Official Opening of Kingston Satellite Unit ….

Art Malik, Hollywood actor and star of hospital drama Holby City, was guest of honour at the official opening of the new Kingston Dialysis Centre on 26th April 2006. This is our fifth local dialysis unit. It is equipped with 16 dialysis stations.

Art Malik gave a short speech to staff and patients before unveiling a plaque together with David Caminer, to commemorate the official opening. This was followed by a tour of the Centre given by Dr Kwan when he met many of the patients.

Following a buffet lunch, renal nephrologists held a seminar for local GPs and health service workers. David Caminer, aged 90 years, spoke to the audience. He had started dialysis treatment 7 years ago at St Helier Hospital. He said, “Dialysis is a remarkable treatment. It is a testimony to the human intellect that anyone was inventive enough to devise it: still more that anyone was brave enough to put it into practice. The only drawback to dialysis, apart from the high cost, is there is so much waiting around, particularly for transport …..now journeys will be shorter for those of us who live in the boroughs of Kingston and Richmond.”

He paid tribute to Dr Kwan and his management team for providing the equipment and a fine set of nurses and care assistants who create such a cheerful atmosphere it seems like coming home.

FLORA LONDON MARATHON 2006
Final total for our Team …. See page 2
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FLORA LONDON MARATHON ACHIEVEMENT -

Many congratulations!
Our grateful thanks to our Team and all of you who supported them.

From the outset, Jonathan and the Team intended to double their efforts, setting out to reduce their time for this year’s Flora London Marathon while substantially increasing the amount of funds they could raise - AND THEY DID IT! This is an incredible achievement and each one of them deserves our warmest congratulations. Our thanks go to them but a special ‘Thank you’ goes to everyone who supported them. Your contribution to renal research is invaluable.

Our runners’ finish times are given in the order they are pictured from left to right:

Adam Barratt - 4:46:03; Rob Adnitt - 3:29:03; Steve Marsh - 3:47:03; Mary-Kay Sheehy - 4:52:17; Carole Lambe - 5:08:31; Jonathan Kwan - 4:02; Thomas Rhind - 3:48:08; Ajay Bhalla - 4:01:54.

Memorial to Prof. Justus Akinsanya

On Saturday 17th June Margaret and I attended a Memorial Service for Justus Akinsanya at All Souls, Langham Place. We met Maura and Mary from HD.

Justus died last year. He had been a long time patient of the Unit and had been under the care of Christian Koo, our surgeon who died some years ago. It was in memory of Mr. Koo that Justus set up a book prize award which is given annually to a member of the Unit’s staff who has made an outstanding contribution to the treatment of patients under their care.

Justus was born in Lagos in 1936 and came to Britain in the late 1950s. He intended to study economics but instead took up nursing. He moved to teaching nursing and after gaining a BSc Honours he gained a post as Tutor at Kings College. He continued to study and research and in 1985 became one of the early professors of nursing. Justus brought a new concept to nursing - bio-nursing - reminding all that the biological sciences are an important component of nursing. In 1988 he was elected a Fellow of the Royal College of Nursing.

Besides his professional life Justus was much involved in voluntary work. He was a member of the SHAK Committee, Disability Croydon, the Nurses Fund for Nurses, the Nigerian Council of Elders and was a Governor to two schools in Croydon.

At the Reception after the service we were able to speak to Cynthia, Justus’ widow and to see his children, grandchildren and friends. It was a very nice occasion for a special person.
First of all I would like to offer my heartfelt gratitude to all of you who have sponsored my Marathon effort. The other person I would like to offer a special thank you to is Anne Collard, our Institute Secretary, who has been most amazing in co-ordinating all the appeal work for myself as well as the other members of the 2006 Marathon Team. Without Anne’s total dedication and commitment, I do not think I could ever have made the final tally of over £80,000. £52,000 came from individuals and another £28,000 came into the Institute, donated by the Tom and Shirley Springer Trust via my marathon appeal. Over 1000 individuals, 200 online and some 800 offline, have donated! A big thank you!

