

Your local association — Run by patients for the benefit of patients

A MEMBER OF THE NATIONAL KIDNEY FEDERATION

Lorna's Gift of Life



Richard, Lorna and Charlie Ray (born 28 November 2007)

Former dialysis patient Richard Jarvis became a father recently, two years after receiving a kidney transplant from his wife Lorna. Richard and Lorna said they were overjoyed and thanked Addenbrooke's renal team for helping to make it all possible.

Richard suffered from Polycystic kidney disease, an inherited condition that caused his kidneys to fail when he was just 31 years old. Lorna immediately offered to donate a kidney to him. And although her blood group was compatible the couple had to go through

numerous tissue typing tests to establish her suitability. Lorna explained that she never had any doubts about wanting to give Richard one of her kidneys if she could "It's horrible to see someone you love suffer." she said.

Since having the operation at Addenbrooke's in November 2005 Richard's health has improved beyond belief. "It's extraordinary the number of people who see me now and say "You look so well' I wasn't aware I looked really grim before, but I must have done" he said.

Happy 2008 to all our readers



Dates for your Diary

June 21 – Saturday
Cambridge Street Collection
Collectors needed, contact:
Michael Moore 01223 244202

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Spring opening for Hinchingsbrooke

The long awaited satellite dialysis unit at Hinchingsbrooke Hospital is set to open in April this year. More than two years of construction and planning problems have now been resolved. The new unit will have fourteen dialysis stations; relieving the pressure on Addenbrooke's. AKPA have pledged to help purchase any essential equipment not supplied by the NHS.

Help Addenbrooke's Kidney Patients when you shop on-line – visit www.akpa.org.uk/easyfundraising for more information.

My First Thirty Years on Dialysis

**Bob Hinson –
Vice President, AKPA**

The date is 5th October 1977; the place is Douglas House – Addenbrooke’s first Dialysis Centre; I am about to start my very first dialysis session.

Thirty years on, with approximately 20,000 hours or two years spent on a haemodialysis machine, and 10,000 needles later; I am writing this article.

In that year (1977) I was told by a Consultant at Bedford Hospital that my condition of end stage renal failure was the end of the line, and my wife Marion should take me home as there was no more they could do for me. Fortunately for us, a junior doctor who had just come to Bedford from Addenbrooke’s heard of my case. He suggested it might be possible for us to meet Dr David Evans the head of Addenbrooke’s Renal Unit.

We were taken to Cambridge to meet Dr Evans and a panel of doctors. The meeting took the form of a job interview, which we later learned was because of the limited number of dialysis places available; it was literally the power of who should live or die.

As I was under forty years of age, with no other illnesses, and we were both deemed to have a certain amount of common sense. It was agreed that we could be trained for home haemodialysis. That was the only treatment on offer and once trained we freed up spaces for other patients to come onto the training programme.

On leaving, Dr Evans made two statements that have stayed with me through the last thirty years:



Bob then

1. We would be joining one of the most elite clubs in the country.
2. He could only give us five years, as at that time they had no experience of side effects of longer periods of dialysis.

The next stage was to go through all the usual checks and have a Fistula formed.

This in itself was still quite new. Most patients were still using shunts; permanent tubing looped into arm or leg, which were prone to infection and clotting. When my fistula healed I was ready to start my first dialysis session.

We spent the next six months at Douglas House going through the various training stages. Sisters Mary Nugent and Hazel Leeson were our tutors during this period, and we had to be assessed at each stage as to our competence to deal with various

emergencies and problems during treatment. One example of this was changing a bubble trap whilst dialysing, this required about fifty clamps and ten pairs of hands. Thankfully, we never needed to carry out that exercise.

