

**South West Thames Renal & Transplantation 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: 266391)

They did it! Many Congratulations to our Team

Mike Bending was back at work at 7.30 am on the Monday. He commented “I am the 33,230th fastest marathon runner in the country. But I was beaten by 9,825 ladies, 3 rhinoceri, 2 loud speakers, a dragon and a banana. They gave me a bronze medal. Does this mean I was third?”

Andy Harris said “I got round eventually and now, the morning after, the pain is really setting in. I did not aim for a specific time, just to complete the course, take in the atmosphere and enjoy the day. I was spurred on by the help and encouragement of the other runners and the crowd. I felt I was really achieving something. Maybe, next year I will dress up and totally enjoy it.

Sarah Weymiss, a nurse at St Helier said “It’s always depressing to be passed by people in costume. It was too hot. Never again!” As this was Sarah’s fifth marathon, will she be running her sixth next year?

Mark Sandicott, a friend of Barry Kerr who is a patient, also ran for the Fund. We have no information on him.



Mike Bending, 6hrs.40 mins



Andy Harris, 5hrs. 16 mins.



Chris Waterman, 6hrs.12mins



Matt Spencer, 4hrs. 29 mins



Tasha Price, 4hrs. 35 mins



Sarah Wemyss, 4hrs.39 mins

**FLORA
LONDON
MARATHON
2005**

STOP PRESS!
**Funds raised from the
Marathon could
exceed £25,000. Final
figure in next issue.**

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 8th July 2005.



South West Thames Kidney Fund



By the time this edition of *Renality* is published, the South West Thames Kidney team will have done their darndest in terms of the marathon effort and, hopefully, we will have been able to achieve the goal of somehow completing the 26.2 miles by running, jogging, swaggering, walking, strolling, ambling, struggling, staggering, crawling and slithering. If any of us failed in the attempt, it will not

have been for want of trying.

The most exciting aspect of preparation for the marathon has been the hours and hours of effort put into fundraising and seeking sponsorship. My family, particularly Carol and daughters Joanna and Laura, have spent hours and hours and hours filling in letters and ordering more and more stationery. Anne Collard, our Administrator in the Institute, has been unbelievably hardworking in doing everything possible to maximise our efforts.

The response from so many well wishers of the Kidney Unit has been quite outstanding and I think that the sponsorship so generously given will go some way to helping us continue our work in the coming months.

The fundraising effort has made me realise more and more how important an organised office is in supporting an Institute like the South West Thames Institute for Renal Research and I think it has really brought home the message that it is vital for us to set up a supporting secretariat to work on the constant need to find new ways of fundraising. I am hoping that we will be able to set up an office for perhaps one afternoon a month in the first instance to keep up the momentum of publicity. I am calling for volunteers who will be prepared to give up half a day a month to work in such a secretariat. The type of work involved might vary between quite high powered negotiations with Members of Parliament but we also need willing helpers to do the photocopying, stuff the envelopes and make the tea.

This sort of activity can turn into a most enjoyable hobby and anybody who comes anywhere near the Renal Unit in a helping capacity can be guaranteed a happy afternoon with plenty of hard work, plenty of humour and plenty of opportunity for new personal achievement.

Mike Bending, Chairman

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ODE TO MIKE B

He jogs the streets both night and day, preparing for that awesome race.
The starters gun cracks – no delay, start to run – maintain the pace.
Bending elbow, bending knee, flexing joints and muscles free.



Keep on jogging, breathe, relax.
Cardiac output VO₂ Max
All steady, sound and constant too.
Fluid balance – ISQ
Maintain the pace
Enjoy the race
Ignore the pain
Reflect the gain

The research target is in view. Thank you for the work you do for us, of faulty filters cast - your effort will not be surpassed.
Our tribute then to Michael B, whose marathons complete,
St Helier's own nephrologist and renal runner athlete!

Anon

GO FOR IT!

Branch News:

Sutton Branch:

The Branch is planning a garden party in June /July. For details contact Richard Sammons on 020 8647 2882.

Frimley Park & Guildford Branch:

A successful Quiz Night was held on 4th March. £390 was raised for the Fund. A can rattle at Sainsbury's, Farnham raised over £500. A sale of goods at a Car Boot sale is planned for 1st May at Old Kiln Museum, Tilford, Farnham.



Giving through your Tax Return.

Tax payers who complete self-assessment returns can nominate a charity to receive their tax repayments as a donation. The S W Thames Kidney Fund would greatly appreciate such donations. If you would like to give in this way, our Charity unique code is **RAH51FG** and this needs to be entered on your return.

Transplant Guidance.

UK Transplant is the NHS organisation responsible for matching and allocating donated organs for transplantation. It has been consulting on the conditions which should apply before a patient becomes eligible for a transplant. The guidance is expected in the near future.

