



kidneytalk

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

Welcome

My name is Trevor Cook, I'm a patient and since January, Chair of the KPA.

I have spent much of the last six months visiting all of the dialysis units, wards and clinics to ask patients and their families what they would like the KPA to do for them. I've also consulted partner organisations; clinicians, scientists and the KPA Trustees.

Lots of people wanted a newsletter - and here it is. They also wanted more local patient focussed help from the KPA which improved the quality of their treatment or the environment in which it takes place.

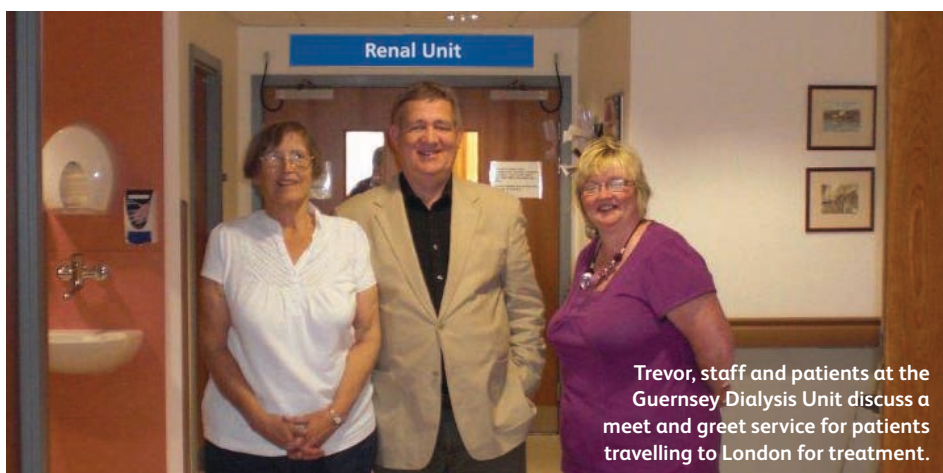
I responded quickly to these requests and many of you have seen improvements such as libraries being provided by the local council, trips out, TVs spring up in waiting areas, DVD players, and much more to come.

I have been busy with partners and those of you with failing eyesight will get help from the Metropolitan Society for the Blind, Kidney Research UK will partner us for some fund raising events and I have been to see the first transportable dialysis machine in action.

The Trustees met on the 4 August and fully supported the direction of travel of the refreshed KPA.

I know that I have met many of you since January and look forward to continually sharing with you the development of a KPA fit for supporting over 2000 patients attending one of the World's best hospitals.

Trevor Cook, Chair GSTTKPA



Trevor, staff and patients at the Guernsey Dialysis Unit discuss a meet and greet service for patients travelling to London for treatment.

ALL CHANGE!

It's been a busy time in the kidney service with staff changes, new units opening and new units being planned.

Dr Simon Steddon and Mr Geoff Koffman are now the Joint Clinical Directors, Julie Murray is Head of Nursing and Jon Spencer is General Manager. You will have noticed some new faces in the clinical areas but also many familiar ones, this may be due in part to the fact that the trust was recently rated as the best place to work for job satisfaction in an NHS staff survey!

DIALYSIS SERVICES...

The home dialysis service continues to thrive and Guy's and St Thomas' is one of few kidney units in the UK to offer nocturnal home haemodialysis which is when people dialyse six nights a week while they sleep. We are also now offering assisted APD for people who need help with peritoneal dialysis at home.

TRANSPLANT SERVICES...

The numbers of kidney transplants performed continues to rise each year. Last year (2009/10) 185 transplants were carried out and Guy's and St Thomas'

continues to be a leader in transplantation in the UK. New techniques and new therapies mean that transplant success rates are excellent. You can read more about some of these new therapies in this newsletter.

INPATIENT SERVICES...

Richard Bright ward has now moved to the 6th Floor of the Borough Wing and Patience ward is located below it on the 5th floor of the Borough Wing. The nursing teams on these wards are headed up by Anne Manalaysay and Ricky Sosa. Both wards were recently re furnished to improve the environment for patients, visitors and staff.

Scientists working for us...