“Any patient considering this form of treatment must consult carefully with their partner or carer”

Over the thirty years the process of haemodialysis has changed very little but the equipment has changed considerably. The very early artificial kidneys known as a Kiil or Meltec were large pieces of equipment. They consisted of three pairs of plastic board three feet by one foot by inch thick, with membranes clamped between each pair. We had to strip these

New AKPA Website www.akpa.org.uk

Richard and Lorna Jarvis have designed a new AKPA website www.akpa.org.uk, and we hope it will become a useful source of information for all Addenbrooke’s kidney patients.

It contains fund-raising news, campaigns and various links to other useful websites, also an on-line version of *Newsflash* and the skin cancer leaflet. We hope that not only patients, but also families, carers and friends will find this site useful.

Please try it out and give some feedback, any comments should be sent to the website e-mail address.

The Easy way to internet Fund-raising

Also, thanks to Lorna and Richard, AKPA is now registered with *Easypfundraising*. This is an internet site with links to various well known retailers. If you log on to

www.easypfundraising.org.uk you can select AKPA as your preferred charity; then make purchases from the retailer of your choice, who will donate a percentage of the transaction to AKPA.

A small number of members have tried it and already raised over £100 this way. What could be easier? It’s a win-win situation. Do have a try – for more information see AKPA website.

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down after every session, clean, re-build and check for leaks. Any leak meant stripping them down and re-building. It was a large sink and wellies job.

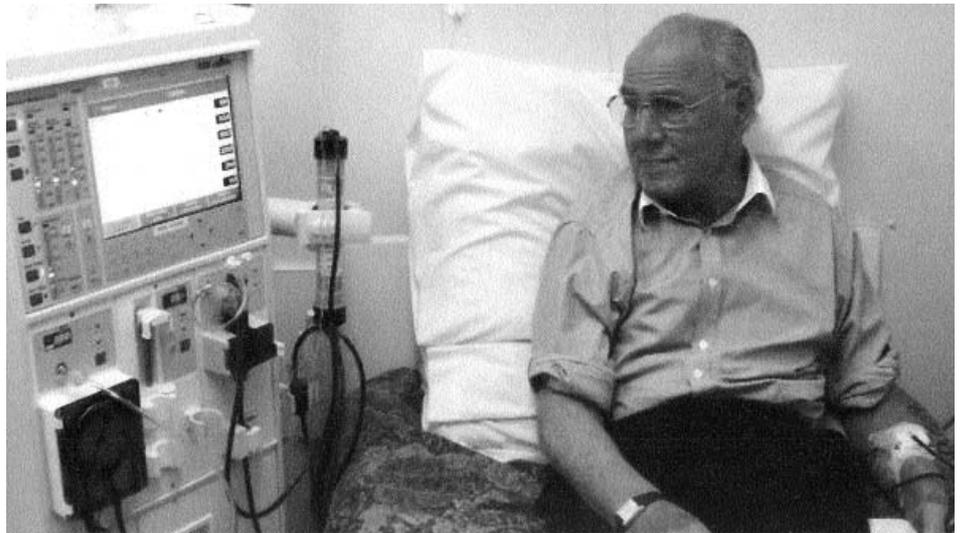
Part of our home training was to spend all morning in what was known as the kidney room, stripping and re-building used artificial kidneys – a soul destroying start to any day.

The final stage of training was to be let loose in the Douglas House Portakabin where we had to deal with dialysis problems ourselves. Meanwhile the home dialysis technicians started installing a Portakabin at our home with all the equipment needed to be self contained.

One problem we had in those early days was the attitude of other people to kidney patients. BT Engineers regarded us as someone to keep well clear of, they associated us with hepatitis, and when installing a telephone in the cabin came with protective suits refusing to come near the patient.

Holiday Dialysis in other units was not allowed because of the risk of hepatitis. So holidays were only available to home patients and could be achieved by taking away a portable machine called a Redy. This still required the two of you, so the helper did not get a break. We took one away on a number of occasions dialysing in hotels or apartments in the UK and Europe, and even once on a cruise ship around the Mediterranean using the ship's hospital bay for the dialysis.