A sale of goods will be held in
The Foyer
Farnham Hospital
Manor Road (Off Hale Road)
Farnham
on
Wednesday 11th May
from 9am
Proceeds in aid of SWTKF
DO COME & SEE US THERE!



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

Helping the Fund thank you to all who have thought of so many ingenious ways to raise money



Open Gardens - Valerie Canning, a patient of the Unit, and her husband John have decided to open their garden to raise money for the Kidney Fund and have persuaded friends to do the same. (See details of all three gardens opposite.)

This will be a very enjoyable afternoon out for those of you interested in gardens.

Thank you to Valerie, John and their friends.

DISCO and Live Band

Compere:

**DJ Neil Long of
Radio Jackie**

Saturday 11th June 2005

8.00 pm - midnight

**Working Men's Club,
London Road, Kingston**

Proceeds in aid of SW Thames Kidney Fund

For tickets and details, contact:

Michelle Collins on 020 8336 2077

Fleet Half Marathon

Paul Marsh ran in the Fleet Half Marathon on Sunday 20th March and raised £121.50 for the Fund.

He says he finished in 2 hours 48 minutes, slower than he expected—but then, it was his first half marathon. Congratulations Paul and thank you.

Paul is pictured (left) with his parents, Geoffrey and Lis. Geoffrey is a patient of the Renal Unit.

Open Gardens

Sunday 8th May 2005

12 - 4pm

at

14 West Hill, Sanderstead

18 West Hill, Sanderstead and

2 Sundown Avenue, Sanderstead

***Teas, homemade cakes and
plants for sale***

**Donations of £1 per garden will be
encouraged**

All proceeds to S W Thames Kidney Fund

Disco and Live Band - A patient of the Renal Unit, Michelle Collins, is organising a disco with a live band on Saturday 11th June. (Details opposite.)

We do hope as many of you as possible will be able to support her efforts.

Thank you Michelle for your support.

Thank youto Tony Vickery who has donated the tips he has been given during the last few weeks while working at his local Car Wash. Tony's father, Lionel was a patient of the Unit. His mother, Lee, is a keen supporter of the Frimley Park and Guildford Branch.

Thank you There have been many donations for Dr Bending's Marathon run and it has been impossible to trace all the donors to send 'thank you' letters.

We would like to thank those who have donated through this Newsletter.

A sponsored Walk by Paul Fischer, the proceeds of which will be shared equally by AFC Wimbledon Stadium and S W Thames Kidney Fund.

Paul is IT Manager at the Renal Unit and his story is below:

On the May 28th 2002, an FA Commission granted permission for a group of businessmen to relocate Wimbledon FC Ltd to Milton Keynes, 70 miles away from its history, home and community. Initially devastated at the loss of the club, within a matter of weeks the supporters, took a fresh approach by creating their own team. Backed by the Wimbledon Independent Supporters Association (WISA) and the Dons Trust, AFC Wimbledon was born. Just six weeks later, having obtained a ground share, senior status and many hundreds of season ticket applications, the Dons played their first friendly on Wednesday 10th July against Sutton United at Gander Green Lane, in front of a staggering crowd of over 4,500.



On the 25th June 2003, AFC Stadium Ltd purchased the Kingsmeadow Stadium for £2.5 million, from Mr Khosla. At the end of March 2005, the outstanding debt, to Mr Khosla, for the purchase of the ground stood at £675,000.

AFC Wimbledon, WISA and the Dons Trust, have a strong community involvement, from assisting in the annual Merton Cleanup weekend, helping to remove graffiti from around Merton; to providing Community Football Schemes; and playing host to Kingston's Family Funday, which this year will be held on Sunday 15th May.

On Saturday 9th April, there was a Walk for Wimbledon, from the former ground of Wimbledon FC, on Plough Lane, to our current stadium at Kingsmeadow, Kingston, a distance of 7 miles. Sponsorship for this event was shared between the AFC Wimbledon Stadium Fund and the Mayor of Merton's charity appeal.

However, a group of around 9 hardy or should that be foolhardy supporters of AFC Wimbledon, wish to go one better. We plan to walk from Kingsmeadow Stadium to the last match of the season, which will be played on the 30th April, at Burgess Hill Town Football Club, Leylands Park, Burgess Hill, West Sussex. A total distance of 45 miles, to be covered in one and a half days, with an overnight stay in Horsham.

Proceeds from sponsorship of this walk, will be split 50:50 between the AFC Wimbledon Stadium Fund and a local charity of the individual walkers choosing. As members of the SWTKF have been trying unsuccessfully to get me to run the marathon on their behalf for the last few years, I have decided to make the SWTKF my nominated charity.

There is a possibility of a few local radio stations, interviewing us along the route, which I think is more daunting than the walk itself!!