A meeting with **Professor Sacks**

Our meeting expanded my knowledge of kidney research issues. Steve Sacks and his team in the Medical Research Council Centre for Transplantation are pursuing several goals.

He told me about the programme of the British Science Festival in Birmingham (from 14th-19th September this year), especially the Centre's main event, "Extending the life of the Transplant", which will feature author Sue Townsend and BBC broadcaster Vivienne Parry. The ethical issues facing transplant science will be debated.

This event will underscore the Centre's aims of educating the lay public about the issues and problems of kidney transplantation and focus on medical science's drive to improve kidney supply and to extend the life of the transplanted kidney.

On another matter, do you have any knowledge of what Genome-Wide Association Studies are concerned with and how they relate to kidney patients' experience?

As Steve explained, it's an approach that involves rapidly scanning markers

across complete sets of DNA (or genomes) of an extensive patient base to plot genetic variations linked to transplant outcome. The aim is to apply the acquired information to developing better

strategies and treatments in detecting, treating and preventing transplant rejection or other causes for failure.

The impact of these studies, led by Graham Lord in the Centre, which involve an increasing number of patients, could be substantial, predicting and planning for those patients identified as likely to develop problems after kidney transplant. If certain genetic variations are found to be more significantly frequent in those with kidney problems, compared to those without them, the variations can be said to be "associated" with the disease. They will serve as powerful pointers to the region of the human genome where the disease-causing problem resides.

The Centre also has a new success story to report, (published on June 1st in the "Journal of Clinical Investigation"), where a study has identified a "set" of biological markers in the blood which could be used to predict whether transplanted kidneys will have a long life, or will fail.

The aim of this study, led by Maria Hernandez-Fuentez, Rachel Hilton and Robert Lechler, is to deliver improved personalised care to kidney transplant patients in future, by safely adjusting the amount of medication taken to prevent rejection of the donor organ. The study has discovered that some very rare patients receiving a kidney do not experience organ rejection when they cease taking their immunosuppressive drugs. Patients can, in future, be screened with the expectation that some may be identified who can safely withdraw or reduce their dosage of immunosuppressants. The implication is the prospect of extending the life of transplanted kidneys, which would (together with all the other research projects being undertaken by the Centre) represent a significant improvement in kidney treatment.

I enjoyed a very fruitful chat with Professor Sacks, who told me of two new appointments in the Centre, Professor Randy Noelle (from Dartmouth USA) and Dr. Antonia Cronin. I hope this article is informative and helpful to all of us who are hoping for or who have had a transplant. I shall be inviting both newcomers to talk about their work in future newsletters.

By Peter March



SPOTLIGHT ON > Anthony Dorling

Anthony Dorling is a member of the KPA Committee, he qualified in Medicine from the University of London in 1987, did general medical training in hospitals around the South East of England and then did a PhD at the Royal Postgraduate Medical School at Hammersmith Hospital, before embarking on specialist training in Renal Medicine in 1995.

He became a Senior Lecturer (later 'Reader') in Immunology at Imperial College London and Honorary

Consultant Nephrologist at the Hammersmith in 2001, moving to King's College London and Guy's Hospital in October 2009. Outpatient work is mainly with kidney transplant donors and recipients.

Tony has compiled a list of research underway at Guys and some of which is supported by the KPA. This will be published annually and breakthroughs will be reported in future Newsletters.



The British Transplant Games

You may not have heard of the Transplant Games, however to the competitors, their families, supporters and staff here at the Evelina Children's Hospital the Games are a major highlight of the year. We would like to tell you a little about the Games and why friends like you our kidney patient's association are so important to us.



In the children's kidney transplant unit here at the Evelina Children's Hospital (St. Thomas') there are approximately 90 children under our continued care following their transplant. We believe each child should be supported and encouraged to reach their potential in life, whatever that may be.

One way to help the children achieve this is by encouraging them to focus on training for the Games and by encouraging their healthy competitiveness and good sportsmanship. We are very proud team managers who see evidence of this sportsmanship from the Evelina children every day of the Games however, it doesn't end there as we see evidence of it regularly throughout the year in our transplant clinic and ward. We were so proud of the sportsmanship of one young

teenager 10 years ago that we now award the Evelina good sportsmanship shield annually. Last year's winner was Matthew Bell, pictured here receiving his award from Cathy, one of the team managers. Matthew is a real games veteran, now aged 16 years; he will be competing in his 13th Games this year – an amazing achievement!