I have been very fortunate during my thirty years on home dialysis, especially the fact that I am only on my second fistula. But I did go through a period some years ago when after open heart surgery and a leg amputation I



Bob now

considered going onto unit dialysis, but after a few weeks I soon realised the independence I had lost and quickly went back to home dialysis.

During all this time I have been able to continue working as a Consultant Design Engineer, home dialysis being very convenient and fitting in well with my profession.

Any patient considering this form of treatment must consult carefully with their partner or carer that they are fully committed and understand the responsibilities. Home dialysis can put an enormous strain on family relationships as you are never far away from the treatment. I have been very lucky in that respect that my wife Marion has stood by me through all the ups and downs of the last thirty years and without that support I would have not got through.

I was very privileged to have served on an early AKPA committee and later as Chairman for many years, also as Vice Chairman of the NFKPA (now the NKF). This national association was

founded by the late Brian Pearmain a home patient who also set up AKPA. It was quite pioneering then as we were still struggling to build up the number of machines available and to present a professional face to the government for recognition. I presently have the honour to be the only patient to be awarded the life time role of Vice President of AKPA and very proud to be so.

On the odd recent occasion I have had to dialyse in the unit, I look around and realise how drastically things have changed. And when I think of the five years the late Dr Evans gave me originally I can only pass on my experiences to new patients and assure them that there can be a good life outside dialysis, and put in the right context it is not all bad. There are times when that might be hard to accept, but of all the terminal illnesses this is one that you can have some control over.

I would like to devote this article to all the dear friends we have made over the years, some whom are sadly no longer with us.

Record AKPA Christmas Card Sales

Over the last few years AKPA Christmas cards have sold in an increasing number of outlets and are a major source of fund-raising. Vice-Chairman Val Long, who is responsible for organising card sales now has outlets in four Cards for Good Causes shops around East Anglia as well as several outlets around the Hospital and satellite units.

Dorinda Ray has also run the mail order service for many years now and distributes cards to members all around the country.

Our thanks to Val, Dorinda and all the volunteers who have helped organise and sell cards for us.

Val's Wedding Present

As well as selling loads of Christmas cards, AKPA vice chairman, Val Long recently got married to John Slade. Val and John asked for charity donations in place of presents and raised £198 for AKPA.

Our congratulations and thanks to the new Mr and Mrs Slade.

Collecting and Connecting



Michael Moore and Barbara Vining

Once again, committee member Michael Moore organised our annual street collection in Cambridge City centre. Despite miserable weather the collectors managed to do very well collecting just under £300 during the morning.

Michael's efforts bring in more than just tins of spare change, our collectors also do a good public relations exercise for AKPA. Many people stop to chat and find out about the work of AKPA or swap experiences of family renal problems.

Our thanks to Michael and all the collectors:

Jayne Wyatt and family, Michelle Butler and family, Malcolm Peck, Margaret Wilson, Barbara Webb, Barbara Irving, Barbara Vining, Dorinda Ray and Daughter, Monica Taylor and Brian Wood.

Tesco Collection

A collection at Tesco's Fulbourn on December 8th, organised by Barbara Irving raised £316 for AKPA. Barbara's son David played guitar and sang to entertain and encourage contributors and they were ably assisted by Barbara Vining.

Our thanks to them all for a brilliant effort.



St Neots Ladies Circle raised £1000 towards equipment for the new Hinchingsbrooke dialysis unit. Presenting the Cheque to Tony Weaver are (from left to right) Nicky Mitchel, Julia Edwards, Jean Donaldson and Sarah Arber

Jenny's Marathon

Staff Nurse Jenny Jennings has completed six half marathons in the last two years, raising over £1000 for AKPA.

Jenny says that running has been part of her life for the last few years. Initially taking up the sport to keep fit, she entered for the Great South Run in Portsmouth. And then encouraged by the level of interest and support generated in the dialysis unit, raising money for AKPA became an incentive.