The next bit of exciting news is the opening of our newly up-graded Local Dialysis Unit, the Elizabeth Ward Dialysis Unit, in the Mayday Hospital, Croydon last month. This up-grade included a major expansion of the dialysis facility, from 11 stations previously to 23 stations, as well as a complete make-over internally. This much needed extension will undoubtedly benefit a large number of our patients who live in the Croydon area and beyond. We shall be planning an official opening in due course. We are currently looking for a local celebrity to conduct this (any suggestions are most welcome) and you will be invited along to celebrate the opening with us.

Our Local Dialysis Unit in Kingston has now been going for some four months and it is working exceedingly well for our Kingston patients! The Official Opening is reported on page 1. For our patients living in the Woking/Cobham/Chertsey area, I am pleased to inform you that we are in the final stages of concluding the paper work to site a brand new 24 station Local Dialysis Centre in the West Byfleet area, with a completion date scheduled for the end of 2006. Again once this centre is opened, the travelling time of many of our regular dialysis patients will be significantly reduced. We shall keep you posted on this in the future editions of Renality.

The expansion of these various local units and service provision over the last 5 years have been quite phenomenal and it is a testament to the dedication and sheer hard work on the part of a number of the senior management staff in the Unit, particularly, Kay Sandhu, our General Manager and Sara Youngman, our Clinical Nurse Manager. Other personnel who deserve some credits include Angela Bascombe, our Directorate Accountant, Alison Jones, the Unit Business Manager, Suzie Mallinder, the Unit Dialysis Manager, and a large number of other dedicated staff who have all contributed to its success.

As an advance warning, there will be some disruption of our Outpatient Clinic at St Helier, as building work will start in September this year, lasting for 3 months, to upgrade this area. We apologise for any inconvenience this may cause to those of you who attend your clinic appointment during this period.

Very soon we shall be conducting a “Patient Satisfaction Survey” using a remote control digital electronic pad. The Renal Unit will be one of the first departments in St Helier to try this out. We are eager to collect responses from you to inform the future improvement of our service. I hope most of you, when requested, will participate.

Three months on from my marathon run in April, my aches and pains have gone, my joints have stopped protesting, my lost toe-nails have re-grown, and I have regained more weight than I lost during my training, …I am not certain whether I want to do another one for punishment again……. Any advice will be gratefully received!

Jonathan Kwan
Proposed plans for the waiting area of the Renal Unit at St Helier Hospital
Proposed Refurbishment of Renal Reception and Waiting Areas

Together with your help (the proceeds of the ‘Buy-a-Brick’ Campaign, amounting to £100,000 raised two years ago), the Renal Unit Management Team and SHAK have worked together to fund the refurbishment of the reception and waiting areas for patients attending clinics. This is the second phase of the refurbishment; the first phase was carried out last year when the reception area was created for patients attending for dialysis.

The plans for the waiting area are shown on the opposite page (plans for the reception area were printed in the last edition of Renality). It is hoped the plans will have gone to tender by the time you read this and building work should start later this year.

Once the reception desk is moved to the area near the entrance to the Renal Unit, two new consulting rooms will be built on the patio area. The present consulting room will become a WC and access to the phlebotomist’s room will be from the waiting area. A nurse can be stationed at the upper level for weighing patients and taking blood pressure. On the lower level, we will have a small coffee bar.

Altogether, there will be another consulting room, an extra WC and a coffee bar. We hope these alterations and improvements will make waiting for appointments more efficient and pleasant for patients.

Going away for the holidays?

It’s trouble enough trying to make all the arrangements without the added factor of trying to arrange for haemodialysis while on holiday. We have taken quite a few steps to help things run as smoothly as possible. I would like to explain about some of the requirements for acceptance at the holiday dialysis centres and the procedure with regards to dialysing when you return from holiday.

Dialysis units must be vigilant about protecting patients from exposure to infections. The holiday dialysis units therefore require information on MRSA and infections such as Hepatitis B, Hepatitis C and HIV. On return from holiday, we need to check that you have not contracted any of these infections from the holiday dialysis centre. It can take any time from 4 weeks to 3 months for the blood tests to become positive, so it is important that you dialyse in a single room until the blood test results are available. Some satellite dialysis units do not have single rooms and as such, you might have to be transferred to either the main unit or a satellite unit that has single rooms, while we wait for the blood test results.