If anyone wishes to sponsor Paul and AFC Wimbledon Stadium, please contact him on 020 8296 2514 or email: Paul.Fischer@epsom-sthelier.nhs.uk

"This is a good luck message from Best Sellers to wish you all a very good and happy run. We wish you all the best in your fundraising and would like to take this opportunity in not invoicing you for your printing and please can you donate this to your cause"

Best Sellers Printing Service supplied and printed the tee-shirts worn by our Marathon runners. We have SWTKF tee-shirts for sale. Have you bought yours?.



S W 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.

We have just returned from the British Renal Association / British Transplant Society joint meeting in Belfast where the Institute was well represented with three posters by Doctor Ramaswamy Diwakar, Matt Hazell (presented by Dr Mark Dockrell), Miss Nicki Thomas and Mrs Ioanna Nicolescu-Duyaz.

Ioanna was also awarded a travel bursary by the Renal Association to help with the costs of her attending. Additionally Dr Phanish Mysore’s work was recognised by the opportunity to give one of the limited availability verbal presentations, for which he received a commemorative glass pyramid from the Meeting Secretariat. All of these presentations generated a lot of interest and questions and confirmed the Institute’s position as among the leaders in the field of our research into cell signalling related to renal disease.



As well as in the UK, Dr Mark Dockrell kept up our international presence and represented the Institute at the prestigious Keystone Symposium in examining how some of the signals we are interested in at the Institute can be used to develop new treatments for diseases such as



chronic kidney disease. We are all now working hard to get ready for the biggest meeting on the renal calendar which is the American Association of Nephrologists later on in the year. This is the biggest gathering of clinicians, scientists and companies involved in the fight against kidney disease in the world, and the Institute and the Renal Unit has always had high profile amongst those from the UK who attend, a tradition which we intend to maintain.



As I am sure you are all aware, the Institute and its work in trying to find new ways to combat kidney disease is a costly venture. However we believe, and I hope all of you agree, that we need to continue trying to find new ways to help alleviate the problems faced by kidney patients and discover new treatments which can slow the progression of these diseases or even provide a cure, which is the goal which all of us have. We are therefore profoundly grateful for the support given to the Institute by the South West Thames Kidney Fund. This year, the Fund is continuing the support of the Anthony Eisinger Lectureship which funds Dr Mark Dockrell as well as supporting a variety of other projects in the Institute.

Our contribution to the research effort of the NHS in the Trust has been 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. This includes the support for a new 3 year PhD studentship to be supervised by Dr Dockrell, a project grant to fund a new research fellow to help me with my research and a part time

laboratory scientist for two years to help with the LOLIPOP study (looking at renal function and measurement in the context of ethnicity to see whether our current models are good enough). The Trust is also continuing the support for the salaries for Mrs Ioanna Nicolescu-Duyaz, Mrs Lucia D'Mello and a replacement for Mr Matt Hazell, who has recently left us to be a little closer to his home area of Oxford. We thank him for his hard work over the last months and wish him all the best for the future, though I suspect we will meet again in the future! The National Kidney Research Fund and Department of Health is continuing the support for Miss Sarah Yates who is carrying out a lot of the analysis of samples from LOLIPOP, and Ms Nicki Thomas has also been awarded some extra money by the National Kidney Research Fund to provide her with some extra support for her work with helping educate patients so they can understand the disease process, treatment options, and thus take back some elements of control of their lives.



I hope that you can see from the above how vital the Institutes work is and the contribution it is making to research into the causes and in particular the treatment of kidney diseases. Please help us to continue our research into better prevention, more effective treatments, improving the quality of life for renal patients and their carers and hopefully finding a cure, and support the South West Thames Kidney Fund in any way you can. Remember, it's not too late to sponsor Dr Mike Bending's run in the Flora London Marathon (see this issue for further details)! We, and I hope some of you, will be there to cheer him on!!

Remember

“No Funding = No Research; No Research = No Cure!”



Anne Collard has received ten entry forms for the Hydro Active Women's Challenge, a 5K (3 miles) fun run to be held on Sunday 4th September 2005 in Hyde Park, London, Birmingham City Centre and Sefton Park, Liverpool. Deadline for entry is 4th August but last year the places were filled very quickly.

It costs £15 to register, but you get it back if you do not get a place. Each runner will get a Finisher's medal, tee shirt and goody bag. SWTKF receives £5 for each accepted entry.

S W Thames Kidney Fund Renal Symposium and A.G.M

The annual symposium for patients took place on Sunday February 13 in the Whitehall Theatre, St. Helier. It was a very interesting, entertaining and thought-provoking day.

There were three guest speakers. In the morning Dr. Donal O'Donoghue, Clinical Director of Renal Medicine, Hope Hospital, Salford, spoke about the prevention and management of early renal disease and how a patient centred service should enable the building of a better future for renal patients. He was followed by Dr. Michael Wilkes, Chairman of the BMA Medical Ethics Committee. He spoke about the need to reform the organ donation system and pointed to the UK's poor record on the number of transplants. After lunch, the AGM of the Kidney Fund took place and the proposed amendments to the Constitution were accepted without opposition. Mike Bending told of the possible financial difficulties and the need for more fundraising. Paul Colville-Nash explained the pivotal position of the Fund in the Institute's Finances. The final speaker was Mark Dockrell of the Institute who enthused the audience with his account of their present work and their goals.



