

Renality

May 2004

The NEWSLETTER of

South West Thames Renal &

Trans-

*plantation Unit,
Epsom and St Helier
University Hospitals
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: 266891)



Kidney Research Investment NEEDS YOUR HELP!

WILL YOU HEED OUR CRY?

It really is very important that we, the patients and carers, get behind the Institute and push it to prominence. The Staff, the Scientists are working very hard researching to find better treatments for us. They have had a lot of success and there is much more around the corner. We have to work very hard to raise the funds or give the funds to give them the opportunities to help us. Every penny you give to the S W Thames Kidney Fund goes to help pay the costs of the Institute.

Please help in whatever way you can. To help with fundraising please ring Anne Collard on 020 8296 3798, Pat Godden on 020 8777 7371

To make a donation, please use the enclosed leaflet.

***“Fancy being overtaken by a WOMBLE
though I did beat the Telephone Box and Elvis”***

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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 16th July 2004.



Kidney Research Investment

1954 - 2004

This year sees the 50th anniversary of human kidney transplantation. We have come a long way from Boston in 1954. In the early days only one in four transplants was a success and the result of failure was normally loss of the patient's life. Now, in 2004, nineteen out of twenty kidney transplants should be successful ... and if not the patient survives to have a second or third attempt.

The Renal Unit at St Helier has striven over the years to keep pace with these developments. We were among the first to introduce renal transplants to district hospitals (where the patients live) and to introduce CAPD to the UK in the 1970s. In the 1980s we pioneered outreach clinics and renal computing. Outreach clinics take the doctor to the patient and application of computer networks means that the vital monitoring data is always available to ensure progress and safety.



In the 1990s, driven by patients and their relatives and friends, the S W Thames Kidney Fund eventually provided a renal research Institute to begin to make a contribution to the scientific understanding of the causes and progression of renal disease.

This venture has been successful beyond expectation and, driven by David Newman and Mark Dockrell, the Institute is now producing its first doctorates in 2004.

At the Renal Association annual meeting in Aberdeen in April, Dr Diwakar and Dr Phanish presented leading papers on the mechanisms of renal damage due to proteinuria.

We are evolving from a unit which has pioneered the unbelievable clinical achievements of the last 50 years into one that now has the potential to reduce the burden of renal disease and delay the rate of progression of renal disease in the future.

All of this endeavour demands increasing resources and investment and so the South West Thames Kidney Fund has resolved to increase our sphere of influence and to increase the level of fundraising to invest in the renal future.

A recent road show in Croydon was very successful in stimulating local support and a new Chairman, Mr Pynee Sanjivi, has rallied support and started to



plan many more fundraising activities. Pynee is an example to us all. A few hours of focussed work a week on behalf of the fund can make a major difference but it takes qualities of planning and leadership and focus. Have **you** got these hidden talents as well?



Our new drive for Kidney Research Investment is taking three directions:

1. Local fundraising initiatives

We must increase local groups of Fund supporters working at more and more ingenious ways to generate income from sponsorships and bring & buys and social events. These may vary from a local evening raising £100 or so to a major organisation of a sponsored swim raising £10,000. Just as much appreciated are the many individuals who make donations or raise small amount: £5 - £10 for the sale of surplus vegetables or the sale of cakes or knitwear.

2. National fund raising

We need to tap into the resources of large companies and industries and fund granting organisations. Have **you** ever worked for, or with, a large organisation which makes charitable grants? Your life story as a kidney patient might enthuse an ex boss or employer to make a significant contribution from company resources.

3. Grants

With increasing scientific profile, the South West Thames Institute for Renal Research is hoping that eventually most of our Research and Establishment will be funded by peer reviewed grants from Government, Purchasers, Research Councils and Medical and Pharmaceutical Industries. Only when we have achieved this will the future of research here be truly secure.

This KRI for Help must be the way forward for our renal community in the twenty first century. If we achieve a fraction of our aim we will make a significant difference to the lives of our children and our children's children.

Mike Bending, Chairman SWTKF

What do patients think?

Although I have lived with the knowledge for the past 14 years that I had something chronically wrong with my kidneys and was losing protein initially at over 40 times the average daily rate, it was only when I was asked to undergo a second biopsy at St. Helier that the truth was revealed in March 2003 and a name was pinned on my condition – FSGS (Focal Segmental Glomerulosclerosis) – a progressive disease for which there is no cure and on which steroids would in all probability have little or no effect.



