April 2006

Renality

The NEWSLETTER of …..

South West Thames Renal & Transplantation Unit,

Epsom and St Helier University Hospitals NHS

NHS Trust

South West Thames Kidney Fund (Registered Charity Number: 800952), supporting the

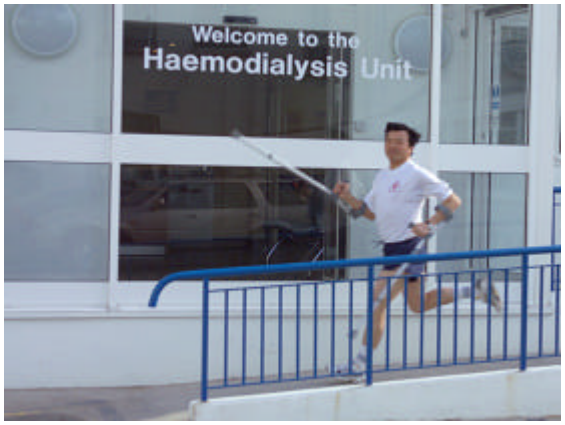
South West Thames Institute for Renal Research

and

SHAK - St Helier Association for Kidney Patients (Registered Charity Number: 266391)

****

£32,100 promised … before the London Marathon had taken place.



Training is a serious business for Jonathan - he runs down this ramp every evening

By the time you read this, the Flora London Marathon 2006 will be all over. (We went to print a week before the event.) Team members will have started to relax and recover from their aches and pains. They will have recounted stories of their experiences during that gruelling run. Hopefully, we will be able to pass some of them on to you in our next edition of Renality.

We know that they have been dedicated in their training and probably suffered some doubts as to whether or not they would be able to keep up the pace and complete the course. We know that Jonathan has completed two Half-Marathons within the last three weeks as part of his training and we are sure other Team members will have done the same.

A week before the event, the Team took some time off for a 'get-together', a Team photo and a well deserved meal. **We thank you all for your tremendous effort and hope you had a successful day.**

If you have not sponsored the Team yet, please contact Anne Collard on 020 8296 3698.

The Marathon Team 2006 (from left to right):
Adam Barrett, Rob Adnitt, Steve Marsh, Kay Sheehy, Carol Lambe, Jonathan Kwan, Tom Rhind and Ajay Bhalla

Renality in COLOUR!
(Just this edition)

What do YOU think of it?
Please let us know -
See back page

The hottest news recently apart from the 2006 Renal Unit Marathon Team (more of this later) has been the opening of our state-of-art Kingston Dialysis Centre last month. This centre with 16 stations was built with NHS monies alone with no commercial partner involvement. This is a "first" for our unit, the other 4 satellite units were all set up in partnership with dialysis industry providers; and it is perhaps a mark of our "management maturity" as a patient-focused cost-effective healthcare provider. We were able to make savings on previous years' income to make possible the capital investment on this centre. The official opening of this Centre will be conducted by the famous actor Art Malik, a Kingston Resident, at noon on 26 April 2006.

In parallel with the above development, intensive building work activity is also taking place in our Elizabeth Ward Dialysis Unit in Mayday Hospital, Croydon. By July of this year, we shall take possession of a much-extended newly refurbished unit with 23 haemodialysis stations, hugely benefiting our patients living in the Croydon areas. The capital investment for this project was secured by our successful bid to the London Renal Modernisation Fund two years ago.

Apart from the above, we are also actively working on 2 other projects; the first one is the reconfiguration of our Chertsey/Woking Satellite Dialysis Unit and the second one is the refurbishment of the Unit's Reception and Outpatient Department. The latter project is long overdue and we are hopeful that we can deliver on this by the end of this calendar year.