Members of the audience

The Koo Memorial Book Prize.

Christian. Koo was the Unit's Surgeon from 1995 to 1998. He died of a heart attack at the very early age of 41, suddenly ending an outstanding career and depriving the Unit of a brilliant and caring surgeon. One of his patients was Justus Akinsanya, Emeritus Professor of Nursing, a strong supporter of the Unit and for many years a member of the SHAK Committee. Justus was very impressed not only by Mr. Koo's skill but also by his attitude to him as a patient.



The Prizewinning Team

Justus and his family decided they would like to honour the memory of Mr. Koo and after consulting Dr. Kwan, hit upon the idea of an annual memorial book prize. They have set up a Fund from which an annual prize will be awarded to a member of a health care team in the Unit who has made an outstanding contribution to the care of Renal patients.

On Friday 15 April the first awards were presented by Justus: Caroline Duncan, Ruple Patel, Mary Thomson, Diane Evanden, Dawn Finch and Sue Beharry won the prize with Gail Gibbs, who could not be present, for their joint work "Implementing the Protected Meals Initiative". The Judging Panel had a difficult task because there were a number of excellent submissions but had no hesitation in recommending their final choice.

Many congratulations to the winners and we look forward to future years awards.



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

Salman Sayyedali, a patient, asked SHAK if he could collect for us at his Mosque. He told the worshippers about SHAK and what it means to be a kidney patient and as a result he collected £755.

What a great effort. Thank you very much Salman and thank you too all your generous friends at the Mosque.

Pat Anderson, a patient using the satellite unit at Farnham Hospital, approached SHAK for help in providing a library for the patients there. We were happy to oblige and have provided funds to provide a bookcase, books, audio tapes and audio tape players. This working together by the patients is the best sign of a good unit. Thanks to Pat for approaching us.

SHAK is always keen to hear from satellite units if they need anything to improve the unit.



Message from Jonathan Kwan

Dear Friends

We are certainly moving progressively forward and definitely not backward!!!

I hope you are thinking what we are thinking – renally of course!!!

The Unit provides the only real alternative for patients with renal conditions living in our catchment area!!!

Please support us wholeheartedly, and we promise to deliver!!!

Dr Bending, despite his tender years, finished a gruelling 26 miles of the London Marathon on Sunday 18 April at just over 6 hours in the name of raising money for Renal Research. This act of total selflessness

exemplifies one of the most quintessential qualities of all the staff working

in our Renal Unit. A lot of us do go into extraordinary lengths in contributing toward the well-being of our patients and the excellent upkeep of the Unit: through working “above and below the call of duty” in providing clinical care; sacrificing own private time fighting for increased funding for renal provision; working for SHAK and South West Thames Kidney Fund, our 2 charities; funding raising for renal research, representing our Unit in Medical conferences, etc.....

After a prolonged period of gestation (I only wish we could move things faster in the NHS) we have finally got the contractor to move in on 21 April to start on the building work of the new waiting area for haemodialysis patients. This project is funded by the proceeds you all helped to raise – “Buy a Brick Campaign”. In all, you have raised just under £100,000! Our very very sincere gratitude to all of you! Not to be accused as the Scrooge, the Trust, through its own Charitable Fund, has also kindly agreed to top it with another £50,000 donation, giving us a total of £150,000 to spend on this project. This sum may seem large for such a small project; unfortunately, due to health and safety regulations, building costs in the hospital setting are generally 2 to 3 times the costs of domestic buildings. Nevertheless, within 3 months with good intentions and prevailing winds, we shall have a pleasant and comfortable waiting area for our haemodialysis patients who currently are made to wait, rather unsatisfactorily, in the corridors or in the outpatient waiting areas. Hopefully this rather sorry state of affair will soon change for good.

Since the last edition of Renality, the NHS, through a very detailed process of public consultation- the “Better Healthcare Closer to Home” proposal, has now made the decision in support of the amalgamation of both St Helier and Epsom Hospitals into a brand new State-of-the-Art Critical Care Hospital to be built on the site of the old Sutton Hospital linking onto the Sutton Branch of the Royal Marsden Hospital. This new Critical Care Hospital will also be supported by 10 additional local care hospitals, to be run by General Practitioners and their Primary Care Trusts, providing most of the non-emergency and outpatient care. At this moment in time, we are however unable to say how the Renal Unit will fit into this Epsom & St Helier scheme. Suffice to say that, there will be another public consultation in the very near future on the Provision of Renal Care to the residents of South West London and Surrey and their hinterlands. I hope to be able to keep you apprised with the latest development on this front in the future editions of Renality.