She has completed six half marathons (13.1 miles) up to last December with another just before Christmas and she says she is looking forward to running a full marathon in the next two years to celebrate her 60th birthday.

Our thanks to Jenny for an amazing achievement.



Staff Nurse Jenny Jennings being presented with her certificate by Tony Weaver

Doreen's Sale Raises More Funds

Doreen Scarff of Elliot Lodge, March recently raised £610 for AKPA by making and selling cakes, jams and marmalade, and running a raffle and tombola.

Doreen's husband who died seven years ago was a kidney patient, and they always supported AKPA, sometimes raising as much as £1000 annually.

Doreen has continued this tradition and this is her 24th year of fund-raising. She also said that it would be her last, but friends have told her that she should do one more to complete 25 years. She says that she will probably do a small one for this year.

Our thanks to Doreen for this and all her support over the years.

Barbara's Stalls

Barbara Vining has been consistently raising funds for AKPA for very many years, and last year ran several very successful stalls in the outpatient's reception area. The stalls sold craft items, bric-a-brac, cards and gifts, most of which were kindly donated. They raised a total of £1140 and in accordance with Barbara's wishes the money was used for patient welfare and support for clinic twelve.

Barbara and the committee would like to thank everyone who donated items, helped with the stalls or who purchased goods from them. They are a brilliant way of raising funds and publicising our work. Thank you all.

After many years of tireless work for AKPA including selling Christmas cards and serving on the committee, Barbara has decided to retire from running stalls. Announcing her intentions at the AGM in June, Chairman Tony Weaver, on behalf of AKPA, offered heartfelt thanks for her sterling efforts over the years.

Barbara's Patchwork Helps Community Room



AKPA Patron, Lady Walker of Gestingthorpe, drawing the winning ticket for the quilt

This magnificent, intricate and handmade patchwork quilt was raffled by Barbara Vining to raise money to buy furniture for the Dialysis Centre community room. The quilt, which was won by Mrs Colbert of Hemingford

Gray raised £164. Many years of work went into making the quilt; it was started by Barbara's Aunt around twenty years ago and then added to and finally completed by Barbara and friends in her sewing circle.

Crown Appeal's Continuing Success

The Crown Appeal, founded by Amanda Pigg and Angela Kenton have continued their amazing fundraising successes with another £5000 presented to AKPA to help purchase much needed medical equipment.

The Appeal have already raised £5000 for AKPA earlier in the year and this sum has been used to purchase an ECG machine for the Kings Lynn satellite unit. Dialysis nursing staff have stressed the importance of having equipment like this to hand but NHS funding is often not available.

Amanda and the AKPA committee thought it appropriate that the Crown Appeal money should first go to the Kings Lynn unit where Amanda's father received holiday dialysis and



Nursing staff with the new ECG machine

their latest donation will also be used for medical equipment.

Our thanks to Amanda, Angela and all the Crown Appeal fundraisers.

The Richardsons' Art Donations

Mrs Eve Richardson, who regularly raises money for AKPA from sales of art, has presented us with another cheque for £400 on 22nd Dec last year.

Eve told us that this is the 7th year she and her family have donated money to AKPA bringing the total to £3,125. Adding that she and her husband Ray wished AKPA success in all the good work they do.

Our thanks to Eve and her family for all their efforts.

A big thank you to everyone who helped raise funds or donated to AKPA.