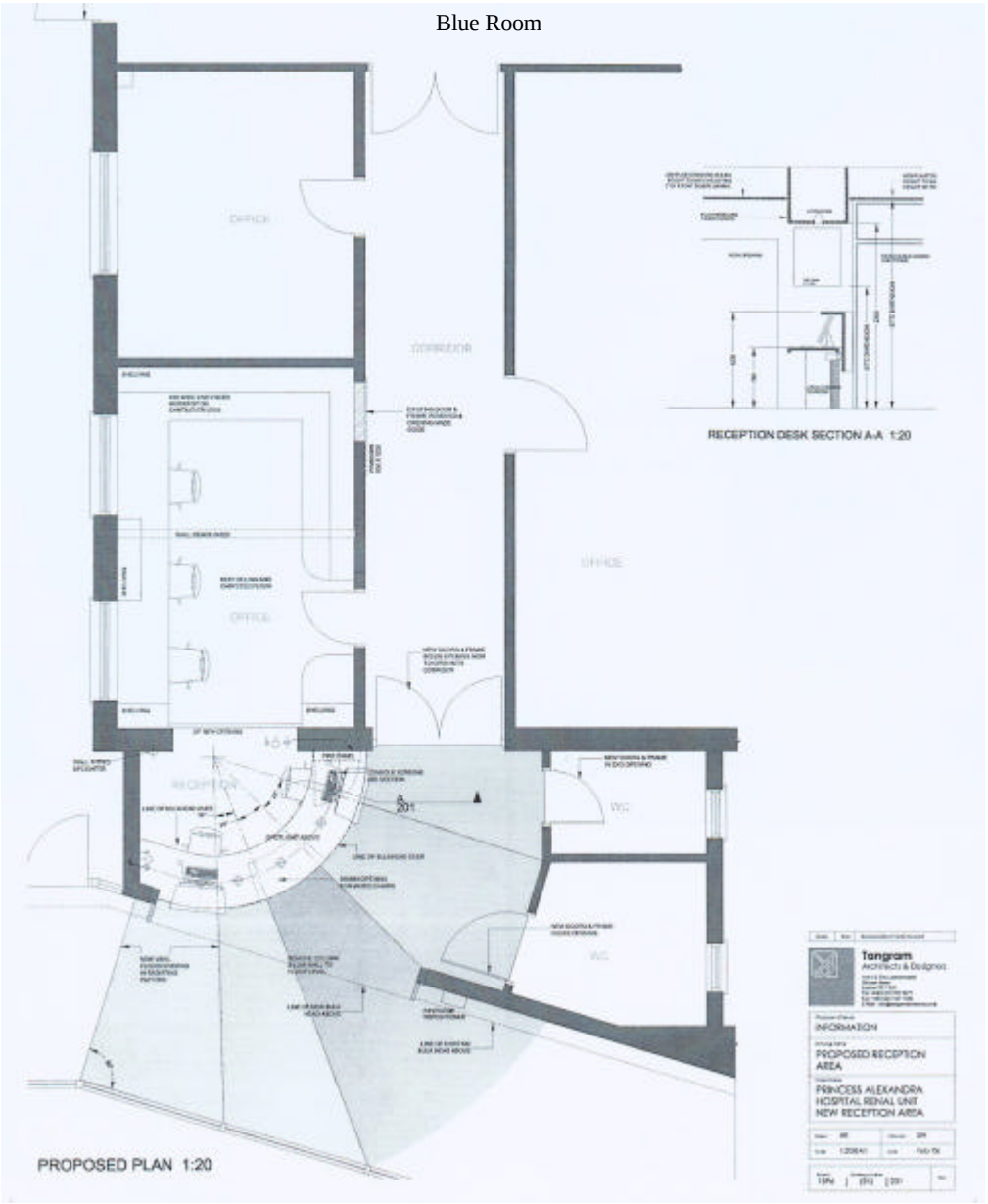
Having received a number of national awards this last couple of years, including "Investor in People", "Innovative Team of the Year" and "First in Class in Patient Education", we are currently busy in securing the national "Patient Friendly Accreditation" award. These awards not only brought some prestige and fame to the Unit, but more importantly, they have provided us with a very powerful motivation for our staff in continuing to deliver exemplary care to you, our patients.

I am most grateful for my fellow members of our 2006 Marathon Team, numbered some eight mortals, 2 women and 6 men, coming from different walks of life, with the sole aim of raising funding for our Research Institute. On a personal note, training for my first ever marathon attempt has been an interesting voyage of self-discovery. Until recently, my regular exercise consisted solely of typing on the keyboard. If I ever had a feeling for exercise, I simply laid down until the feeling went. Training, as I discovered in the last few months, requires a lot of self-discipline, which I found rather wanting. However, the pressure of not delivering my part of the bargain in the face of an overwhelming response in the donations and pledges I have received so far, £21,000, provided the best stimulus for me to keep running. One also gets to know one's body much better than before, particularly for someone like myself who has never ever tested his physical limitations before. You know when you can push yourself that much harder and when you need to back off before injuries set in. Suffice to say, I went through a few of these phases. A pleasant surprise for me recently was beating a number of my junior doctors at a recent half-marathon, and they were some twenty years younger! To me the mental game for the marathon is how to overcome boredom – I have just started reading the book called "The Loneliness of the Long Distant Runner" by Alan Sillitoe. I hope to finish this before the big day! The first half an hour of any of my runs was physically demanding as one was warming up, the next half an hour is plain cruising with music blaring down my ears from my iPOD, thereafter it was sheer boredom……. My saviour turned out to be the introduction of "Podcasting" by the BBC. For those yet-to-be-initiated, Podcasting is a term given to the downloading of BBC programmes onto iPOD or similar MP3 players. Podcasting allowed me to listen to many different radio programmes, which I would otherwise have not the time to do so. I would recommend anyone to try this out as an alternative to mindless music!

I hope Spring comes soon…… (jogging in sub-zero temperature is no fun at all).

Jonathan Kwan

Proposed plans for the new reception area at the Renal Unit (plans for the waiting area ,which will include a coffee bar, are still being finalised). The reception desk will be in front of the office (wall will be knocked out) near the corridor to the Blue Room. The two WCs (right) will be refurbished and we hope they will open on to the corridor to Secombe.



Many congratulations to our secretarial staff ….

Hazel Sanders , Secretary to Dr Makanjoula and **Leah Rollins** , Secretary to Dr Marsh and Dr Gallagher, have both been awarded with the AMSPAR (Association of Medical Secretaries, PA's and Receptionists) Medical Technology Certificate. Both passed with flying colours; Hazel gained a distinction and Leah, a credit.
This was an intensive course of 20 weeks which is normally a year's study but it was provided in-house by the NVQ Department of the Trust. The girls are to be doubly congratulated as, until two years ago, neither of them were even medical secretaries.

Belated congratulations go to **Janet Dell**, Dr Kwan's Secretary, who was awarded an NVQ Level 3 in Business Administration last year. Janet is the first person in the Renal Unit to have gained this qualification. It represented a lot of hard work and dedication on her part.

Unfortunately, we do not have photographs of any of these award winners but we offer them our warmest congratulations.