I felt a mixture of relief and shock – relief that at last we knew what we were dealing with but shock that there was no known cure. I asked my consultant what I could do to help myself, hoping that I could at least slow the decline (I was losing kidney function at an average rate of 4% per annum) and delay the arrival of dialysis and / or a kidney transplant. Lowest blood pressure possible, removal of salt from the diet, regular exercise – these were a few of the suggestions I received and thanks to the medical profession, I was already being treated with all the correct blood pressure and cholesterol-lowering drugs.

Since joining the SW Thames Kidney Fund, my husband and I have attended lectures which have been fascinating – they have helped to explain kidney disease in greater detail and the reasons why some of the suggestions made by my consultant are so important in trying to delay this condition. I have an endless quest for knowledge and the Fund answers so many questions which I feel unable to pose during a consultant's very pressurised clinic time at the hospital. It is brilliant to have access to leading consultants and scientists who are more than happy to talk about various aspects of their work.

After attending a meeting of the Kidney Fund, I inevitably come away feeling very positive that so many good people are working to understand the causes of kidney disease, often under difficult political conditions, but with a focus and dedication which is to be envied. I feel that through joining this group, I am in the best possible place to learn about new developments which may help me in my fight against FSGS.

The SW Thames Kidney Fund supports an internationally-recognised Research Institute which is instrumental in pioneering new research into the causes of renal failure which is for the good of all – knowledge is power.

Joanne Booth-Mason



What are these boffins doing ? Is all this scientific research just something for 'Tefal Heads' to do to keep them out of the way of normal people ? What is the point of scientific research ?

Should I be a Plumber ?

I don't know how many of you remember but back in February there was a little spate of news items and headlines like "Boffin quits to be a plumber" in the Sun and "Biologist quits to earn more money fitting gas boilers" in the Telegraph. Well I'm not about to write a tirade about the poor wages and professional development of scientists. But something struck me

while I was watching one of these stories being covered on the BBC. The Beeb did a little "vox pop" where they asked members of the general public who should be paid more a plumber or scientist. A number of people gave a similar kind of answer, something to the effect of "well a plumber, because if you've got a leak you call a plumber but I don't know what these scientists are doing - they're not doing anything to help anyone are they?". Oh my

heart dropped right down my un-blocked sink. For me, as a scientific researcher, this is a slightly difficult question to answer because I have worked with an assumption of the value of research for over 15 years - probably even longer. So where to start ? I can start by telling you that to do research people usually start with questions, How ? or Why ? Why do some people go bald and not others ? or How do birds fly ? Some people tend to ask more questions than others. Why ? Well I don't know. We'd have to do some research.



Then the next step is how do you go about answering the questions. It used to be thought that the answers were all out there, we just had to look at the world with unbiased open eyes and the answers would come to us. But in modern science we tend to take a more structured view. If you have a specific question you develop a series of tests that will produce an answer that you can be pretty sure of and other people could copy and get the same answer. This is harder than it seems to develop the tests that directly address your question, and it takes some training and a little skill. For example if I noticed that a lot of people with lung cancer also were drinkers, so my question does drinking cause lung cancer ? I study a bunch of people who spend a lot of time in the pub drinking and I compare them with a lot of people who spend their time in church, say, not drinking. I might find that the people who spend most of the time in the pub are more likely to get lung cancer. But I would have failed to notice that pubs are very smokey places and generally churches aren't, and what about people who drink but also go to church and what about people who drink but don't get lung cancer and Here's an even better one, a real one. It was noticed a few years ago that girls who wear ankle bracelets are more likely to become pregnant as teenagers but unless I've missed something wearing ankle bracelets is not the usual way of

conceiving a child, so no, wearing ankle bracelets does not make teenagers pregnant.

Okay we do research because we want to ask questions, and we do scientific research because we want to get the most reliable answer we can. But is that any reason to pay scientific researchers more than plumbers ? It depends on the questions your asking.