This is for the benefit of you and the other patients. Janet Dell, Dr Kwan’s secretary, is the holiday haemodialysis co-ordinator. She has produced a very helpful brochure and will help you locate reputable dialysis centres close to your holiday destination and arrange for all the necessary documents to be sent across. If you are in need of advice or information about planning the holiday, or want clarification on issues about what happens on your return, please contact Janet on 0208 296 2384. She’ll either have the answer, or know a man (or woman) who does.

Dr David Makanjuola
Dear Kidney Fund Supporters,

Once again we are so grateful to our supporters which allow renal research to continue to flourish in the Renal Institute on the renal unit at St Helier Hospital.

Over the years we have built up an annual marathon team. Sporting activity and its sponsorship has always been a major source of income for the Fund. This year the Clinical Director of the Renal Unit, Dr Jonathan Kwan, announced that he was going to halve the marathon run time record and double the record income. He just about achieved both objectives and Jonathan’s efforts this year, together with his team, have raised over £90,000. It is not too late to make further contributions and it’s just possible that with a real final push we might help Jonathan top the £100,000 mark – what an achievement?

Sporting activity has always been important to renal patients and anybody with a long standing physical illness must do everything possible to maintain a vigorous general good health. This is why it is so exciting to see some of our renal transplant patients competing in the UK Transplant Games which occurs every year and in the International Transplant Olympic Games which occurs at different venues over the world every 2 years. One middle-aged transplant patient has even taken up a new sport this year and he is being coached to perform the long jump for the first time.

So many of our supporters and well-wishers have taken up this sporting theme. Two young sisters, Sophie and Emily Tidman, recently raised £250 with a swimathon.

If you have any ideas for further fund raising events or would like to support the Kidney Fund in any conceivable way, do please phone Anne Collard on 020 8296 3698 or email Anne.Collard@epsom-sthelier.nhs.uk

Further information of our fund raising efforts can be found on the web at www.swtirr.org.uk

With very best wishes,

Michael Bending, Chairman

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**British Transplant Games 2006**

**Thursday 17th August – Sunday 20th August**

I am pleased to welcome this year a new member of the St Helier Team, Ran Pulik, and to welcome back to the Team Sholto Downs and Ewa Skonecka.

This year’s Team which comprises Sholto Downs, Helen Hayton, George Lebon, Nick Martin, Craig Morrow, Ran Pulik, Ewa Skonecka, David Slater and Peter Warren will compete in 43 events in a total of 23 different competitions over the four days of the Games and will be encouraged and supported by nine supporters.

Should you wish to enjoy a trip out and add your support, why not come along to the athletics day, Sunday 20th August at the University of Bath. There is no admission charge and we would be pleased to see you there.

Graham Morrow, Team Manager
London to Warwick Bike Challenge
On 20 June 2006, Richard Bowen (husband of Sarah Bowen who is a sister on Richard Bright ward) and Guy Biggin cycled from their office in St Bride’s House, London to Warwick University near Coventry for the Horwath Clark Whitehill annual charities group conference to raise funds for the Kidney Fund. The trip started by beating the deadline for getting to London with a bike and being ready for a planned start shortly after 8.00. They negotiated their way via Kings Cross to Barnet where they joined the first of many country lanes. The planned route then passed through St Albans and Leighton Buzzard (they got lost in both), but otherwise habitation was limited to delightful little villages (losing their way many times). Their target was to arrive in time for dinner and although hampered by quite strong winds and a persistent client on the ‘phone, they arrived at the University at 8.30pm, slightly sore but rewarded with an excellent meal. Their generous sponsors have contributed over £1,000 to the SWTKF. Congratulations and thank you.
Visit: http://www.justgiving.com/bigginbowenbikekidney

Cycling Back to their Roots …
On June 24, Katy and Ian Hall cycled for three days from their home in Barnstaple, in Devon to where they used to live in Ashstead, Surrey - a distance of 212.8 miles. The ride was done in memory of Katy’s father, Gerald Golding, a former patient of the Renal Unit for 10 years. As a result of their tremendous effort, the South West Thames Kidney Fund has benefited by £1,000.