South West Thames Kidney Fund

Dear South West Thames Kidney Funders,

The Annual General Meeting of your Kidney Fund on the 19th February 2006 was one of the best ever. As usual it was held on a Sunday between 11.30am and 4pm. The business meeting passed some small, but very important, amendments to our Constitution allowing a far more business-like approach to raising industrial capital to support our vital renal research. The reasons for the change were eloquently outlined and proposed by Paul Colville-Nash and Paul's depth of insight into the methods of funding scientific research is a very considerable asset to the Institute at St Helier.

Before lunch, we were entertained by a brilliant and humorous quiz master, Mark Dockrell. He had us rolling around in the aisles with mirth. Mark will be presenting another unique quiz as a fund raising event later in the year – ***don't miss this hilarious evening.***

On a more serious note – Mr William Ayliffe, Consultant Ophthalmologist from the Mayday Hospital gave a sparkling talk on eye complications in renal disease and the ways to avoid them and preserve precious sight. Those of you who were present will have benefited so much from hearing his words of wisdom. We all know that to stay fit and well as a renal patient it is so vital to learn from the experts what we can do to help ourselves. Mr Ayliffe has returned his honorarium of £100 to the Kidney Fund and refused to accept any expenses for giving up his Sunday afternoon with such a far sighted talk (sic pun intended).

The whole meeting was wound up by a most instructive talk from Dermatologist Dr Chris Harland. Again, this was so valuable for all kidney patients with all the up-to-date tips on how to avoid or reduce the risk of skin cancers after renal transplantation. His main message goes a long way to allay fears and anxieties.

For our Annual General Meeting in February 2007 I am planning a narrative competition. There will be prizes for the best 10-minute account of the most hilarious dialysis holiday and in another category, a prize for the best 10-minute presentation on big achievements despite being on dialysis or being a renal patient.

All renal patients have their own amazing stories to tell and these stories are so important to encourage new patients and to illustrate how much life there can be despite dialysis and transplantation. If we receive enough high quality anecdotes we may even publish in book form and sell to other renal units.

I would therefore urge you to pick up your pens and start scribbling. Please submit your reports, as humorously as possible, to me within the next few months. Some of the short-listed contributors will be invited to entertain us at the Annual General Meeting on Sunday _____ February 2007 next year.

Do put this date in your diary ***now*** and join us for a very amusing and instructive day.

With personal best wishes to you all,

Yours sincerely

Michael Bending, Chairman

SWTKF Branch News

Frimley Park & Guildford Branch:

Shirley and John Smith held a very successful coffee morning at their home on Valentine's Day. More than 40 people attended and enjoyed meeting old friends. The occasion raised £460 for the Fund. We thank John and Shirley for their hard work.

A most enjoyable Quiz Evening was held by members of the Branch in March which raised the sum of £380.

Also, a collection was held at Sainsbury's, Farnham. Although it was a particularly cold day, members of the public gave a total of £568.
Future events include a Car Boot sale planned for 22 April and a further two collections are due to be held in July and August.

Sutton Branch:

The Branch held another of their very popular dinners recently and a good time was had by all. The evening raised £400 for the Fund.

Hydro Active Women's Challenge …. Sunday 3rd September - in Hyde Park

Ann Collard has entry forms for this 5K Run in Hyde Park. This is an event for women of all ages, fit and not so fit.
Entry costs £15, £5.00 of which is donated back to the Kidney Fund. You will be supplied with a SWTKF T-shirt to wear on the day. Every entrant will receive a goody bag which will include a finisher Hydro Active Women's Challenge T-shirt and medal. (Pictured is last year's Team and they had a good time.)
Why not make up a team of daughters, mothers or other female relatives and friends and have a good day out. Places fill up fast, so if you would like to run/walk/jog the 5k and raise funds for renal research, please contact Anne on 020 8296 3698 or email Anne.Collard@epsom-sthelier.nhs.uk

World Party & Croydon Mela

Saturday 15th + Sunday 16th July 2006
12 noon to 8.00pm

South West Thames Kidney Fund (Croydon Branch) are making it a fundraising weekend. Once again, Pynee Sanjivi and friends will be selling drinks and snacks and can rattling throughout the weekend. Do stop by and speak to them.
Volunteers are needed on the two days to help at the SWTKF stall .
If you can help at all, please telephone Pynee Sanjivi on 07931 137062,

Additionally ….

Nicki Thomas, Lead Nurse for Research, will have a stall nearby with a team offering blood pressure monitoring (for a small donation to the Fund). If you are there, do speak to her.

WATCH THIS SPACE

Do you fancy walking on FIRE - or ICE???

Our last FIRE WALK proved to be very popular

Anne Collard is hoping to organise another such event in the Autumn

We have some volunteers for an ICE WALK already!

This will be a very special 'Bring your own bottle' event

Look out for the details in our next issue - NOT TO BE MISSED!

We would like to thank many people who have helped SWTKF in their various ways. We mention some of them ….

Miss Barbara Bryant celebrated her 70th Birthday by donating the £70 to Dr Kwan's Marathon effort which she had received as a birthday present. Thank you and many congratulations on reaching your coming of age.

Thank you to Marion Mantle who held a sale which raised £100. You may remember that Marion donated a kidney to Carolyn Joslyn who organised the 'Stars in their Eyes' concert a couple of years ago.

Our grateful thanks to Mrs B A Stagg who raised £467.00 for SWTKF by doing a 'sponsored slim'. Hard work for Mrs Stagg but we hope she found it worth her while.

The Kidney Fund received a legacy of £74,634.77 from the estate of Patricia Snow which has been most gratefully received.

