

Throughout last year a series of meetings were held at Guy's and in the community dialysis units to ensure that patients and carers are kept up to date with service developments. More importantly these meetings are an opportunity for patients to comment on 'what works well' and 'what could be improved'. We can't always deliver everything that patients want but often we can make improvements based on the feedback so if you are invited to a meeting please try to come along or send us your comments via email, letter or phone.

By Ros Tibbles
Service Improvement Nurse

Vitamin D biology and research

Vitamin D biology and research is one of the most interesting and potentially important areas in medical research at the moment. Vitamin D levels have been implicated in the general population with cardiovascular health, cancer risk and many other chronic conditions like diabetes. Many auto-immune and other conditions interestingly show a relationship with latitude – so some conditions are very rare in places in the world bathed in sunshine (clearly not the UK, with or without ash clouds), while in more Northerly climes (the UK par excellence) the prevalence of these diseases is much higher. This is relevant because our vitamin D comes from sun exposure, and also from diet. Of course, we kidney doctors speak a lot about sun avoidance for example with transplant patients, but transplant patients also have profound vitamin D deficiency, which could be harmful to bones, the kidney, the heart and also raise cancer risk.

Sadly, in chronic kidney disease, the traditional historical focus for vitamin D has only been on bones alone (lack of vitamin D leads to rickets in children and osteomalacia in adults), but as well as this important function, we desperately need more research on the effect of vitamin D deficiency on immune cell function (acute and chronic rejection), on heart size (evidence that vitamin D reduces the size of the heart muscle, which counteracts the effects of anaemia and of high blood pressure), and the risk of cancer that all kidney patients face.

The nice thing about vitamin D deficiency is that it is very easy, cheap and straightforward to correct it by oral supplements. Lets also try to support more research into this fascinating and potentially very beneficial pathway.

By Dr David Goldsmith
Consultant Nephrologist

INCOMPATIBILITY

The new word on the street?



SO WHAT IS INCOMPATIBILITY?

This is when a transplant between two people is not possible because they are incompatible by blood group (ABO incompatible) or HLA type (tissue-type incompatible). Incompatibility is due to the presence of antibodies in the recipient against the donor. Antibodies are usually associated with fighting infection but in transplantation they can attack the new kidney and cause it to fail. Antibodies against blood group are inherent (with us when we are born) and the amount of antibody varies from person to person. HLA (tissue-type) antibodies are different because they are acquired. This can happen after a blood transfusion, pregnancy (for women) or previous transplant and the antibodies remain in the blood and act like a 'memory'. Incompatibility is a complex area of transplantation and the terminology can be confusing. The most important thing to remember is that blood group (ABO) and tissue-type (HLA) antibodies are different from one another but both can cause incompatibility. In the past we would have turned down an incompatible living donor transplant.

WHAT HAS CHANGED NOW?

If you are planning an incompatible living donor transplant, it may be possible to have treatment to remove the antibodies from the recipient which would include medication by intravenous infusion, anti-rejection medication and antibody removal treatment. If this is possible for you, an individual treatment plan would be made which would start up to 1 month before the transplant.

WHAT IS ANTIBODY REMOVAL TREATMENT?

Approximately five days before the transplant we begin the process of antibody removal which involves a treatment similar to haemodialysis using a special filter and machine. The amount of treatment required varies according to the amount of antibodies in the blood of the recipient. The treatments are usually without complication but are time consuming and are in addition to any dialysis required.

ARE THERE OTHER OPTIONS?

The first step is always a detailed discussion about the options that are available including:

- Seeking an alternative, more suitable donor. A compatible living donor transplant is always preferable in terms of outcomes so alternative donor options should always be discussed at the beginning. Other willing, perhaps more suitable, donors can be overlooked if this is not discussed.
- Paired / pooled donation (national kidney exchange scheme)

This is when a donor and recipient are incompatible, so they are matched with another donor and recipient pair in the same situation and the kidneys are exchanged or swapped. Since the start of the scheme in January 2007, six recipients have been transplanted at Guy's in this way.

HOW CAN I FIND OUT MORE ABOUT THESE OPTIONS AND TREATMENTS?

These decisions can be quite complex and difficult to make and we are very happy to meet with recipients and donors as often as they need in order to make sure that they make the choice that is right for them. If you are reading this article and would like to know more, please feel free to contact any of the nurses in the living donor team or antibody removal team.

By Lisa Burnapp

Consultant Nurse, Living Donor Kidney Transplantation
Lead Nurse-Living Donation, NHS Blood and Transplant

By David Curran

Formerly Clinical Nurse Specialist, Antibody Removal

DAD'S ARMY



Sunday 12 December saw some of our favourite comedy characters return for a re-inactment in aid of charity. Captain Mainwaring and his merry band of men trod the floor boards again at the New Diorama Theatre in North London raising money for the GSTTKPA.

A full house was fortunate to watch an amusing interpretation of Jimmy Perry and David Croft's "The Godiva Affair" – whereby the local people of Walmington-on-Sea are trying to raise money to support the purchase of a new Spitfire plane. The platoon decide to drum up support by performing a morris dance at the fundraising carnival however it is the identity of the Lady Godiva figure that ends up grabbing the town's attention.