This last week also saw another milestone in the service development of the Unit, the arrival of our fourth Renal Network Transplant Surgeon. This complement of international (or intergalactic as some may like to believe) surgeons, sharing with the Renal Units in St George’s and Brighton, Messrs René Chang (originated from Malaysia), Eric Chemla (France), Jiri Fronek (Czech Republic) and Adil El-Tayar (Sudan), will I believe dramatically transform the renal surgical care to our patients. The achievement of full establishment of surgeons has been very long in coming! Long may it last!!!

For those of you who are interested in the progress of our Kingston Dialysis Unit, I can now confirm that all the preliminary work has been completed and building work should start very soon with scheduled opening in the autumn this year.

And finally, giving the right stimulation and encouragement (plenty of donations for Research in support of our Renal Research Institute), I may follow the foot-steps of Dr Bending, booking myself a place for the next year’s marathon!!!

Jonathon

Infection Control Champions Working Wonders in the Renal Unit

Recent national figures show that Epsom & St Helier University Hospitals NHS Trust has continued to see a reduction in MRSA infection rates in its hospitals.

Steve Lennox, Director of Nursing said that the Trust is working with staff and patients to improve how infection control is tackled throughout the Trust.

One of the Trust's latest initiatives has been to introduce 'Infection Control Champions' - three senior nurses in the Renal Unit who have received additional intensive training in infection control. They act as infection control role models and wear a unique uniform. They monitor clinical practice when on duty and at least one day of their working week is dedicated to training staff and patients in infection control, in order to maintain high standards of care.

(Story and picture by permission of 'Weekly News', Epsom & St Helier University Hospitals NHS Trust)



*Left to right:
Angela Wright, Anna Hurley Adelina Shanmuganantha*

EXPERT PATIENTS PROGRAMME (EPP) STARTING IN THE RENAL UNIT

We have now confirmed the details for our new self-management course starting in the Renal Unit on **28 April 2005**. The self-management course, sometimes called the Expert Patients Programme (EPP), is an NHS-based training programme that provides opportunities to people who live with long-term chronic conditions such as kidney disease. The course is different from the Patient Education Programme (PEP) run by the Renal Unit. PEP gives important information about your condition before dialysis starts; this course complements that information and gives you the chance to find out what you can do for yourself once you have started dialysis or have had a transplant.

The course involves learning skills to:

- Manage your symptoms
- Deal with stress, depression and low self-esteem
- Manage pain
- Develop coping skills
- Relax
- Work more closely with people who are caring for you
- Plan for the future

The course is run over six consecutive weekly sessions on a Thursday afternoon. Each session starts at 1pm with lunch and finishes by 4pm. Over the six weeks you will find out about easy to learn ways of dealing with symptoms such as fatigue and pain, as well as ways to improve your general health and well-being. Two course tutors, both of whom also have a long-term health condition, will lead the course.

At the time of writing we have around 10 people from the renal unit who have signed up for the first course. We would really like to hear from you if you feel that you could benefit from this programme. If you have any questions or if you would like further information, then please do not hesitate to contact me or Celia Eggeling.

Nicki Thomas Research Lead Nurse
Tel: 020 8296 2641
Email: Nicola.Thomas@epsom-sthelier.nhs.uk

Celia Eggeling Renal Social Worker
Tel: 020 8296 2940



March 25th is a date that will be firmly etched in my mind for the rest of my life and the year 2005 marks the 10th anniversary of my kidney transplant.

On March 10, 1995, I went on the kidney transplant waiting list only to be told that I would need to wait for 2 years for a transplant as I have B+ blood type. While this blood type is only found in 6% of the British population, 40-45% of South Asians are B+. I also discovered that South Asians have a 6-8 times higher probability of renal failure. The waiting list for kidneys in Britain then was over 5000.

I started peritoneal dialysis on March 14th and ten days later, on Saturday, March 25th, my wife and I were awoken by the telephone at 1:00AM from the hospital advising me that they had a kidney available for me and instructing me

to come to the hospital as soon as possible. I received my transplant that same morning at 8:00AM. It took the kidney 10 days to start working and those were ten long and tense days.

Against all odds, God provided in a most miraculous way. It is a new lease of life that He has given to me and I realise I am living on borrowed time. I am grateful to the professional and efficient staff at St. Helier Renal who have made this and the past 10 years possible.

I was one of the fortunate ones who have been able to enjoy the benefits of a normal life with a transplant. Let me share with you how this transplant has transformed my life over the past 10 years.

My family: I am married to Celia and have 2 sons, Arun aged 17 and Sanjay, aged 15. We are a very closely-knit family and have enjoyed growing up together. My health has allowed me to take care of my family in every respect, including financially. Without my transplant, I would have had to rely on state benefits or my wife would have had to go back to work during the formative childhood years. We have been able to enjoy travelling abroad to visit family and friends around the world including Japan, China, Tunisia, Dubai, and the US.