Thank you to Karen English. Karen celebrated her 30th birthday by opening her own fundraising page: http://www.justgiving.com/Kazs30th so that people could donate to the Kidney Fund as a present to her. At the time this edition goes to print the total she had raised was £951.28.
That is an incredible sum which is much appreciated.

Donations ….
amounting to £10,000 have been made to the Kidney Fund in memory of Jean Harrington by her husband and their very close friends. This is very much appreciated and SWTKF may put the money towards a particular piece of equipment for the laboratory as a lasting memorial.

RECYCLE your Inkjet and Laser Cartridges and old mobile phones and raise funds for SHAK and SWTKF

Ask your friends and family to give you their used cartridges and mobile phones (with chargers) and bring them to the cartridge recycle bin in the Renal Unit

Please note:
Hewlett Packard laserjet toner cartridges that are no longer worth anything for recycling. The numbers are:
Q2670A, Q2671A, Q2672A, Q2673A

Swimathon aids SWTKF

Sophie and Emily Tidman (pictured) and a team of children completed a Swimathon in aid of SWTKF early in April at the Rainbow Centre in Epsom.
Sophie did the 200 lengths in an amazing 1hr 42mins. Emily and her team managed it all with Emily doing 130 lengths and the rest being completed between the others at a time of about 2hrs 15mins.
They think they have raised around £150.
Many congratulations to Sophie and Emily and their team and thank you very much.

A Bikeathon for SWTKF ….

Jane Cridland, whose niece has been moved from Great Ormond Street Hospital to the Renal Unit at St Helier, and her sister wish to fundraise for SWTKF. They have started well. They have persuaded Suzy Raitt to take part in the Bikeathon in and around Woking on Sunday 7th May and raise money for renal research (even though the Bikeathon has been arranged to raise money for Leukaemia). Suzy will be cycling 29 miles. Our thanks to Suzy for all her effort. (Unfortunately, we do not have a picture of her.)

and another sponsored cycle ride …

Katie and Ian Hall are going to do a sponsored cycle ride called **'Cycling Back to Our Routes'** from Barnstaple in North Devon to Ashstead, Surrey at the end of May/start of June. This ride will be in memory of Katie's father, Gerald Golding, a former patient of the Renal Unit. Thank you to Katie & Ian.
Good luck to our cyclists. If you wish to sponsor them contact Anne Collard on 020 8296 3698.

NURSING RESEARCH NEWS

I was delighted to receive some money from the Kidney Fund and SHAK last month to support my ongoing project, so I'm writing to let you know how the project is progressing. The purpose of the four-year project is to see whether kidney damage caused by diabetes can be slowed down through improved education.

The type of education that is being developed and tested is a teaching programme run in GP surgeries which emphasises self-management. We know that kidney damage is slowed down through good blood pressure control, good blood sugar control, and lifestyle change such as stopping smoking and losing weight. In this project, I aim to improve patients' knowledge of kidney disease in order that they themselves can help manage their condition.

The project started in February 2004 and the first thing I did was to see how diabetes was managed in GP surgeries. So I sat with GPs and practice nurses in six local GP surgeries during diabetes clinics. At the same time I started mapping the care of all patients in these surgeries who had early kidney damage. In 2005 I started interviewing patients who were at risk of kidney damage. The aim of the interviews was to find out how much people know about kidney disease, and how much they understand about the consequences of renal damage.

From what I saw in the GP surgeries and from what I found out in the interviews I knew that much more education was needed. Patients told me that they knew little about kidney problems and certainly did not understand the importance of good blood pressure control and taking the appropriate tablets. So I am now developing the education programme and this is where the money comes in!

Many patients told me that they learn best by one-to-one teaching from a nurse or doctor. However it is unrealistic to assume that every GP or nurse working in each doctor's surgery will have enough time to spend with everyone talking about prevention of kidney damage in detail. I decided that we needed a film about kidney disease which every patient at risk would have access to. There also needs to be written information and also a blood-pressure machine for patients to monitor blood pressure at home if needed.

I have been working with a local film production company, and the producer and a cameraman have recently been filming in a local GP surgery, in a patient's home and also in the Renal Unit. My thanks go to all of you who contributed – many of you who dialyse in the main unit at St. Helier on a Tuesday morning will have seen the film crew. At the time of writing I am waiting for the first draft of the film to be sent to me, and I will then ask patients, nurses and doctors to comment before the final film is produced.

The final stage of the project will involve testing the education programme. Over the next eighteen months I will see whether education really does make a difference to how far kidney damage can be slowed down. So I will be checking on patients who have seen the DVD, who have had extra information about kidney damage and who have monitored their blood pressure at home. If results show success in slowing down kidney damage then I hope to be able to roll-out this type of education across the whole region.

I'd like to thank all of you who have so kindly raised money for the Kidney Fund. I really hope that this project will show how we can prevent or slow down kidney damage in people who are at risk.

Nicola Thomas
Lead Nurse for Research

South West Thames Institute for Renal Research

Hello once again to all the readers of "Renality" and supporters of the **South West Thames Institute for Renal Research** through the **South West Thames Kidney Fund**. As I write this article, the sun is out (though perhaps not for long looking at the clouds in the distance!), spring is upon us, and I hope you are all looking forward to the coming summer.

We are now preparing for our attendance at the joint British Renal Association British Renal Society meeting in Harrogate in May. This is the premier meeting of the renal community in the UK. Previously held a couple of times a year, the conference is now held once annually and it is an opportunity to showcase our research and meet others engaged in the fight against renal disease. The Institute will again have a big presence with 13 abstracts having been accepted by the organisers for presentation to the meeting. This shows the level of interest in the work we carry out and confirmed the Institute's position and growing reputation as among the leaders in the field of our research into the ways in which cells in the body decide what to do in renal disease and how to stop them from doing it if its bad!