NKF Annual Patients Conference 2007



The NKF Annual Conference was held in October at the Blackpool Hilton Hotel. A full conference report will feature in the next issue of *NKF Kidney Life*, due out after Christmas. In the meantime, if you wish to hear audio recordings of all talks and panel discussions, they are available now on the NKF website. Go to www.kidney.org.uk and click on **NKF Conferences then 2007 – Decisions, Decisions October 2007.**

Kidney care – a service for the 21st century



Donal O'Donoghue,
National Clinical Director for Kidney Services, Consultant Renal Physician, Salford Royal NHS Foundation Trust

“UK Services for kidney patients fall

behind parts of Europe and the developed world. But examples are being seen of hospital trusts, and their support teams, acting successfully on the Renal NSF's messages. The general practice registration system provides a real opportunity to identify either those at risk, or with early kidney disease – a real prospect of prevention. Dialysis should be planned using an arterio-venous fistula, without prolonged admissions or risk of MRSA. Transport systems are key. Patients who could benefit from transplantation should be listed pre-dialysis and transplanted as soon as possible. There is much to do to ensure patients and their carers benefit from a consistent, high quality service, based on patient needs and provided by a supportive multidisciplinary team. Working that way, I have no doubt that we can provide a 21st Century world class kidney care service.”

Rising to the challenge – changes in attitude to living donation



Mr Paul Lear,
Consultant Vascular and Transplant Surgeon, Southmead Hospital

“The last decade has seen real change in the attitude and activity in living

donor kidney transplantation. This has been due partly to the development of

minimal access surgery techniques to remove the kidney, and advances in immunosuppression drugs which have started to make HLA matching less relevant in this form of transplantation. The number of unrelated (spouse/partner) donors has grown far in excess of the more traditional donor/recipient pairs, with graft success rates similar for all parties. With the new legal framework there is potential to transplant patients who have willing but incompatible donors by the process of organ exchange. Despite the recent surge in patients entering the national waiting list, do we have the means to reverse the tide and start to see numbers fall?”

Living donation – brave or stupid?



Chetna Reay, *kidney patient*

“Three years ago in June 2004 my mother was diagnosed with kidney failure. This was something that happened to other

people and as such I did not have a clear understanding of the condition or the consequences of living with the disease. As a family we quickly realised that this was here to stay and that transplants were available but the chances for mum were probably low, due to being in the ethnic minority grouping, suffering from diabetes and her age. I began to do some research on the Internet and found that live donation was a possibility. However my mum was against the idea as it meant there could be a risk to my life and subsequent problems this could cause.” The aim of Chetna's story was twofold, to encourage people to register onto the donor list and also, if a loved one is in need of a transplant to consider becoming a live donor.

Youth and kidney failure



Jen Dickinson,
kidney patient

“Learning to live with kidney failure is as much a battle with our minds as it is a battle with drugs and dialysis schedules.

What we regard as

the limitations and restrictions placed on us by kidney failure lies I think in our beliefs rather than in our bodies.”

Jen gave a moving personal account of the impact of kidney failure on her own self confidence as a young person and some of the strategies and decisions she made to overcome this.

Privatisation and capacity expansion of HD



Dr Roger Greenwood, *Clinical Director, Lister Hospital*

Dr Greenwood gave an overview of dialysis provision over the last thirty years, comparing the

UK with the rest of Europe and with the United States. Early provision in the UK was relatively poor, but quality and patient choice have improved markedly in recent years. He stressed the importance of our highly developed patient choice and multi-disciplinary support. He also spoke very positively about our holistic continuity of care, pre-dialysis preparation, primary care and district nursing, empowered nurses and our excellent infrastructure and information on health. There are currently no personal financial pressures on our doctors, and patient choice is not determined by commercial pressures. He pointed out that our current system relies upon big dialysis centres surrounded by a

steadily expanding number of satellite units, and how we are used to the fact that the latter are increasingly run by commercial companies, and run very successfully too. He described a new pattern of provision which has been trialled in the Cheshire, Merseyside, Sheffield and Hull areas and which is due for expansion very soon. This involves central funding and contracts held by the Secretary of State rather than locally, raising a number of potential threats to the quality of provision. Dr Greenwood accepts reality and the need to continue to move forwards, but warned that we must be very careful to avoid the splitting of multi-disciplinary teams and any erosion of modality choice. The challenge for the next few years will be to maintain our mixed economy and preserve our holistic approaches.