My work: The kidney transplant has given me all the energy I need to do my work. I am a management-training consultant who has been able to train some 2,000 people over the past 10 years and speak at conferences and seminars all around the world. I am also actively involved in raising funds for a number of charitable causes, mostly in South Asia for health, development and education projects. I have had the opportunity to serve as a School Governor, Trustee of a major NHS Hospital Trust, a church leader and director of a number of companies over the past 10 years.

My passion: With good health, I have been able to continue to raise the awareness of kidney disease, transplantation and organ donation with a specific focus on South Asian communities. I have had the privilege of working with the National Kidney Research Fund, TIME (Transplants in Mind) and UK Transplant on a number of initiatives. Given my background, I have also had many opportunities of speaking to hundreds of South Asians from different backgrounds including Hindus, Muslims, Sikhs and Christians in temples, mosques, gurdwaras and churches.

Without a transplant the last 10 years would have been a very different story indeed, and one that I would probably not be writing.

The bad news is that there are still over 6,000 people waiting for a kidney transplant today. Some never get on to the transplant waiting list for a variety of reasons. Some 1,000 people die every year waiting for a transplant. I have met hundreds of people of all ages and backgrounds who have not had the privilege I have enjoyed.

The good news is that transplantation is now saving and transforming the lives of thousands of people. Sadly though, there are not enough donated organs for everyone who needs them. As a result we see six-year-olds having to be in hospital three times a week for up to 12 hours which brings tears to my eyes.. They should be kicking a ball and enjoying life. It doesn't have to be like this. Young mothers in their early 30s having to cope with bringing up 2 or more toddlers is an all-consuming task with the best of health. It is made all the more difficult having to cope with dialysis, hospital visits, and medication as well. It doesn't have to be like this.

It is for all of us to take seriously the challenges faced by people with kidney disease every day.

How can you help?

- Sign up to the Organ Donor Register and make your wishes known.

- Consider live-related organ donation
- Continue to raise the awareness of the need for organ donation and transplantation in schools, businesses, and community groups.
- Speak about the issue openly – it is not a taboo subject

Together as we make a concerted effort between health professionals, communities and individuals, we have the solution to the problem in our hands. Only then will my story be able to be repeated by countless hundreds and thousands all over this country.

Deepak Mahtani
 South Asian Development Partnership
www.southasian.org.uk/organdonation

SHAK HOLIDAY HOME

FOR S.H.A.K. MEMBERS
 Would you like a holiday for
 yourself and family?
 FROM 1ST MARCH TO
 31ST 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),
 £75 for 4 Nights (M,T,W,Th Inc.) £50 per weekend (3
 Nights, F,S,S).**

Preferences will given to patients booking whole
 weeks.

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

Obituary

We were very saddened to learn of the death of Christine Angus-Beatty recently. She suffered a heart attack.

You may remember that Christine and Ernest married last year.

Christine had been a patient of the Renal Unit for almost 25 years and was a keen supporter of the work of the Unit. She and Ernest served on the SHAK Committee for a time but Christine will be remembered for setting up the Telephone Support Network together with Celia Egging, Renal Unit Social Worker.

Our condolences go to Ernest and the family.



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 two 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.**

SHAK NEWS

A message from your Chairman

A new committee has been set up for the Renal Network. It is chaired jointly by Lorraine Clifton, Chief Executive of Epsom & St. Helier and Peter Homa, Chief Executive of St. George's. Its purpose is to support the two Renal Units to provide the best clinical services; to move towards one management and to facilitate the creation of a consolidated service. It appears that we may make slower progress towards a consolidated service than previously envisaged but each step will be sure. The development of a Tertiary Centre has been placed on the back burner until the problems of consolidation are solved.

A fourth Surgeon has been appointed. This is brilliant news. Though Adil El-Tayar is here as a locum, I hope he will stay a long time. I would like to welcome him and Jiri Fronck who started as the third surgeon about 2 months ago. There have been plans to have a fourth surgeon for a long time. We can only say Thank you, At last. We hope their arrival will allow the access surgery programme to catch up with the demand.

We are having a collection outside Waitrose, New Malden on Saturday 18 June. If you can help: if you could stand for an hour and hold a collecting tin, please telephone me. The more collectors, the less time others will have to stand. An hour is not a long time but if you have to stand for 2, the legs begin to ache and it becomes hard to smile at the customers.

A lot of you have asked about the Water Fountain. It was removed because the rental was becoming excessive. A new one has been ordered and should be installed by the time you receive this letter.