We actively encourage all our children who are well enough to compete to do so. Our team motto is 'Simply the Best' and our anthem can be heard on numerous occasions throughout the weekend (with apologies to Tina Turner!!!). The Games can cost on average £750 per child; we try as a team to subsidise the cost for the families, removing any additional financial burden that families with a chronically ill child can have and remain so very grateful for the long term and continued support from the KPA without which we wouldn't be able to achieve our amazing goals.

In addition to your support, we are very fortunate to have the support of Guy's & St Thomas' Charity and we actively fundraise amongst the team. Fund raising events this year include Cathy's parent's traditional Irish Dance (now in its 13th year), A teenager

and some parents abseiling down Guy's tower, some amazing marathon runners, sponsored walks, boot and cake sales to mention a few!! Our fund-raising will culminate at a sponsored run during the transplant games when some teens and families

will raise money and awareness of organ donation during the Games. They will be joined by Grainne, on a sponsored waddle through the streets of Bath wearing her full size penguin suit, pictured in this article.

The Games weekend is a hugely positive but emotional experience for all involved. Spending time with other families and staff away from the hospital



allows the children, parents and families the opportunity to relax and receive vital support and friendship. August 2010 will see 36 children competing as

Evelina VIPs being very positive ambassadors for transplantation and our trust. We will write again to let you know how our wonderful team got on, so watch this space!

Ongoing Clinical Research Studies at Guy's

Research Studies	Principle Investigator
1 WTCCC3 (Defining the genomic and immunological signature that determines the outcome of renal transplantation)	Graham Lord
2 Antibodies to DPB in renal transplantation - the evolution of an important theoretical concept?	Bob Vaughan
3 Tcell f(x) and Rituximab on High Risk patients	Nizam Mamode
4 Randomised controlled trial of anti-CD20 in patients with C4d+ Chronic Allograft Neuropathy (Rituxi-CAN C4)	Anthony Dorling
5 The incidence of perioperative myocardial infarction in renal transplant patients	Nizam Mamode
6 Epityping - a new approach to HLA typing designed for solid organ transplantation	Bob Vaughan
7 An investigation into the potential benefit of full HLA typing and HLA specific antibody epitope definition on renal allocation	Bob Vaughan Maria Hernandez Fuentes
8 Predicting kidney transplant outcome by genetic polymorphism with a focus on donor complement system genes	Steve Sacks Paramit Chowdhury
9 Image Guided daVinci Urology Surgery	Steve Sacks Steve Thompson, Prokar Dasgupta
10 Patency and complications associated with using an early cannulation graft (Flixene) in the upper limb	Francis Calder
11 A randomized controlled trial and economic modelling of open, laparoscopic and robotic radical cystectomy for bladder cancer	Prokar Dasgupta Shamim Khan
12 Coagulation disorders caused by antibody removal techniques in ABOi and highly sensitised kidney transplant recipients	Nizam Mamode
13 Quantitatively assessing the benefit of living donation	Nizam Mamode
14 Catheter Study	Jonathon Olsburgh
15 Randomised controlled trial of oral rapamycin or paclitaxel coated balloons to prevent native arteriovenous fistula restenosis	Mike Robson
16 Lignocaine instillation versus placebo for pain reduction in patients undergoing intradetrusor injections of Botulinum Toxin A to treat overactive bladder	Jane Watkins Shamim Khan
17 Exploring the experiences of patients withdrawing from dialysis: the perceptions of bereaved carers	Emma Murphy
18 UK Calciphylaxis Registry	David Goldsmith
19 Obtaining (control) biopsies of normal human bladders	Chris Dowson Shamim Khan
20 Are biomarkers of tolerance useful to predict success in immunosuppressive weaning protocols?	Maria Hernandez Fuentes Rachel Hilton
21 Randomised trial of rituximab in a steroid avoidance, Symphony style protocol	Nizam Mamode
22 Immune Profiling in Transplant Recipients to allow Non-invasive Prediction of Graft Rejection and Individualisation of Immunosuppressive Drug Therapy	Paramit Chowdhury Steven Sacks
23 Effect of early phosphate control on bone metabolism and coronary calcification in CKD	David Goldsmith
24 Use of excess ureter from transplant donor kidneys for research purposes	Jonathon Olsburgh
25 Monocyte subsets in Chronic Humoral Kidney Transplant Rejection	Sarah de Freitas Steve Sacks, Frederic Geissmann