Ethics in transplantation



Professor Nadey S Hakim, *Consultant Transplant & General Surgeon*, Hammersmith Hospital.

“Early days of transplantation saw ethical issues

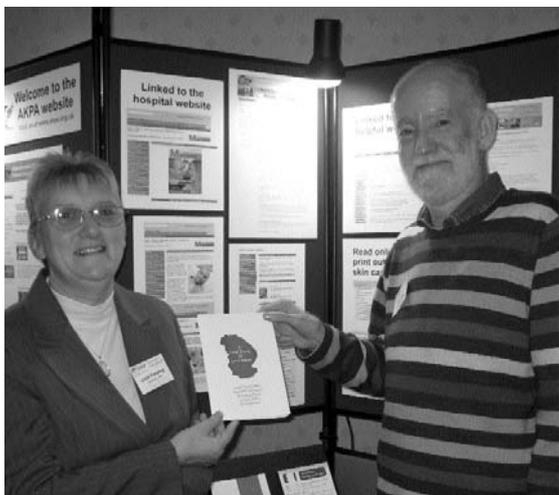
with regard to experimentation and new treatments being used on patients. As patient and graft survival improved, it became unethical not to transplant. Nations vary in their current state of medical development. In less developed countries, the ethical concept of justice requires priority be given to general medical and health programmes. Expensive transplants help but a few. Legal, political, religious and social readiness for human transplantation also varies. Some societies have well-established criteria for ‘brain death’, others do not, therefore cadaveric transplantation is not possible. In most countries the ethical basis for live donation has been firmly established in law and confirmed by biological outcome. Waiting times are rising and immediacy is particularly advantageous for children. Despite improved results with cadaver donor transplants, the scarcity of human organs and the difficulty in providing cadaver organs means the role of live donation as an ethical alternative can only increase.”

“Live Life then Give Life” by Big Buzzard and The Organ Grinders



Andy Williamson, *living-donor transplant recipient*

Andy announced his arrival in the conference hall with a rousing piece of jazz as he walked through the audience to the podium. *Live Life then Give Life* is a new song released as part of a campaign to increase the number of living kidney donors, and to encourage everyone to join the NHS Organ Donor Register. Andy Williamson (sax) and Maff Potts (organ) co-wrote the song. On 7 August 2007, Maff donated one of his kidneys to his friend Andy, who had been on dialysis for 2 years. The song, released by Flat Five Records, will be available on iTunes and other download sites during November, and Andy is hoping for a Christmas hit!!! All royalties earned will go to the charity ‘Live Life Then Give Life’ which campaigns on behalf of all those needing organ transplants. For more information, please contact Andy Williamson on 07980 680052 or asw@bigbuzzard.co.uk



KPAs swapping ideas

Coffee and lunch breaks are always a good chance to meet folk from all over the UK and pick up tips and ideas. This year, there was a record number of seven display stands set up by KPAs, and these were spread around the exhibition hall between the medical and support industry stands. One of the first visitors to our stand was Linda Pickering, the Chair of Lincs KPA, seen here (above, left) presenting Alan Craig with a copy of Lincs KPA’s new patient

information booklet. Linda had been so impressed with AKPA’s booklet last year that Lincs KPA followed suit, and published an acknowledgement to AKPA in their credits.

The exhibition was a chance to show off AKPA’s excellent new website (above, centre), created by Richard and Lorna Jarvis. Our display panels showed enlarged printouts of our impressive web pages, and our ‘webmasters’ had provided a CD of the website. This allowed members of other KPAs to

explore our website on a laptop, to give them the taste of the real thing.

This year’s conference was attended by AKPA members Rodney Morris, Paul and Ronald Cookson and Alan & Wendy Craig. Also present were old friends of AKPA John and Margaret Evans from BODY, and David & Jean Collyer from Guys & St Thomas’s KPA – relatives of AKPA member Cathy Wills. David & Jean Collyer are pictured here with Rodney Morris (left).