I must say a special thank you to Wilkinson's store in Sutton. SHAK is one of two local charities to which they give surplus stock. My garage was bulging at the seams at one stage but we took two car loads to the car boot at Wimbledon Dog Track and sold most of it to raise £350. We are planning to go to another car boot, this time nearer where we live, on 1 May and raise more funds. The receipts are being split between SHAK and the Kidney Fund.

I would also like to say thank you to everyone who donates money to SHAK. Every week we receive donations. Many of them are in memory of people who have died. Thank you very much to you all. Everyone involved in the running of SHAK is very grateful.

Peter Simpson



Proceeds from Race Night come to SHAK

Tom Sayers, a patient, was a football referee and is a member of Wimbledon Referees Society. He persuaded them to make SHAK their charity for the proceeds of their Annual fundraising night. They run a video race evening and on Friday 25 February we went to a Rugby Club in Motspur Park for a most enjoyable evening. The racing was colourful and absorbing, the crowd were very friendly but very exuberant and the bets disappeared on the Tote table as though our horses had not run. We were served a lovely fish & chip supper, piping hot. The bidding to own a horse for the last race was frenetic and everyone there was very generous. We received a cheque for £448.70.

Many many thanks to the Wimbledon Referees and their friends for their generosity. Many thanks to Tom Sayers for making SHAK their charity that night.

British Renal Society /National Kidney Research Fund

Patient Information Survey

What is this survey about?

The British Renal Society and the National Kidney Research Fund plan to produce a comprehensive, up to date library of information for kidney patients about all aspects of kidney disease and its treatment. It is intended to supply this information on Digital Video Discs (DVDs) which patients will be able to keep at home and use as and when they require information.

We feel that DVDs should be useful because you can get a lot of information on a small disc and they can be dubbed in a variety of languages. They are cheap to produce so all patients can be given them and it is possible to skip from one piece of information to another using a menu system. Some patients however may not be comfortable with this form of information or may not have the equipment to use them.

This survey is about the information you have been given in relation to your kidney disease and dialysis, what information you would have liked to receive and how you would most like to receive information in the future.

The results of this survey will help us to make sure we provide the right amount and type of information for the majority of kidney patients.

How is SHAK taking part?

You may find that you have one of the survey questionnaires in this edition of Renality. Not all copies of Renality will have a questionnaire included as we are only sending out 200 copies to a random sample. If you do have a copy of the questionnaire enclosed, please would you send it back in the attached envelope within one week of you receiving it? Your help is very much appreciated. Thank you.

If you do not have a questionnaire, but would very much like to contribute to the survey, then please call Nicki Thomas, Research Lead Nurse on 020 8296 2641 and she will send a copy out to you.

Peter Limmer puts away his teaspoons



Peter has been running the SHAK Trolley for the last couple of years and built up a thriving business. Now he feels the need of a rest and he 'retired' last month in time to take his family on holiday.

When staff heard of this they had a collection - organised by Sue Trowbridge - and presented Peter with a voucher to spend at a garden centre together

with some shrubs for his garden. Also, SHAK presented him with some garden hand tools. Peter was very popular with staff and patients and he will be greatly missed.

Mary Libreri, also a patient, has kindly taken on running the trolley on Tuesdays but many patients have said they would like to have the service on other days.

The work is not arduous and we guarantee whoever does it will make a lot of friends. If anyone is interested in helping us for a morning a week, please contact Margaret Simpson on 01252 792196 or email: mps@mpsimpson.demon.co.uk

Renality and SHAK membership

ALL patients receive Renality. If you wish to be a member of SHAK you must register

There are many advantages to being a member of SHAK: Petrol allowance, Allowance for HD away from home, Use of the Holiday Home and Amenity fund
MEMBERSHIP IS FREE

Show by Gemini Dancers for 'Buy-a-Brick'

Andrea Ford, AIDTA, has been running the Gemini Dance Group for many years. As can be seen from the photograph of some of her pupils from previous performances, she has achieved a high standard and has great support from the parents of her pupils.

For Andrea and her brother, the show she put on in February was very special. They put on a Charity Show in memory of their Mother, Shelagh Ford, who was a patient of the Renal Unit for many years.



The Show itself raised £6000 and sale of videos and DVDs of the show a further £254.94. This was a wonderful donation and a marvellous boost to the "Buy a Brick" fund which has now reached almost £100,000.

Thank you very much to Andrea Ford and her brother, and the dancers and parents of the Gemini group for this wonderful effort.

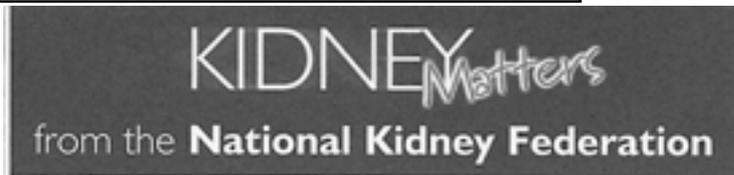
Renality is available on
Audio Tape
Our grateful thanks to

Audio Book Choice Ltd, of Crawley
Basepoint Innovation & Business
Centre, Crawley and
Bayfield Media, Tonbridge Wells

Mrs Barbara Bryant was the first patient to ask for 'Renality' on tape. As a result, she was delighted to receive a selection of audio books from Stefan Novak of Audio Book Choice Ltd, (also a patient of the Renal Unit).