Research Studies	Principle Investigator
26 Understanding the pathogenesis of ANCA-associated vasculitis	Mike Robson
27 Transplant ureteric stent removal. Early vs standard removal. A randomised controlled trial	Jonathon Olsburgh
28 Biographical & spiritual disruption in renal patients	John Watts
29 Tacrolimus vs prednisolone for the treatment of nephrotic syndrome secondary to minimal change disease: A Randomised Control Trial MINTAC study	James Pattison
30 The IMPACT SHPT Study: Study to Evaluate the Improved Management of iPTH with Paricalcitol-centered Therapy vs. Cinacalcet Therapy with Low-dose Vitamin D in Hemodialysis	David Goldsmith
31 A prospective, multicentre, observational study evaluating an antigen specific antibody removal protocol for ABO incompatible renal transplantation in the UK ABOUT-K study	Nizam Mamode
32 Quality of life, coping and common mental disorder among patients with failing kidney grafts, failed grafts and those never transplanted	Sarah Afuwape Sue Cox
33 Investigations into Urinary Tract Infections (UTI) in transplant patients	Jonathon Olsburgh
34 To describe trajectory of illness and care received during the last year of life for those people with ESRD who die following withdrawal of dialysis.	Emma Murphy
35 Defining the importance of adenosine metabolism for allograft accommodation after renal transplantation	Anthony Dorling
36 Sirolimus and microcytosis	David Goldsmith
37 Renal function (GFR) and BP control in a cohort of ARVD patients post renal artery intervention	David Goldsmith
38 Attitudes to Medication Use Amongst Kidney Transplant Patients	Jim Ottaway
39 T Cell Interferon-Gamma Release Assay (TIGRA) in immunocompromised individuals (TBNET-TIPS)	Marlies Ostermann
40 Locating prostate tumours using a haptic, rolling indentation probe	Kaspar Althoefer, Prokar Dasgupta
41 Randomised controlled trial of laparoscopic, open and robot assisted prostatectomy as treatment for organ-confined prostate cancer LopeRA	Prokar Dasgupta
42 Bladder cancer: Open versus Laparoscopic or RObotic cystectomy. A study to determine the feasibility of randomisation to open versus minimal access cystectomy in patients with muscle invasive bladder cancer BOLERO	Prokar Dasgupta Shamim Khan
43 Renal Protection against ischaemia-reperfusion in transplantation REPAIR	Jonathon Olsburgh
44 Identification of the most suitable subpopulation of regulatory T cells for cell therapy in renal allograft recipients.	Ben Afzali, Gio Lombardi Robert Lechler
45 A randomised trial to compare effects of aggressive versus standard targets in blood pressure on target organ damage in children with CKD	Manish Sinha
46 Advanced Renal Care Project	Fliss Murtagh, Heather Brown, Sue Cox
47 Effect of weight loss surgery on preservation of kidney function and cardiovascular disease risk factors in obese patients with stages 304 CKD: a randomised controlled trial	Iain Macdougall P. Chowdhury
48 Pilot study - Weight loss surgery and combined mortality and cardiovascular morbidity outcome in obese haemodialysis patients.	Iain Macdougall P. Chowdhury

And Finally...

To find out about our services and staff visit www.gstt.nhs.uk/services/kidney

Also we are pleased to announce the arrival of www.mykidney.org.uk our new

website developed in collaboration with King's College Hospital and the KPA.

The website was launched on World Kidney Day at The House of Commons and contains information for patients and carers, which we hope to develop further soon.

We want to hear from you.

We want your feedback, comments and suggestions for both the new website and this newsletter.

You can send your thoughts by email to chair@gsttkpa.org