They said “We did it! We’re not entirely sure how.” Ian and Katy cycled from home to Ilminster, 64 miles. On the second day they did the 76 miles to Stockbridge and on the third day they cycled the last 72 miles, arriving at Ashstead, their final destination.

Congratulations to you both and thank you.
Visit: http://www.justgiving.com/lankatyhall

Open Garden
Valerie and John Canning are keen supporters of the Kidney Fund and they opened their garden to the public again this year. They make it a family affair and enlist their help in making visitors feel welcome, selling plants and serving teas and cakes. These helped to boost profits and a total of £445 was raised for SWTKF. Thank you to you both and all your helpers.

Donations to South West Thames Kidney Fund
West Kent Masonic Lodge £400
Whitgift Foundation £100
Good Samaritan Lodge £210
Rivermead Lodge £720

Additionally, we have received many private donations in memory of former patients including £2,000 from Diane & Terry Pinchin in memory of Diane’s father. We thank all of you for your generosity.
Three Peaks Challenge for Renal Research

Kevin Connelly and the NatWest Team, Charing Cross decided to attempt the Three Peaks Challenge (climbing three of the UK’s highest mountains in 24 hours) and raise funds for renal research. Also, it was undertaken specifically for Kevin’s brother Paul who is a patient of the Renal Unit.

The Team completed the Challenge in 25.5 hours on 1 - 2 July 2006. They said they were a little disappointed they did not complete within the time but they were held up by heavy traffic. Kevin said “It was very tough”. They think that when all the sponsorship money has been collected, they will have raised more than £2,500 for South West Thames Kidney Fund. This is a remarkable achievement and we congratulate the Team on their success. Thank you very much.

Summer Charity Dance

Organised by the Transplant Team at the Renal Unit with live music, a raffle and food, the Dance took place on Saturday 24 June at St Gertrude’s Church Hall, in South Croydon. It proved to be a huge success with about 80 people attending.

Highlight of the evening was the Slave Auction which was a dinner at the winner’s house to be prepared and cooked by Christina Ho, Transplant Sister, assisted by James Marsh and Consultant Nephrologist in the role of Butler. Kirsty Archer and Sarah Milton would double as waitresses and scullery maids.

A grand total of £982.50 was raised from the event which was in aid of SWTKF. The Team must be congratulated and we thank you for the hard work you put in to make the event such a success. Not only that, you have committed yourselves to further work in preparing the meal. (It is unfortunate we do not have any photographs to show you.)

More Fundraising Events planned ….

50 or more girls and women are taking part in this year’s 5K Hydro Active Challenge on behalf of the Kidney Fund. Among them are Debbie Frewin and Michelle West, both of whom have had a kidney transplant and Anne Pearce who intends donating a kidney to a patient in July, this year. Other runners include women from various departments of the St Helier Hospital Trust, several women from the Renal Unit and the Institute (including Nicki Thomas and Anne Collard). Angie Morrow and her team are taking part again - and plan to WIN this year (with the help of a good tail wind)!

If you are in Hyde Park on the day, look out for the Kidney Bean Team (Debbie, Michelle and Anne, above) … Jerome K Jerome revisited - with Three Men in a Boat

Paul Mansell together with Jack Mayhew and Dan Batterton, teachers at Hinchley Wood School, want to raise money for SWTKF. They plan to row from Oxford to Kingston over 5 days, from 25 - 30 August. Paul is a close friend of Kevin Connelly and likewise, wants to raise funds specifically for renal research as well as doing the trip for Paul Connelly.
Summer is well and truly here it would seem, with a few weeks and weekends now of glorious weather; lets hope they continue. To all the readers of “Renality” and supporters of the South West Thames Institute for Renal Research through the South West Thames Kidney Fund, I thank you for your continued efforts and support as I write this summer edition of the Institute bulletin.