If we have a problem that causes sickness or even death that's a pretty important question for the people who get sick, and they have a right to someone trying to find the answer, so do their friends and family who are affected by their illness. And they deserve to have the problem addressed by people who have spent some time learning about sickness, who are interested in solving the problem and who know how to ask the right questions. More than that, if the illness means that people need to spend a lot of time going to hospital, it costs money for them to be treated in hospital. And when they are in hospital they can't be at work which means they're not paying taxes and that costs the government money as well. I admit that people have been looking for cures for some diseases for a long time, but that's often because the diseases can be compared to very complicated jig-saw puzzles and it takes a long time to get all the pieces in the right place. But if you think about kidney disease, it costs about the same amount of money for someone to be on dialysis for a year as it does to pay an experienced scientist for a year. There are about 15 000 people in Britain on dialysis. If by asking the right questions it takes me 5 years to find a treatment that means people avoid going on to dialysis for 5 years, not only will it give the patients 5 more years without dialysis and therefore hopefully a better quality of life but it will save £2, 250.000.000,which is a lot of plumbing.



7th Annual Flora Light Challenge for Women



As Golden Bond Holders for the London Marathon, the SWTKF has been given 10 entry forms for the Annual Flora Light Challenge for Women (3 miles) to be run on Sunday 5 September 2004 in Hyde Park and also, in Birmingham City Centre.

Entry fee is £12 (paid by the runner) of which £5 goes to the charity of the runner's choice.

Each runner receives a Finishers Medal, a T-shirt and a Goody bag. The closing date for entries is 6 August (earlier if entry limits are reached).

For an entry form and further details, contact Anne Collard on 0208 296 3698.

SWTKF Branch News

Croydon Branch:

Following the recent Road Show at Shirley, Croydon, we welcomed Mr Pynee Sanjivi, who volunteered to become the new Chairman of the Branch. We are now certain the Croydon Branch will go from strength to strength under the expert leadership of Pynee.



The **first event** was to provide and serve soft drinks to the Mauriwood Cultural Youth Group who held a concert in The Archbishop Lanfranc School in Croydon on 14th April to celebrate the Tamil New Year. £100 was raised for the Kidney Fund who also had an Information Stand advising on the work of the Fund and also leaflets for patients



Pat Godden, Hon. Secretary, Egbert Peereboom, Hon. Treasurer and Pamela Grant, Committee member ready to serve drinks to the Mauriwood Cultural Youth Group.

The **second event** is a Special Thai Evening to be held in the Thai Elephant Restaurant (details opposite) on Monday 24th May to raise money and at the same time have a good meal and an enjoyable evening out. Just ring Pynee or Pamela to reserve a place. We need to know numbers for the restaurant.

For the **third event** we hope to have a stall at the Croydon Summer Festival to be held in Lloyds Park, Croydon on 17th, the World Party and on 18th July, the Croydon Mela. These events will run from 1 pm - 8 pm with lots of things to see and do. Please come and support us and make yourself known to us.

Pat Godden, Secretary

Sutton Branch:

The Branch held a Bangladeshi/Indian meal at the Akashi Restaurant, Wallington on 3rd February. The evening was a great success and a good time was had by all. The event raised £850 for the Kidney Fund.

The **next event** will be held at La Romantica on 11th May and this promise to be another excellent occasion. (See details opposite)

A Special Thai Evening

Not to be missed

In aid of

**SW Thames Kidney Fund
Monday 24th May 2004**

VENUE

***Thai Elephant Restaurant
466 London Road (near Mayday Road)
West Croydon***

**Many dishes to choose from
Dinner starts at 8 pm
£16 per person
(includes donation to SWTKF)
(excludes drinks)**

CHARITY RAFFLE

Support this worthy cause, please bring along an item (or promise) to be raffled on the night

BOOK NOW TO AVOID DISAPPOINTMENT

To reserve a place please telephone:

*Pynee Sanjivi 020 8665 8245 or
Pamela Grant 020 8776 0467*

SW THAMES KIDNEY FUND

Supporting Research at the Dialysis and Transplant Unit, St. Helier Hospital, Wrythe Lane, Carshalton, Surrey.

Sutton Branch Dinner Evening

May 11th 2004, 7:00 for 7:30 pm

At

“La Romantica”

8 Mulgrave Road, Sutton, Surrey.

A Varied Three Course Menu

This will be another excellent night, so why not make up a table of family, friends, customers or colleagues - or come by yourself and make new friends. It is hoped that the event will raise much-needed funds for the SWTKF. The cost per ticket is £16.50, Drinks may be purchased separately. For further information, contact any of the Committee members below.

Richard Sammons 020 8647 2882 -

Pat Harris 01737 352154 -

Richard and June Harvey 020 8643 5228 -

Judy Ashworth 020 8643 0160

Branch News cont.

The Sutton Branch has been given two good quality paintings which the group would like to offer for auction. The Branch members would like to meet someone who has expertise in this field as they feel the need of some advice. Do you know of anyone who could help them?