Our contribution to the research which takes place in the NHS has been again recognised by the award of a number of grants by the Research and Development Department at the Epsom and St Helier University Hospitals NHS Trust. I am delighted that as a result of this, Mr Alex Pearson will be staying with us for a further year. Alex came here several years ago as a student studying for his scientific Doctorate under the tutelage of David Newman, the previous Scientific Director who passed away tragically a few years ago in a mountaineering accident. Alex has now submitted his Ph.D. thesis and we are hopeful that he will soon be "Doctored". The Trust is also continuing the support for the salaries for Mrs Ioana Nicolescu-Duvaz and Mrs Arti Katheria who are working with Dr Mark Dockrell and Mr Alan Gibbons. He is doing sterling work helping Miss Sarah Yates process the some ten thousand samples we are analysing as part of the "LOLIPOP" study. This is funded by Kidney Research UK and the Department of Health, looking at renal function and measurement in the context of ethnicity to see whether our current methods are good enough and investigating the links between heart disease and kidney disease.

The specialist analytical skills that we have developed in the Institute are also now being used by others in the research community in the UK and we are helping analyse samples for several studies in University College, London. In these we are using the techniques we have for measuring blood borne signals which control the immune system (currently helping Dr Khalid Haque, a consultant neonataologist in the Special Care Baby Unit at St Helier Hospital develop better ways to treat sick premature babies – see my article in January this year) to investigate what happens in

people in intensive care who get blood infections and end up on life support as a result of septic shock. The data we have obtained so far shows some interesting changes which the intensive care specialists hope will enable them to monitor these patients more effectively and help develop new ways to save the lives of these very sick people. The same technology is also being used in studies interested in trying to understand how aspirin works – Yes, that's right, Aspirin! Although it has been around for centuries (its origins go back to the Egyptians!!), we are continually finding new things out about it and how it works as an anti-inflammatory drug. It now seems that as well as stopping the body make things which cause inflammation and blood clotting (hence aspirin stopping these and "thinning" blood), it also makes the body make a whole new set of things which can help the body repair itself after damage and our assays are helping scientists understand what these new signals can do.

As ever, we in the Institute are continually grateful for the kind support given to our work by your fund raising on our behalf. Please continue to help us in achieving our goals aimed at all levels of kidney disease by funding our research into better prevention, providing more effective treatments, improving the quality of life of all renal patients and their carers, and hopefully finding a cure.

Remember

"No Funding = No Research; No Research = No Cure!"

and support Dr Jonathan Kwan and the other runners in the Flora London Marathon 2006 who are running in support of the South West Thames Kidney Fund. Hopefully you will all have seen the sponsor forms but if you want more information, see the articles in this issue of Renality. To make a donation, please ask any of the South West Thames Kidney Fund members, Renal Unit and Institute staff who will be very happy to help, or go to "www.justgiving.com/jonathankwan".

Multi-professional triage team for chronic kidney disease (CKD) - improving care and reducing the burden in secondary care ….

CKD will be part of a Quality Outcomes Framework (QOF) project which has been running in Guildford PCT for two years. Initially, it concentrated on musculoskeletal ailments but from 1st April, CKF will become part of it.

Nicki Thomas, Lead Research Nurse and Hugh Gallagher, Consultant Renal Physician for the patch will be working with Simon de Lusignan, a national expert for the development of QOF for general practice and Jeremy van Vlymen.

The aim is to develop an educational initiative to improve awareness of chronic kidney disease and the quality of care in the Guildford & Waverley area. It is hoped patients will be involved in events at different stages of the initiative and feed back important information about their experiences to the GPs involved.

SHAK has written to the Team endorsing the initiative.

Renal Patient View

In the last issue of Renality I wrote an article about a new initiative whereby patients could access information about their condition and also the results of their blood tests on-line over the internet. This initiative is called Renal PatientView, and it is a national project which is being rolled out throughout the UK.

Thank you to those of you who have contacted me about it, but unfortunately I have to report that the scheme is taking much longer to get going than expected. The reason is that there are many computer projects at St. Helier Hospital which are taking priority, and we are unable to start this project in the renal unit without the go-ahead from the main IS (computer services) board.

Please accept my apologies for the delay – we now have a provisional start date of May 2006.

Nicola Thomas
Lead Nurse for Research

SHAK NEWS

Dear Friends

By the time you receive this letter Dr. Kwan and the other 7 Marathon runners will be over the worst of their exertions and looking at the rewards of their run. Have you sponsored them? This is a great opportunity to give encouragement and to promote research into renal disease. It is not too late to send a donation.

Janet Dell, Dr. Kwan's secretary, has been busy compiling **a leaflet about holiday dialysis**. It sets out all you need to know about booking the holiday, what dialysis is available, where payment is necessary and the return to the Unit. It deals with holidaying in the UK, holidaying in E111 countries, holidaying elsewhere and travel insurance. It also contains the policy and practical measures necessary after holidaying abroad if there is any risk of blood-borne diseases. The leaflet is being promoted by the Renal Unit and will shortly be available to all HD patients. The best advice it contains, and which SHAK heartily endorses, is please talk to Janet Dell **before** making any arrangements. She has lists of dialysis units abroad and in the UK, she will ensure you have all the documents you will need and will be able to advise you of any steps you need to take to ensure a great holiday.