Since then, a number of people have asked for audio copies.

If you wish to receive 'Renality' on audio tape, please contact Margaret Simpson on 01252 792196 or email: mps@mpsimpson.demon.co.uk



The National Kidney Federation has produced a wide range of information leaflets on topics of interest to kidney patients. An order form can be obtained from 'National Kidney Federation', 6 Stanley Street, Worksop, Notts. S81 7HX, telephone 0845 601 02 09 or through SHAK.

Leaflets 20p each:

Kidney Basics

Introduction to Haemodialysis
Daily Haemodialysis—Frequently asked questions
Introduction to Peritoneal Dialysis
About the Kidneys
Frequently Asked Questions

Kidney Diseases:

Symptoms and Problems

Anaemia
Treating Iron Deficiency in Kidney Disease
Glomerulonephritis Questions and Answers
Haematuria
Kidney Cysts
Pain in Kidney and Urine Diseases
12 Steps Towards Pain Control

Proteinuria (Protein in Urine)

Small or Single Kidney

Kidney Diseases

Diabetes and the Kidney
Focal and Segmental glomerulosclerosis
What is Vasculitis

*Incorporating: Henoch-Schonlein Purpura
Microscopic Polyarteritis
Wegeners granulomatosis*

Autosomal Recessive Polycystic Kidney Disease

Adult Polycystic Kidney Disease

Renal Artery Stenosis

IGA Nephropathy

Minimal Change Nephropathy

Nephrotic Syndrome in Adults

Kidney Disease in Myeloma

Drugs:

Commonly Taken Drugs (for Kidney Failure)
Over the Counter Drugs

Tests and Procedures

Kidney Biopsy

Miscellaneous:

Keeping Fit on Dialysis

Sexual Relationships in Kidney failure

Sexual Relationships in Kidney Failure
Introduction and Safe Sex
Sexual Relationships in Kidney Failure for Men
Sexual Relationships in Kidney Failure for Women
Having Children

Holiday Series:

Holiday Tips and Guidelines
Holiday Guidelines for PD Patients
Holiday Guidelines for HD Patients
Holiday Guidelines for Transplant Patients
Holiday/Travel Vaccinations in Transplant Patients

Holiday Facilities for Kidney Patients

European and World wide Destinations £0.35 each
UK Destinations £0.35 each

Ethnic Language leaflets:

Anaemia in Kidney Failure

Bengali Gujarati
Hindi Punjabi
Urdu

Transplantation Series - 20p each

Top Tips
What are the complications of transplantation?
What is transplant Rejection?
Sexual problems following a transplant
Cancer after a transplant
Skin care in renal transplant patients
Blood Pressure, cholesterol, heart disease and circulation problems
Infection after transplantation
What Drugs are needed after transplantation
Diabetes after transplantation
How are kidneys allocated from cadaveric (dead) donors
Is the kidney transplant psychologically stressful?
How long does the transplant operation take?
Are work and normal life possible after a transplant
*inc: How long does a transplant last?
Is it possible to have another transplant if the first one fails?*
What is kidney transplant, will it cure kidney failure?
*inc: Where is a kidney transplant placed?
Can everyone on dialysis have a kidney transplant?*
Can a transplant come from a relative, partner or friend
inc: How do people who have died donate kidneys?

How long is the wait for a kidney?

inc: What details are given about the kidney donor?

Living Donor Information:

Living Donor Information
Reimbursement of Living Donor Expenses

BOOKLETS—priced individually

Reflux 0.30p
Alport's Syndrome 0.30p
Lupus and Lupus Kidney Disease 0.35p
Fabry Disease 0.25p

Bones, Calcium, Phosphate and PTH in Kidney failure 0.40p

Incorporating:

- *Types of Bone Disease that can occur in people with Kidney Failure*
- *What Treatment can be given for Calcium Phosphate and PHT problems*
- *Surgery to remove Parathyroid Gland*

• *These leaflets may be purchased separately at a cost of 25p each.*

What is Peritoneal Dialysis? 0.35p

Peritoneal Dialysis - Frequently Asked Questions 0.30p

Are there different types of Peritoneal Dialysis? 0.30p

INFORMATION PACKS - priced individually

Benefits £1.00
Includes Know Your Benefits & DLA Tips & Guidelines

Free of Charge:

Friends Membership Form
Profile
Helpline Cards
Know Your Numbers card
Transplant Know Your Numbers card

ALL LEAFLETS AVAILABLE IN LARGE PRINT ON REQUEST

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.

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