The Institute had a very successful meeting at the British Renal Association / British Renal Society meeting in Harrogate in May. 13 projects were presented to the meeting and generated much interest in the scientists and doctors attending. The Institute continues to hold a good position in our area of research - the ways in which cells in the kidney go wrong in renal disease; how to stop them from doing so and getting them back on track again.

We have also to say huge congratulations to Mr Alex Pearson - as was. In my last issue I mentioned he was getting ready for his PhD viva and I am really happy to be able to say…HE HAS PASSED! He is now Dr Pearson; he had a truly amazing few days about the time of his exam as he got married on the Saturday and “doctored” on the Monday!

We have recently purchased a new piece of equipment in the Institute as part of setting up a “bug room”. This was very kindly donated by Mr Dennis Amy in memory of his wife Mrs Helen Rosamunde Amy who sadly passed away a little while ago. In this room, we are going to use some special bacteria (so they can’t infect us) to make genetic tools for us to help in our work. In the next issue of Renality we will explain more about this and hopefully have some photos to commemorate Helen and Dennis’ family’s generosity.

We must also acknowledge the amazing achievement of Dr Jonathan Kwan’s London Marathon campaign which you can read about elsewhere in this issue. Congratulations on a fabulous time, thanks for all the money raised, and a particular thank you to all of Jonathan’s supporters for their sponsorship.

The Institute staff are continually grateful for all of your support. Please continue to help us 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!”

Paul Colville-Nash, Scientific Director

….. and another event being planned for SWTKF -

How do you fancy walking on FIRE ...or ICE?

The shortest sponsored walk in the world .... ARE YOU BRAVE ENOUGH TO TAKE UP THE CHALLENGE?

A Fire Walk was last held in November 2003. The event proved to be a huge success with many people taking part - some completing the walk TWICE! Many supporters turned up also and all said they had enjoyed themselves tremendously. The next event is being planned for the Autumn and will include an ICE walk as well as the FIRE.

The next edition of this newsletter may not be ready in time to let you know the details but look out for advertisements around the Renal and satellite units,
Renal Researchers of the Future

Many of you are aware, I hope, of the high powered high tech research that we carry out in the Institute laboratories, which is directed to giving us a better understanding of kidney disease and help us identify potential therapies.

What you might not know is that we work with youngsters in their late teens just before they go to University. SWTIRR have been closely involved with the Nuffield Foundation for several years. What this means is each summer we host a 17 – 18 year old who is planning to go to University to study medicine or science. They come and work with us in the labs; learn about research science, learn a little about kidney disease and hopefully this increases their awareness. It may mean that in the future they will consider working either in renal care or renal research or it may just mean that they are a little more sympathetic to our cause. But we also get very useful work from them.

This year we are lucky, because of our reputation we have two people interested in coming to do some work with us, both of whom have been awarded Nuffield Foundation studentships. My plan is that the girls will work together, thereby getting more useful work done. And they will focus on an area very important to many of us: Diabetic Nephropathy. We hope these projects will help us get an insight into how high sugar levels affect the kidney cells and if the projects go well we will apply for more money from Kidney Research UK to delve deeper and learn more about how we might treat diabetic nephropathy.

You might think there is only one “I” in SWTIRR but you would be wrong. SWTIRR has two: one eye on the present and one eye on the future; looking to improve care today and develop better treatments for tomorrow.

Mark Dockrell

KNOW YOUR BLOOD RESULTS

Did you know that you could look at your blood test results on-line?

Renal PatientView is an exciting new system that allows you to log onto a special website from your own homes to check your blood test results (with explanations), and read information about your kidney problem and treatment. One of the benefits is that you can see your recent blood results before you come to clinic so you can be ready with questions for your doctor, nurse or dietitian. Your GP will also be able to access the same information about you if you wish.

This system has now been tested and it is up-and-running in the renal unit. If you’d like to sign up, then please contact Keith Romilly (Tel: 020 8296 2514 or email keith.romilly@epsom-sthelier.nhs.uk) to make an appointment. The appointment will be about 30 minutes long - you will be given a password and some training when you visit. See www.renalpatientview.org for more information and a demonstration.