The plans for the new Outpatient reception are finalised and I hope the work will start soon. It has been more difficult to decide on the best layout for the waiting area (the present reception and waiting area) but we think the best solution has been found and the final plans will soon be drawn up. One special feature for SHAK is the replacement of our Tea Trolley by a permanent refreshment bar. (See page 3)

The formal opening of the Kingston Dialysis Unit takes place on 26 April. Margaret and I will represent SHAK at what promises to be a nice occasion. SHAK has agreed to provide TVs for each couch but we are having great trouble finding suitable 15" LCD Digital TVs at a reasonable price. We need 16. It looks as though the manufacturers are trying to sell all their analogue sets before digital becomes the rule.

The trial of small 7" TV sets in the St. Helier HD ward has started with two sets installed. 7 sets will be installed for the trial. If the reception is good and the HD patients like them then every bed and couch in the HD ward will be equipped.

I have become involved in talks about the **facilities available for patients at Ashford Hospital, Middlesex**. The dialysis unit there is part of the Hammersmith Hospital Renal Services even though the hospital itself is part of the Ashford and St. Peters Trust. The unit is set to close by the end of the year and the patients have to move elsewhere. Of the 72 patients 29 are part of the North Surrey PCT and they want them to move to the proposed new Unit at St. Peters, Chertsey. Hammersmith wish to retain its patients and are offering them dialysis at Ealing, Isleworth, Hammersmith and a new unit to be built at Hayes.
SHAK is saying the patients should have full information about all their options and should be able to make a free choice.

Margaret and I are standing down as Secretary and Chairman at the AGM in November. Would you like to be involved in our place? Please telephone if you are interested.

Peter Simpson

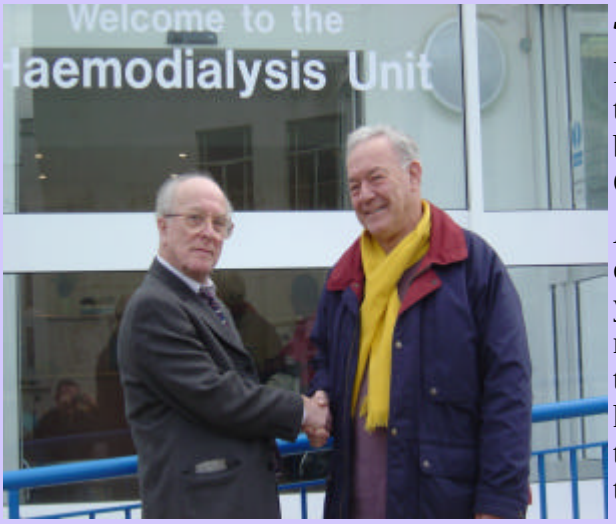
Have you logged on yet?

Our website has been up and running for just over three months now

Log on to **www.shak-online.org** and see for yourselves. Ravi Patel, a SHAK Committee member, set up our website last year and has now got the site working well. Ravi has spent a lot of time on it and with the co-operation of some of the staff at the Renal Unit, he has compiled a list of interesting and informative articles. These include information on kidney failure, anaemia in kidney disease, blood pressure, diet, haemodialysis and much more on related conditions.

You can find out a little about SHAK's history, our present committee and some of the services we give to patients today. It includes information on travel precautions for kidney patients. It gives an 'inside' view of our Holiday Home at Bognor Regis.

Take a closer look and let us know what you think of it. You can contact Ravi by email: **ravi@shak-online.org**



Peter Simpson meets Mr Michael Clark

SHAK benefits from donation

Peter Simpson met Mr Michael Clark and his son at the Renal Unit to receive a donation of £1,000 given by him and his family in memory of his wife, Mrs Christine Clark who died suddenly.

Although Christine was not a patient of the Unit, she cared for her Mother, Mrs Dorothy Field, aged 92 years. According to Mr Clark, Mrs Field is doing remarkably well and receives dialysis treatment at the Woking Satellite Unit. The family felt Mrs Field has had such good treatment from the staff, both at the Renal Unit and at Woking they wished to make the donation to SHAK.

THE RENAL NETWORK

The Renal Stakeholder Seminar was held on 17 March. Its purpose was to hear and discuss the proposed models of care which would be necessary if a Renal Network is to be established incorporating all the Renal services of St. Helier and St. George's Hospitals.

The first presentation was by Dr. Kwan and concerned Inpatient services. He spoke of the likely rate of growth (8 to 10% per year) with the added factor of the new classification of Chronic Kidney Disease which altogether could mean that 0.5% of the population will need inpatient care. The number of inpatient centres will depend on the number of patients and the size of these centres. There may be scope for having lower intensity activity where specialist cover is not needed more locally. He gave three options: one large centre, two centres - one located with transplant surgery, three centres.

Dr. Marsh introduced the paper on Renal Failure surgery. The main concern here is whether access surgery should be centralised and performed by the renal surgeons or whether non complex cases could be dealt with locally, possibly by vascular surgeons. Four options were put forward but the present set up of the Renal surgeons travelling to the Inpatient centres was recommended.

Dr. Nelson introduced the paper on Outpatient and Dialysis. Its theme is that these services should be offered as local to the patient as possible - that HD patients should not have to travel for more than 1/2 hour.

SHAK welcomes the Outpatient and Dialysis proposals and has sought to argue that this principle should apply as far as possible across the three models of care. Due to the format of the meeting it was not possible to make all our points there but our suggested amendments and comments have been sent to the Chairs of the Working Parties that produced the papers. The revised final editions of the papers will be considered and drawn together by the Renal Steering Committee at its meeting on 13 April.