AKPA Annual General Meeting June 2007

Developments in the Renal Department

Dr Nick Pritchard

Consultant Nephrologist

Dr Pritchard began by saying that some of the proposed changes mentioned at the 2006 AGM have still not been made, but things are moving forward slowly.

Clinics

The lack of space in some clinics is being tackled with plans to expand rooms in clinic 12 so that nursing staff are able to spend more time with patients. There are now more spaces in the Haemodialysis clinic and the Low clearance clinic, which has been in existence for two years is being expanded with improved IT support. Funding for the recently developed Tubular disorders and renal genetics clinic has been taken over by Nephrology.

Transplantation

There was a big expansion in 2006 with a record 120 transplants. Hopefully this will continue with the expansion of a wide range of transplants, including: kidney pancreas transplants, paired donation and non-related altruistic donation.

Also, an expansion of the Desensitisation programme with antibody removal should lead to fewer live donors being turned down because of blood grouping or antibody problems.

Haemodialysis

There have been many changes during 2006/07 including a new, extended unit in G2 to take excess capacity awaiting the opening of the Hinchingsbrooke unit. A new water plant is in operation and High flux dialysis is now available. The home haemodialysis programme has been expanded with eight home haemo patients and more improvements planned.

The West Suffolk satellite unit is running a twilight shift. King's Lynn is currently full but hopefully there should be an expansion of services in the near future and the long awaited Hinchingsbrooke unit will open in April 2008.

Questions to Dr Pritchard included:

Q: Twilight patients have reported problems seeing a doctor.

A: Since January there has been a monthly ward round to see everyone once a month. Apologies if this has not happened. The plan is to see everyone as routine.

Q: If desensitisation programme is successful will paired donation become unnecessary?

A: No. Only a small percentage of patients' antibodies are of a specific kind and level to enable their removal to allow transplantation. There will still be a number of people unable to go forward so there is still a place for paired donation.

Q: What is the altruistic programme?

A: An altruistic donor is unrelated. There is now a formal assessment mechanism in place. The concern is that people with psychiatric disorders could be donating a kidney for inappropriate reasons. When people have been assessed that kidney will be put forward into the pool.

TRANSPLANT UPDATE

Lucy Kirk

Renal Transplant Co-ordinator

Lucy has been Renal Transplant Co-ordinator for the last two years, taking over from Paul Jones.

She began by presenting a series of graphs showing transplant activity at Addenbrookes during 2005/6 and 2007. 2006 was extremely busy, but 2007 was slow to start. However, the number of kidney and pancreas transplants has doubled.

Lucy went on to describe the various types of donors and the improvements in outcomes. She explained that the transplant team is recruiting more co-ordinators in order to educate intensive care practitioners to identify potential donors and give families the choice to offer organs.

In early 2007 there were 250 patients on the Addenbrooke's active waiting list with another 75 suspended due to ill health or holidays. The UK statistics for 2006 showed a total of 3086 transplants. A record number of non heart-beating

donor kidney transplants took place and there was also a big increase in living donors – now one in four of all kidney transplants: At the end of March 2007, 7234 patients in the UK were listed as actively waiting for a transplant. Eligible patients are picked up earlier at clinics now and it is planned to offer some pre-emptive transplants before dialysis.

CHAIRMAN'S REPORT

Tony Weaver

One of the difficulties of being on a Committee like ours for any length of time, is maintaining a freshness. Whilst



Tony Weaver

this Committee is very enthusiastic, extremely hard-working and totally dedicated, it is the same faces turning up at meetings, doing the running about, keeping the books, writing the thank you

letters, running the raffles and so on. And I have to tell you that they do it with great willingness, without complaint and with a passion. However, last year we were fortunate enough to welcome Lorna and Richard Jarvis to our Committee and it has been very refreshing to have some young blood fresh and stimulating ideas. I don't want to steal their thunder, but I am sure you will be pleased with the new website that Richard will tell you about and also the shopping experience that helps the AKPA whilst you indulge yourselves. But more of that later.