Please do not hesitate to contact me if you have any questions or queries.

Nicki Thomas, Research Lead Nurse Tel: 020 8296 2641
Kidney patient volunteers needed

We would like some help in improving health services for people like you:

- Have you been on dialysis or had a transplant for more than 5 years?
- Are you over 16 and under 30 years?
- Would you be happy to talk to a researcher from Surrey University about what it's been like living with renal failure?

We would like to hear your views about living with kidney failure and about your NHS treatment to help improve health services for young adults with renal failure (on dialysis or with a transplant), especially at transfer from paediatric to adult care and afterwards in adult units.

If you are interested in participating or would like more information, please get in touch with:

Helen Lewis,
Department of Sociology,
University of Surrey
Guildford, Surrey, GU2 7XH
Tel: 01372 725716
email: h.lewis@surrey.ac.uk

We apologise ....

In our last issue of Renality, we gave the wrong dates for the World Party and Croydon Mela.

The correct dates for these events were Saturday 15th and Sunday 16th July (not June). We hope this error has not caused people too much inconvenience.

We will report on the events in the next issue of Renality.

Can I help with fundraising?

Book me for:
- ‘COFFEE & Cards’ anytime, anywhere,
- A stall at an event, or simply place orders with me for:
  - Pheonix Greetings Cards, gift wrap and tags
  - A delightful range with something to suit all tastes and occasions

10% of all sales for renal research

Catalogue available
Contact: Jessica Gollop
13 Providence Place
Epsom KT17 4BB
Tel: 01372 726049
Chairman’s letter

On page 14 you will see a report on the present stage of the Renal Network talks and realise that we have reached a critical stage. We will keep you fully informed of all developments.

The new postal charges that come into force in mid August will mean that unless we reduce the size of Renality to three or 4 pages, regardless of colour, we are going to have to pay postage of 35p per copy to send it to you. As we send out 4400 copies this means a total postage bill of £15k. This is more than SHAK, SWTKF and the Unit can afford to pay four times a year. We have done it twice with the coloured edition but unless we can persuade some firms to sponsor Renality or place advertisements we are going to have to have a big rethink about the size, colour and distribution.

You will have seen the plans on Page 4 and the article about moving Reception and refurbishing the waiting area. SHAK will have a purpose built coffee/tea bar in the new area. To enable the full refurbishment to take place, SHAK is making a major contribution of £60,000. This is on top of the remaining Buy a Brick money you contributed directly. We are making the contribution because we feel the refurbishment will play a big part in making outpatients more comfortable and welcoming.

I am very proud to say that the Secombe garden is now complete and looks very good. Unfortunately, the newly laid turf is suffering with the heat and it is difficult to keep it fresh but I hope you are all praying for rain in any case. The Richard Bright garden looks equally good and SHAK is very grateful to Sharyn in Medical Records who has taken on the job of keeping the two gardens colourful and tidy. We now need someone to cut the grass in both gardens on a regular basis. SHAK will buy a Flymo and provide storage for it. So if you can spare an hour once a fortnight, please give me a ring.

Any day now 6 miniature TVs will be installed in the Link and if they are popular and work well we will move to installing TVs in all the HD wards.

Pynee Sanjivi has expressed an interest in seeing exactly what SHAK’s Chairman does and offering himself for election in November. It is a pleasure working with him and very helpful to me.

Peter Simpson.

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SOUTH WEST THAMES KIDNEY FUND
Croydon Branch

Dinner Evening
July 27th 2006 at 7.00 for 7.30 pm start
at
Paradise Island Restaurant
67 South End, South Croydon CRO 1BS
A superb 3 Course meal plus 1 free glass of wine or soft drink.
This will be a very popular event and spaces are limited to 50 people maximum
PLEASE BOOK EARLY TO AVOID DISAPPOINTMENT

Please contact Pat Godden, Hon. Secretary of SWTKF,
Telephone 020 8777 7371 email: pjgodden@tiscali.co.uk for further details.
Cheque in advance please.
NOTICE TO ALL SHAK MEMBERS