Additionally, they would be pleased to accept other offers of paintings of good quality in order to make an event of this kind worthwhile. Can you help? If you can, please contact Richard Sammons on 0208 647 2882.

Frimley Park & Guildford Branch:

A collection was held at Sainsbury's, Water Lane, Farnham in January. Despite the cold weather, collec-

tors turned out in force and the magnificent sum of £631 was raised. Thank you to all who collected.

Shirley and John Smith held a Coffee Morning at their home on 14th February. This was very well attended and John and Shirley together with their helpers were kept busy all morning. The event raised £400, a tremendous effort.

The Quiz Night held at the Shawfield Centre the following week was hugely successful. Graham Morrow set the questions which kept quite a few people guessing. Even so, people were asking when the next Quiz would be held. The proceeds for the Kidney Fund amounted to over £400. Thanks go to Graham and all those who helped.

“Fancy being overtaken by a WOMBLE!”

FLORA
LONDON
MARATHON
2004
Congratulations to
you all and
Thank You!



Laura Bending



Rachel Withers



Zafar Maan



Robert Adnitt



Dirk Froese



Nicki Hudson



Richard Pollitt

Gary Saunders, Christopher Hayton and Sascha Khan (no photographs) were included in our ten runners in the London Marathon on 18th April.

We were delighted so many runners could take part on our behalf. We do hope none of them have suffered any long term effects though they must have felt a few aches and pains the next day. Despite being overtaken by the Womble, Robert Adnitt managed to complete the course in 3 hrs. 42mins.—well inside his personal best of 4 hrs. Gary Saunders finished in about 4.5 hrs. He stepped on a discarded water bottle after the first 2 miles and needed massage but completed the course. Richard Pollitt completed in under 4 hrs. He said “It was a marvellous day with a wonderful atmosphere. The bands playing for the runners were absolutely incredible”.

Robert commented that the best bits were the support he received from his family at Bermondsey, Canary Wharf and The Mall (His wife, Sue Woodcock and others were zooming round on trains to see him), crossing Tower Bridge and beating the Telephone Box and Elvis. The worst bits were the abrasion scars on the legs from shorts and a nagging feeling that he might just do it again!

If you would like to contribute to the sponsorship of the Team, cheques can be made payable to SWTKF and sent to Anne Collard c/o SWTIRR, Renal Unit, St Helier Hospital, Wrythe Lane, Surrey SM5 1AA.

Message from Jonathan Kwan, Clinical Director



As you are reading this, we are enjoying the fruits of 12 months' hard work, by the Renal Management Team, in extending and revamping our Sir Harry Secombe Ward. This ward has now been expanded to a modern 18-bedded Unit with 2 isolation cubicles. Each bed is plumbed for dialysis treatment and equipped with modern conveniences including telephone, radio and television facilities. This much needed extension, increasing the total number of inpatient beds from 32 to 40 in the 2 wards - Richard Bright and Secombe, will allow us some flexibility in reconfiguring our inpatient service to meet the "single sex ward" ideal. The official opening for this extension is now scheduled for the lunchtime of Friday 21 May 2004. Mrs Lorraine Clifton, our new Chief Executive will formally open the extension.

The number of patients currently enjoying dialysis treatment closer to home in our newly commissioned Farnham Satellite Dialysis Unit is increasing, very soon it will be in the twenties. The Official Opening for the Unit, to be conducted by the local MP, Mrs Virginia Bottomley, is now scheduled for Friday 25th June. Please let us know if you would like to attend.

We continue to upgrade and expand our facilities to improve the patient care environment in our Unit. The next big internal project, utilising the £100,000 you raised for us in the "Buy a Brick" campaign during 2003, is an extension to our current Outpatient reception area and a waiting area for haemodialysis patients. This we hope will be delivered before the end of the year. The next big external project will be the setting up and commissioning of a Satellite Haemodialysis Unit in Kingston by this winter.

The Unit has a long history of investing in our staff in terms of improvement of their working life as well as providing continuous professional development. This may have a lot to do with our success in recruiting and retaining valuable skilled staff to look after our patients. Currently we have zero vacancy in all departments within the Unit! We have bravely invited "Investors in People" of the UK Learning and Skill Council to inspect our Renal Unit this month in the hope that we will reach many of the "Investors in People" standards. With a bit of luck we will be granted the coveted "Investors in People" award.