FOR S.H.A.K. MEMBERS

Would you like a holiday for yourself and family?

Some vacancies in September/ October

Our "HOLIDAY HOME " is based at
THE RIVERSIDE CARAVAN CENTRE, BOGNOR REGIS.

Five minutes away from Bognor Regis Hospital

ONLY £100 Per Week ,Sunday to Sunday (7 Nights),

Facilities Include:

- ***Accommodation for up to six people***
- *The Riverside Club* includes free membership for 6 people - disco, karaoke, live acts.
- ***Fully Licensed Bar***
- ***The Amusement Arcade*** - video games, pool tables, bowling alley, etc.....
- ***For the Young*** - heated fun pool, heated outdoor swimming pool, indoor swimming pool, children entertainers, The Adventure Play Area, etc.....
- ***Family Room*** - to socialise and have fun
- ***Restaurant and Snack Bar***

The Riverside includes Laundrette, Internet cafe and is within walking distance of Tesco Supermarket.

BOOK EARLY FOR YOUR HOLIDAY TO AVOID DISAPPOINTMENT.

Contact: Nita or Ravi on TEL: 0208 407 2525

Email: shak@nitapatel.com

TOWARDS SELF DIALYSIS

At the start of the Renal Network Seminar, a team of 4 from Guys Hospital comprising Dr. Cormac Breen, Nephrologist, Nick Gitsham, Service Improvement, Davinia Springer, Raising Awareness and Ros Tibbles, Senior Nurse, briefed the meeting on their project to encourage HD patients to be responsible for as much as possible of their dialysis.

They have divided the lead up to the treatment into 14 actions and any patient willing is taken through the procedures on a step by step basis. The first step is taking your own weight and then patients progress through the other personal procedures to preparing the machine with the final step being inserting the needles.

Guys have chosen one of their satellite units as the site for the trial and all the patients there have volunteered. They are at different stages of self dialysis with two having reached the final stage and all others progressing as far as they wish.

British Transplant Games University of Bath, Thursday 17th August – Sunday 20th August 2006

Registration Packs are now available and must be submitted by 16th June (Medical Forms 31st July). To conserve funds, if you competed at the 2005 Games, you will receive your pack by Friday 21st April otherwise, if you wish to join us at the Games – as a competitor or supporter - and have not received a pack by 23 April, contact me on 01252 325230 and I will send a pack to you.
To compete, you must have a well functioning and stable graft that was transplanted prior to 16th February 2006.

Graham Morrow
Transplant Team Manager

Wilkinson
low, low prices on brands you can trust Everytime!

Thank you very much to
James Bevan, Manager,
Laura Sheridan and the staff of Wilkinson, (Sutton branch)
for their continued support for
S W Thames Kidney Fund
and
St Helier Association for Kidney Patients

Donation to SHAK
We were delighted to hear that members of staff at Unum Provident nominated SHAK to receive a donation of £500 from their Company. Thank you very much to Unum Provident for their generosity.

OUR TWO CHARITIES - SHAK AND The South West Thames Kidney Fund (SWTKF)

We have had suggestions we should provide more information about our two charities. To put it succinctly SHAK provides the present day benefits, SWTKF provides for the future by funding research to find alleviation and cures for renal failure. Both are run by patients and carers for the benefit of the patients of the Renal Unit.

MEMBERSHIP OF SHAK IS FREE BUT PATIENTS ARE NOT AUTOMATICALLY MEMBERS. PLEASE REGISTER WITH US.

SHAK's benefits include:

Dialysis Away from Home Allowance - from 1st November 2005, SHAK will pay up to £200 per week for 2 weeks a year towards the cost to the patient on haemodialysis when away from the Renal Unit. Payment will not be made to patients using the SHAK Holiday Home.
Petrol Allowance - £25 per month will be paid to patients using their own vehicle to travel to the Unit who make at least 8 journeys a month of more than 15 miles each round trip.
Patient Line Cards - long stay in-patients will be provided with a £5 Patient Line card per week **after** their first week in the Unit's wards.
Holiday Home - For 2006, the rent for the Holiday Home will be £100 for the week, Sunday to Sunday (7 nights)
An Amenity Fund - to help those in genuine need.
Membership of the N.K.F.

SHAK's income comes mainly from spontaneous donations: in memory of deceased relatives and friends; as thanks for the care received at the Unit and as thanks for use of the Jubilee Room. SHAK fundraises through its annual Grand Draw, stalls at fairs and fetes and can rattling collections.

THE MAIN AIM OF SWTKF IS TO FINANCE RESEARCH INTO ALL ASPECTS OF KIDNEY DISEASE AND ALLIED COMPLAINTS SUCH AS DIABETES.
It built the S W Thames Institute for Renal Research and continues to support it. Since its inception, the Institute has grown in reputation and now has international standing.

SWTKF's income comes from fundraising. appeals, donations and legacies. It is organised in 4 branches which brings people together for local fundraising.

Remember

"No Funding = No Research; No Research = No Cure!"

Patient Telephone Support Group

Have you ever wished there was someone you could talk to who had personal knowledge of how it feels to be a renal patient - or what it's like to be caring for someone who has renal failure?

Well you are not alone and in an endeavour to meet patient-need, a Patient Telephone Support Group has been set up.

This service was started nearly three years ago and a number of patients and carers have made calls.

This service , which is run by patients for patients and their carers, consists of volunteers whose experiences will have been similar to yours. Between them they have a wealth of pre-dialysis, dialysis and transplantation experience and are there to offer encouragement and support.