The
Annual General Meeting
of the
St Helier Association for Kidney Patients
will be held on
Sunday 5 November 2006
at 3.00 pm
in the
Whitehall Theatre,
Post Graduate Medical Centre,
St Helier University Hospital

SPEAKERS:
Ms Lorraine Clifton, Chief Executive, Epsom &
St Helier University Hospitals NHS
Trust
Dr Jonathan Kwan, Clinical Director, S W Thames
Renal & Transplantation Unit

Refreshments
Christmas Cards will be on sale

If any member wishes to propose a member for any position on
the Committee, including officers, or wishes to make any
proposal, then please submit the name or proposal in writing to
the Secretary, Mrs Margaret Simpson, C/o The Renal Unit,
giving the name of the proposer and consent of the nominee as
soon as possible before the AGM.

A reminder …. Our website address is

www.shak-online.org

Shak Informal Buffet Lunch

Our lunches are becoming more and more popular.
On 10 June, more than 60 people turned up. It was
really good to see so many patients and staff, even
though it was a good summer’s day (and England
were playing in the afternoon).
The food, organised by Pat Harris, was excellent and
thanks go to her and Pynee Sanjivi who organised
the drinks as well as to all the other helpers.
Mrs Beatrice Howard won the prize of £25 in the
free raffle. She enjoyed the occasion so much she
sent a letter of thanks to SHAK together with a
donation of £50. Thank you Mrs Howard. We will
put the money to good use.

Holiday Insurance

We are frequently asked about
companies that are willing to
insure renal patients at a
reasonable rate when going on
holiday. We are pleased to hear
from patients about companies if
they have had satisfactory quotes.

The company below has been
found to be particularly helpful to
one of our patients. The patient
(with a straightforward
transplant) was quoted £17.90 for
8 days cover to Europe whereas
other companies had quoted over
£100.

However, we must stress that
all companies assess each case
individually.

Details:
Marrs Insurance Brokers Ltd
Refuge House
9 - 10 River Front
Enfield
Middlesex EN1 3SZ
Tel: 0870 920 2522
Fax: 0870 920 2211
Email: marrs@marrs.co.uk

Donation to SHAK

We were delighted to receive a
donation of £20, sent on behalf of
Mrs Maureen Mills whose
husband was a patient at the
Renal Unit. She gave the money
rather than receive birthday
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sent a letter of thanks to SHAK together with a
donation of £50. Thank you Mrs Howard. We will
put the money to good use.
The Renal Network

The Renal Network Board met on Thursday 29 June. Its business was mainly to hear presentations of the three proposed models of care: Access Surgery, Inpatient and Outpatient & Dialysis. The presentations went well and the questions and discussions showed there was still need for additional thought. One of the points under consideration was how many cases of access surgery could be performed locally to the patient by a Vascular Surgeon at their local District General Hospital and what percentage would need the special expertise of a Renal Surgeon which would only be available at the Transplant Centre (St. George’s) or at a Renal Inpatient Centre (like St. Helier). Further thought will be given to the problem before a decision is made. In any case, it will be the clinical judgement of the surgeon in each individual case which will decide the most appropriate care. A significant comparison, however, is Brighton Renal Unit where the great majority of the patients receive their access surgery from Vascular Surgeons locally.

Before the meeting, Pynee Sanjvi and I had met with Chris Eliot and Lawrence Spicer of St. George’s KPA to discuss progress. This round of talks began in 2004 but talk of a network and brave new buildings specially designed for Renal Patients has been going on since about 2000 when the talks on removing transplants started. The four of us agreed that progress was far too slow. St. George’s inpatients are housed in a building the life of which expired 20 years ago. Our Renal Unit is kept furbished and pleasant by the energy, thoughtfulness and financial wizardry of the staff. The trouble is that new buildings take many years to gestate in the NHS. Even if The Trust obtains reasonable planning permission for whichever site the Secretary of State decides on, it could take up to 10 years to build a new Critical Care Hospital.