Now I am turning to the most important message of this Newsletter. Last year we had the "Buy a Brick" campaign. This year we have launched the KRI FOR HELP (Kidney Research Investment needs your help) campaign. We all know that without research, we would not have enjoyed the many medical advances which have resulted in the relief of suffering and new life saving treatment for our patients. The S W Thames Institute for Renal Research at St Helier is in the forefront of kidney research. We are particularly interested in slowing the progression of kidney diseases. **Without funding, this important line of research will not be able to continue.** We are very proud to have a team of dedicated and highly motivated research scientists doing very exciting work in the lab. I would like to urge you to come to visit the Institute to see the ground breaking research activities. I appeal to you to support our very noble aim in investing in your kidney health by making a donation to the "**South West Thames Kidney Fund**", the charity supporting our Research Institute. A leaflet with a tear-off slip is enclosed. Please contact Anne Collard, Institute Secretary, on 020 8296 3698 if you wish to visit the Institute.

New SWTIRR Director

We are delighted to learn that Dr Paul Colville-Nash is to start working at the Institute on 1st May. His start at the Institute has been delayed because of the sudden death of the Director of the William Harvey Institute (Paul was Deputy Director and Paul has been holding the reins there).

We welcome Paul. We know how much the staff have been looking forward to working with you.

Bungee Jumping



Richard Adams, son of a Renal patient, together with four or five friends are intending to do a sponsored bungee jump and proceeds will go to South West Thames Kidney Fund.

Should you wish to support the group, please contact Anne for details on 0208 296 3698.

We wish you all every success.



HSA CHARITABLE TRUST AWARD

Nicola Thomas, Research Lead Nurse, has won a **£5000** scholarship awarded by the HSA (Hospital Savings Association) Charitable Trust. The money will be used to fund her PhD at City University that she started in February 2004. She collected her award at a special event at the Dorchester Hotel on 7 April. Sara Youngman (nurse manager) accompanied Nicki on the day. The photograph shows (from left to right) Sara

Youngman, Surgeon Captain Rick Jolly, OBE (who presented the awards) and Nicki Thomas

Nursing RESEARCH News

The study into kidney disease caused by diabetes is progressing well. The aim of the research is to find out how kidney disease caused by diabetes can be best managed in GP surgeries. Nicola Thomas (Research Lead Nurse) has made links with six local surgeries, and is being assisted by one of the nurses from Richard Bright ward. During March and April 2004 they have been visiting these surgeries and observing diabetes care and management in diabetes clinics. They are now starting to identify the patients in these surgeries who have a small degree of renal failure and will start to monitor these patients over a four-year period. Patients at high risk of developing rapid deterioration of kidney disease will be interviewed and monitored at a later date.

Dr Velasco heads for the Highlands!!



The South West Thames Renal Unit wished Dr Velasco fond farewells as he set off to his new consultant post in Kilmarnock. Dr Velasco has worked in the South West Thames Renal sector for the last 12 years, predominately based at Mayday Hospital where he undertook o/p clinics and also supported the Haemodialysis Unit.

Dr Velasco said he was sad to leave the Unit and was proud to have been part of its' success over the last 12 years. He was looking forward to using the experience he gained to improve services in Kilmarnock.

He thanked the staff and patients for all their support and for making his time in the sector so rewarding.

Dr Velasco has an extensive family in Scotland.

Dr Velasco will be succeeded by Dr Muna Elimri. She has been appointed as for 6 months as the Mayday Nephrology Locum.

ABCD AWARDS



ABCD winner!

Joan Shonfield was shocked and surprised at being named the most recent ABCD winner. The ABOVE and BEYOND the CALL of DUTY (ABCD) award is a local renal unit 'reward and recognition' initiative for staff who are nominated and judged by their colleagues as 'going that extra mile'.

Congratulations Joan!

Kay Sandhu, Renal Unit General Manager, was interviewed together with Joanne Gilbert, Community Engagement Manager of Sutton & Merton Primary Care Trust at the Nelson Hospital, for an article on 'London Jobs' which appeared in the Supplement of the Evening Standard in January.

In the article, Kay explained that she runs a budget of £18 million and that she has to make sure it is spent wisely. £7 million goes to pay the salaries of nurses, doctors and clinicians, £6 million is spent on consumables like dialysis machines, drugs, solutions and dressings and the rest goes on tests and buying in services from other clinics and



hospitals. Kay talked of the way patients' groups had been set up in the Unit which assist in service planning and who meet every six weeks where they focus on key issues they feel unhappy about - such as waiting times. She also mentioned the survey run for haemodialysis patients to find out how best to fit dialysis in with a patient's working life.