So why not give them a ring.
Enclosed with this edition of Renality is a list of volunteers who are available to take calls.

'Living with Transplantation and Dialysis Through Transition to Adulthood, 16 - 30 years', a research study of eligible patients, carers and staff to be carried out in 15 English teaching hospitals. It will be carried out by Helen Lewis, Department of Sociology, University of Surrey, Guildford. (The Renal Unit at St Helier Hospital is included in this study and Helen will be working with Nicki Thomas.)

One of the main objectives of the study is to gain a deeper understanding of the challenges facing young adults, from their own perspective, as they enter and establish themselves in independent adult life with long standing end stage renal failure. Another is to inform the development of health service design and delivery for this group of patients so that service provision can better meet their needs and in doing so, encourage and support adherence to difficult treatment regimes.

Research methods will include patients. self-completion questionnaires, patient face-to-face in depth interviews, semi-structured interviews with carers and semi-structured interviews with staff. Some of these will take place in units where transition units have been set up.

More Choice for HD Patients …. an increase in the number of dialysis shifts at the Satellites

The Renal Unit staff have been able to increase the number of shifts for dialysis as well as rearranging some of the times patients can use the machines. The staff are trying to provide more flexibility and therefore, give more choice to patients. The following list indicates times operating at the various units at present.

St Helier Renal Unit:
4 shifts (approximate times):

Morning	7.30 am - 11.30 am/12.30pm
Afternoon	1.00 pm - 5.00 pm/5.30pm
Evening	6.00 pm - 11.00 pm
Twilight	11.00 pm - 2.00 am

Mayday Satellite Unit:

Morning	7.30 am - 11.30 am/12.30 pm
Afternoon	1.00 pm - 5.00 pm/5.30pm
Evening	6.00 pm - 11.00 pm

It is possible there will be a twilight shift if there is a sufficient number of patients who wish to use it.

Crawley Satellite Unit:

Morning	8.00 am - 1.00 pm
Afternoon	2.00 pm - 7.00 pm

It is possible there will be a twilight shift if there is a sufficient number of patients who wish to use it.

Farnham Satellite Unit:

Morning	8.00 am - 1.00 pm
Afternoon	1.00 pm - 6.00 pm
Evening	6.00 pm - 11.00 pm

Woking Satellite Unit:

Morning	7.30 am - 1.00 pm
Afternoon	1.00 pm - 6.00 pm
Evening	6.00 pm - 11.00 pm

Kingston Satellite Unit:

Morning	7.30 am - 1.00 pm
Afternoon	1.00 pm - 6.00 pm

It is possible there will be a twilight shift if there is a sufficient number of patients who wish to use it.

Renality in COLOUR!

What do YOU think of it?

Renality is produced and paid for by the Renal Unit, South West Thames Kidney Fund and SHAK. Its main purpose is to keep patients of the Renal Unit (including patients attending outreach clinics and satellite units) informed about what is happening locally in the renal world.
The three organisations agreed to trial a coloured edition and see what patients thought of it.
The difference in cost amounts to 25p per copy. We send out approximately 4,000 copies to patients and friends. The additional cost of £1,000 will be shared by the Renal Unit, SWTKF and SHAK.

DO YOU LIKE IT?

SHOULD WE CONTINUE TO PRODUCE THE NEWSLETTER IN COLOUR OR REMAIN WITH BLACK AND WHITE EDITIONS?

WHAT ELSE WOULD YOU LIKE TO SEE IN RENALITY?

Please let us know.
A response slip is included with this edition. Please post it to:

Peter & Margaret Simpson, Ceilidh, Wellesley Road, Rushmoor, Farnham, Surrey GU10 2EH
OR Tel: 01252 792196
OR email: peter@shak-online.org or
margaret@shak-online.org

Renality ***is available on Audio Tape***

Our grateful thanks to our sponsors:

Audio Book Choice Ltd, of Crawley

Basepoint Innovation & Business Centre, Crawley and

Bayfield Media, Tonbridge Wells

For information contact:
Margaret Simpson, 01252 792196

Would you prefer Renality on CD?

A number of patients receive Renality on audio tape and have enjoyed this facility.
Now, Alex Bayfield of Bayfield Media has offered to produce Renality for us on CD. One or two patients who receive the audio tape say they have players for both tapes or CDs.
If you wish to have Renality on CD in future, please contact Margaret Simpson on 01252 792196 or email: margaret@shak-online.org
Tapes are already supplied to patients who need them. In addition, they will be on sale at the SHAK Trolley at £1.00 each.

Contacts:
Renal Unit reception: 020 8296 2283, 020 8296 3100

SWTIRR, Anne Collard, Secretary: 020 8296 3698

SW Thames Kidney Fund,
Pat Godden, Secretary: 020 8777 7371

S.H.A.K., Margaret Simpson, Secretary: 01252 792196
Graham Morrow, Treasurer: 01252 325230

The opinions and views expressed in this Newsletter are those of the individual or organisation expressing them. There can be no assumption that such views and opinions are supported by any other subscribing organisation or individual.

Newsletter deadline:
We welcome letters, articles and opinions from our readers. If you wish to contribute, all items for inclusion in the next Newsletter must reach us by Friday 30 June 2006.

Newsletter editors: Peter & Margaret Simpson, Ceilidh, Wellesley Road, Rushmoor, Farnham, Surrey GU10 2EH
Tel: 01252 792196 email: peter@shak~online.org OR margaret@shak~online.org