The cast were an eclectic mix of professionally trained actors and other more "part time" performers! Everyone pulled together extremely well and at this point I must thank my good friend and director, Alex Orchard-Lisle, who worked very hard in ensuring the play went off successfully.

I have always been a passionate watcher of Dad's Army. Whether it is Pike's soppy voice saying "Mum said..." or "Uncle Arthur" or Corporal Jones' enthusiastic cries of "Don't panic Captain Mainwaring!" the viewer is transported into a highly amusing world of nostalgic comedy. Consequently I was eager to produce a play, about a comedy that I love, whilst at the same time fundraising for a good cause and so I am happy to report in total £1000 was raised for the KPA.

By Henry Kimbell
Director and Vice Chair

Beach holiday... with a difference?

Jill is fundraising for two worthy charities – the GSTT Kidney Patients Association and the Alzheimer's Research Trust



You can donate to support her in this challenge at:

<http://uk.virginmoneygiving.com/JillHolliday>

NATIONAL KIDNEY FEDERATION (NKF) ROADSHOW 2010

The NKF Roadshow was held in Leistershire in October and was attended by a large number of kidney patients, carers and clinicians.

The first speaker was Dr Rob Higgins from Coventry who talked about **antibody incompatible transplantation**. He explained that up to about ten years ago this type of transplant would not have been possible but new techniques have made incompatible living donor transplantation a viable option for many people. Rob stressed that research is ongoing to continually improve outcomes for patients. Following Rob's talk, Paula, spoke movingly about her decision to donate a kidney to her sister Michelle.

Mr Al-Khaffaf, Consultant Surgeon and Michael Heap, Specialist Nurse spoke about the important of regular **monitoring and assessment of vascular access (fistula)**. They explained the various methods for

doing this including the use of the transonic device to detect changes in the blood vessels and prevent fistula failure. As all dialysis patients know, their fistula is their lifeline so there was much interest from the audience.

After lunch this topic was explored further by Suzi Glover, dialysis Matron, who explained the benefits of **'button hole' needling** of a fistula. Sister Sue Sharman, then talked about the ways in which health professionals give **information to patients**. Some light hearted slides of people falling asleep or being 'educated' to death certainly got her point across and the importance of involving expert patients in information giving was highlighted.

After lunch Jane Kaye, Podiatrist,

stressing the importance of foot care. The audience were urged to take off their shoes and socks and practice with the foot file kindly supplied in the conference pack!

From feet to food and the highlight of this year's event – celebrity chef from 'Roast' in Borough Market, Lawrence Keogh. Lawrence cooked a three course meal in 45 minutes suitable for kidney patients. Lawrence also spoke about his personal journey from performing CAPD in the restaurant kitchen to having a successful transplant and becoming a top TV chef.

The final session of the day was about home based dialysis and focussed on the importance of offering treatment choices that promote independence.

The day culminated in a gala dinner which unfortunately I missed as by this time I was on the train back to London. Once again, many thanks to the KPA for funding me to go to this very enjoyable event.

By Ros Tibbles
Service Improvement Nurse

GOLF DAY

The KPA has joined together with the Eyeless Charity to hold a Golf day at the prestigious Stoke Park Golf Course (a world class parkland course) on Friday 8 April 2011.

Players (Team GSTTKPA) are invited to contact **HenryKimbell@hotmail.com**. The cost of the day including refreshments and lunch is £150 and £100 for the under 30s (this is significantly less than the usual cost). Maybe you would like to support the KPA team and lunch is available for £45.

Two lucky patients could join the team on an expenses paid trip by completing and returning the form below.

To Enter the competition for a FREE Golf day please complete the following:

Name.....

Address.....

Postcode.....

Email.....

Please return this form by
18 March 2011 to:
KPA Golf Day,
C/O Renal Offices,
6th Floor, Borough Wing,
Guy's Hospital, Great Maze Pond,
London, SE1 9RT

World Kidney Day and launch of KPA website



World Kidney Day is 10 March 2011 and the KPA will launch a new professional

web site on that day **www.gsttkpa.org**. Please make this website a success by using it for all you kidney information and news.



Extending the life of the Transplant

There's another chance to catch the brilliant MRC Centre for Transplantation event – 'Extending the life of the transplant' on 21 March. Using specially commissioned film and animation, experts will show what it's like to experience dialysis and transplantation and bring to life groundbreaking scientific research that could solve serious problems associated with kidney failure. The audience will also have the chance to ask questions and take part in a debate about the ethics of transplantation.

'Extending the life of the transplant' was a huge hit at last year's British Science Festival. Due to popular demand, the Centre is running it again in London on Monday 21 March from 3pm till 4.30pm at New Hunt's House on the Guy's Campus of King's College London. If you are interested in attending, please contact the Centre directly to reserve a place at **mrccentre@kcl.ac.uk**.



One of the objectives of the KPA is to support research and over the years we have given many thousands of pounds to this end. To help us understand how the money is spent and how it helps people with kidney disease, the MRC Centre for Transplantation at Guy's has offered an

open day especially for kidney patients, their families and friends on Saturday 16 April. This will be an opportunity to see the laboratories, meet the staff and find out more about the latest kidney research. Meet outside Richard Bright ward, 6th Floor Borough Wing, Guy's Hospital, at 11am.