Kay considered the Unit to be lucky to have an extremely active Kidney Patients Association who are active fundraisers and are very quick to say if the staff of the Unit gets it wrong.

There has been a huge rise in the level of accountability in recent years and Kay counts herself lucky to be able to work with a very dynamic clinical consultant and an enthusiastic nurse manager who share the same philosophy - to deliver the best service possible within a limited budget.

Outpatients' Forum

The Unit held an Outpatients Forum on 18 March "Listening to You" when they discussed with patients their concerns about outpatient clinics.

The general feeling was that the reception/waiting area was too small and that it needed better décor and to be more welcoming.

There were complaints about waiting times for appointments which could be long especially when there was only one doctor on duty and there were other calls on their time.

There was a strong feeling that there could be better communication about delays—possibly a display giving waiting times. The early morning clinic is popular and there were suggestions for evening and weekend clinics.

A nurse specialist in attendance might be used for routine follow-up clinics and such a nurse could be available to discuss questions with patients after they have seen a consultant.

Privacy and dignity for patients figured as important and a quiet room for talking to relatives if there is a bereavement or they are upset.

Discussion of the reasons for missed clinics (Did Not Attend) showed that patients found it onerous to attend both for HD and a clinic at separate times. Was co-ordination, possible.

The final area touched on was the information available on discharge after transplantation. At times it was found to be lacking.

The Management are actively looking to see what changes can be made.

Renal Patients' Symposium

The S W Thames Kidney Fund hosted a Renal Patients' Symposium on Sunday 22 February. About 50 patients and carers attended.

The first speaker was Dr. Raj Shah who spoke on "Heart problems and the Renal Patient". He gave a very clear picture of how the health of the organs affect each other and pathways being tried to improve health.

He was followed by Dr. David Mekanjuola who spoke of the developments in Haemodialysis. He started with the very earliest attempts to purify the blood and plotted the course of HD up to the present day with a look to the future.

After a buffet lunch, the A.G.M. of the Kidney Fund was held with a report on its activities over the previous year.

Dr. Ginny Quan then spoke about living donor transplants and the benefits of this altruism with very little chance of ill effects to the donor.

The day ended with Dr. Mark Dockrell's account of the success gained by the Research Institute at the American Society of Nephrologists annual meeting. This is the year's most prestigious meeting for Nephrologists and the Institute presented three poster papers which attracted great interest and much acclaim.

The very successful and very interesting day finished with tea at 4 pm and we all came away feeling overwhelmed with the new insights we had gained and the work being done on our behalf.

SHAK NEWS

The Chairman's Letter.

Paul Steele and I had a meeting last week with Eric Chemla, the Renal Surgeon and James Marsh, one of our Nephrologists. The meeting was to discuss the clinical aspects of the transfer of transplant operations to St. George's. We are opposing the transfer at present because of the promises given during the Public Consultation. Among other things we discussed the shortage of surgeons and the waiting times for access surgery. We now have 2 surgeons and a locum between the two Hospitals whereas before the Public Consultation we had three with a good prospect of 4. Mr. Chemla was particularly concerned about the waiting time for access surgery. At present St. George's patients wait 6 weeks for a fistula operation, St. Helier patients wait 6 months and Brighton patients wait 12 months. This is due to the number of surgery sessions at each hospital and the limited number of surgeons. Mr. Chemla suggested one waiting list for all access surgery. This would reduce the waiting time for St. H and Brighton patients but it would often mean going to St. George's for the surgery.

I would like to know what you think. Do you think we should go for one list to reduce the waiting time or stick to the present system and make a lot of noise to try and get more surgeons recruited? Mind you there is a national shortage of renal transplant surgeons. We have the written promise given at the Public Consultation that access surgery would remain at St. Helier but the promise may prove valueless if there are not sufficient surgeons to make it viable. Should we take the pragmatic approach and make the best of a bad job? Let me know your views. Please write, telephone or email.

The Interim accommodation is up to timetable and we are hoping to view it in mid May. The part for our transplant patients should be ready by the end of June. I have been writing to the Strategic Health Authority asking why they had broken their written promise not to move transplants until the accommodation was ready. It appears that written promises are broken as easily as the many broken verbal undertakings we were given.