With this in mind, the four reps. decided we must press for the implantation of the agreed policy of appointing a Network Director and Network Manager because we felt that once these people were in post they would be a driving force to implement the Network and the necessary improvements for patients. Imagine our amazement when the response to our request at the meeting was to be told that there were alternative ways of running/coordinating the Network. I am going to meet Lorraine Clifton, Epsom & St. Helier Chief Executive in the near future in the hope that we can make sense of the situation and return to an agreed way forward.

Peter Simpson

Her second tandem dive …. but this time, she did it for SHAK

Sue Grayer, an office manager for a Health & Safety Recruitment agency is a 42 year old patient who did her second tandem sky dive at the beginning of June. Her first one was done at Christmas in Gran Canaria and she enjoyed it so much she decided to do another one for charity. She chose SHAK because she has become a patient of the Renal Unit in recent years, although she first developed kidney problems when she was eight years old. She said she wanted to “put something back into the Renal Department to show my thanks and appreciation for all the care that has been given to me”. Sue has raised £245 in sponsorship for her dive so far. Thank you Sue for your courageous effort. It is very much appreciated.
Annual Patient's Conference 2006 -

Chesford Grange Hotel, Kenilworth, Warwickshire.
13 - 15 October 2006

The Programme includes:
• Conference to be opened by DR EVAN HARRIS MP, Chairman of the All Party Parliamentary Kidney Group
• Update on Polycystic Kidney Disease (PKD) Research & Development
• PKD from the patient perspective
• Positive Phosphate Control - why you should sign up for it
• Chronic Kidney Disease
• Pain Control
• Life on dialysis and on the transplant waiting list
• Patient Views
• Question Time

Friday: KPA Chairmen’s Workshop
• Is the money following you? (Specialist Healthcare Commissioning)

Sunday:
• Council meeting
• Workshops (1. The renal diet; 2. tbc)

Special Package - Sat/Sun 14/15 October
Includes: Saturday Conference fee, morning coffee, lunch, afternoon tea, evening dinner, B&B, Sunday Council Meeting

Saturday only -
Includes: Saturday Conference fee, morning coffee, lunch, afternoon tea.

Options | Subsidised Rate per Person
--- | ---
Special Package (double/twin) | £70
Special Package (single) | £90
Saturday only | £45
Friday 13th October B&B (double/twin) | £60
Friday 13th October B&B (single) | £80

For further details contact: National Kidney Federation
Tel: 01909 487795 email: http://www.kidney.org.uk/conf06/conf06-details.html

NB. As usual, SHAK is willing to pay for the Special Package for any PATIENT member who wishes to attend the Conference.

Do you have email? Would you like to have an electronic version of Renality sent direct to your inbox? It is published quarterly and this might be one of the ways we could reduce the costs of printing and postage (mentioned on the next page). If you would prefer to receive the newsletter in this way please let us know. Contact: Peter or Margaret Simpson on 01252 792196 OR email: peter@shak-online.org OR margaret@shak-online.org
Thank you to all of you who returned the survey forms with your views on Renality in Colour. Many of you were encouraging and made a number of useful suggestions for future editions. 44 people commented on the colour. Of those, 75% preferred colour. 50% thought it too expensive.

It has been agreed that this edition will be produced in colour and used as an example in trying to persuade advertisers to use the newsletter. If a large part of the cost cannot be recovered through advertising, we will revert to black and white editions.

We have an additional cost - by the time the next edition is sent out, postage rates will have gone up, even for the black and white version.

Some of the suggestions for articles in future editions include: information on how the kidneys work and why they fail, more information on transplants, advice to transplant patients on diet and drugs, articles from dieticians and possibly recipes for low potassium/low phosphate diet. We have been asked for information on infection control for haemodialysis patients following holidays abroad (we have included an item on this from Dr Makanjuola). Also, we have been asked for information on changes in the Renal Unit e.g. changes of registrars and HSOs.

Many would like to read of patients’ stories and have a letter section. We would like to include one, so who will start the ball rolling? Is there something particular you would really like to say about the Unit, your treatment etc.? Perhaps you have an interesting story to tell. Please let us know!