The talks on the long-term Tertiary Centre are going well. The desired size of the building has been agreed and possible sites at St. George's identified. Some facts and figures are awaited and then the outline business case will be presented to the Department of Health. If this receives approval it will be full steam ahead to refine the requirements and draw up the full business case.

We are now pressing for progress on the Renal Network. We have asked for a Renal Unit (without in-patient facilities) at each District General Hospital. Over half of them have some facility now but we are arguing strongly for care as close as possible to the patient.

The NKF held its AGM at the end of March. There were several constitutional amendments designed to bring it in line with the Charity Commissioners' guidance. The main effect is that the Executive Committee is now the principal authority with the Council taking the role of advisor.

You will see an advert elsewhere that we are holding a lunch for all patients, carers and staff on 26 June. I do hope you will come. I look forward to seeing you there.

Peter Simpson

A spring clean for the Holiday Home - inside



.....and out!



SHAK

invites

All patients, carers and staff of the
Renal Unit

to an

Informal Buffet Lunch

on

Saturday 26th June

To be held in

The Blue Room

at

The Renal Unit

from 12 noon

until 2 pm



*We do hope you
will come!*

At the beginning of April, Committee members Graham Morrow, Ravi and Nita Patel and Peter and Margaret Simpson went to Bognor Regis to clean and open up the Holiday Home in readiness for holidaymakers intending to stay during the new season.

If you wish to book the Holiday Home Contact Ravi or Nita on 0208 407 2525 or email: shak@nitapatel.com

Transport

Provision of transport is an integral part of the Renal Service: it is a valuable resource which is given to patients who are too frail to drive or travel by public transport.

In many cases, hospital transport actually costs more than a patient's dialysis!

We request that patients and carers actively participate in the use of this valuable resource, for example:

- i) cancelling regularly booked transport when it is not required
- ii) if you are admitted to hospital, advising staff that transport is not required.

If you are able to travel independently, the Renal Unit is able to offer:

- 1 Free parking in the main car park (ask the sister in charge for a letter of exemption)
2. Car parking in the renal unit and consultant car park after 6 pm each evening
3. Assistance for those patients on income support
4. SHAK is willing to make a contribution to their members towards petrol for journeys in excess of 20 miles.

For further information please speak to:

HD sisters
Joan Shonfield
Celia Eggeling

Treasurer's Report

The SHAK financial year ended on 31 March and the highlights of the year follow below.

- General donations received were about 16% lower than the previous year at £19,384, mainly due to the magnificent response to the Renal Unit Extension Appeal which raised almost £59,000 in the financial year and now stands at almost £78,000.
- SHAK Christmas Cards made £555 profit and, thanks to Peter Limmer's creativity, sales on the tea trolley doubled this year to almost £1,000! – Keep supporting him.
- Thanks to Sister Maura Pinkney and her team of volunteers, the Tribute Concert raised over £4,000, £3,000 of which was donated to the Extension Fund on the night. The HD unit also received a new (£4,750) Datascope Passport 2 with recorder from funds that were raised from the Sutton "Bed Push".
- £5,550 support was given to members by way of Holiday and Petrol Allowances, Amenity payments and Patient Lunches (did you come to one?).
- The Committee spent £2,000 to provide new cubicle curtains for Secombe Ward, £650 for two medical record trolleys for your hard working receptionists and £1,750 sponsorship to the Transplant Games Team (who returned with 9 gold, 5 silver, 8 bronze medals and two trophies).
- Unlike most investments, SHAK's ended the year 2.25% higher than historical cost and provided a return of 6.27%. General funds on deposit generated £1,566 income.

To see the financial report in full and other things your Committee have been doing for you, the members and patients of the Renal Unit, look out for the date of the Annual General Meeting which will be announced in the Newsletter later this year, **and come along.** Without your support and input, we will only achieve **some** of that you wish for!

Graham Morrow, SHAK Treasurer.

British Transplant Games University of East Anglia, Norwich Thursday 29th July – Sunday 1st August 2004

Registration Packs are now available (15th April) and must be returned to the organisers by 18th May. If you have attended the Games before, you should receive your pack by Friday 23rd April. If you wish to join us at the Games and have not received a pack by 23rd April – contact me on 01252 325230 and I will get one to you. (To take part, you must have a well functioning and stable graft that was transplanted prior to 28th January 2004).

**Graham Morrow
Transplant Team Manager**

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

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