There are several things I feel are worthy of mention. Firstly just to update you on the *AKPA Skin Cancer* leaflet. This has been extremely well received both among our own patients but also at the NKF Conference and in particular Barts Hospital who have used it quite extensively with high praise.

Whilst mentioning the NKF Conference I would again like to take this opportunity to thank Alan Craig who continues to be our representative at a

national level and puts in an awful lot of work producing comprehensive reports of all the meetings to keep us up to date. I joined Alan and Wendy at last year's conference and it is very obvious just how much effort and time he puts into the job. Our thanks to Alan.

Thanks also go to a lovely lady who has worked tirelessly for years for AKPA raising money on sales stalls here in the hospital and at other places. Barbara Vining has also been much involved in Christmas Card Sales and was a Committee Member for a long time. Barbara is always very modest about her achievements but not only has she been successful as a sales lady she has also managed to persuade a whole army of ladies to assist in making things to sell and helping on the stalls, so much so that when she writes to me and says, can you write to these ladies to thank them, there is usually at least a dozen letters needed.

Barbara has now decided that she will not be running these stalls any more after Christmas so I must take this opportunity to offer her our heartfelt thanks for all her sterling efforts over the years and also to her lovely band of helpers. Thank you so much Barbara.

We continue to commit to providing funds for many causes not the least for welfare grants. In addition we are currently pledged to raise money for additional dialysis equipment for the new Hinchingsbrooke unit. And we may have to find a substantial amount of money for the specialist software that Dr Pritchard needs to improve the efficiency of the dialysis unit and provide a better service to those who need dialysis.

We have already promised £5000 to Kings Lynn unit for an ECG machine and this will be funded by the very generous donation from Amanda Pigg, her friends and family in memory of her late father. Amanda's dad used to dialyse at Kings Lynn while he was on holiday in the area and it was thought fitting that the money was used in this way.

Our thanks go to all those people who put themselves out to help raise money for our Association.

One of the ways we raise money is by the sale of Christmas cards. This year we sold, with a lot of help from all round the area, about £4500 worth of cards, a magnificent sum and it is hoped to replenish our stocks and repeat the process this coming Christmas.

I can't finish without a big thank you to the ladies who produced the lovely refreshments for this evening and of course thank you to all of you for coming along.

Addenbrooke's Kidney Patients' Association is your association, here to help and support all our Members and their families but it is of paramount

importance that you continue to charge us with getting it right. You may rest assured that we will continue to do our best as long as we are required.

AKPA Financial Report

Income:

Our income for 2006/07 totalled £66,331, slightly less than last year but still higher than in most recent years. Unfortunately, this is mainly due to a continuing high level of income from legacies and 'in memory' donations, and reflects the sad fact that we have lost many of our long-term supporters.

Income from regular sources, including raffles, 200 Club, Christmas cards, craft stalls, bric-a-brac sales and collecting tins all continue to do well. This is thanks to our dedicated fundraisers, who work away year after year to provide our only regular income. Without them it would be impossible to continue with commitments such as social support for patients. Thank you to everyone who raised money for us.

Expenditure:

Our total expenditure was £52,880. This included a £24,000 payment for the ultra-sound scanner purchased for the transplant unit and demonstrated at last year's AGM.

Other outgoings included financial support to staff attending International conferences where they were involved in the latest developments in renal care and transplantation issues. We also sponsored patients to attend the annual National Kidney Patients Conference in Coventry with grants totalling £980 and supported contestants in the National Transplant Games with grants totalling £625.

Social Support:

Economic and social support for less able patients and their families has always been an important part of our work and a major item on our budget.

We continued to fund the renal social worker and provide welfare support for needy patients. We also provided financial assistance with dialysis holidays for less able patients. Our total expenditure on these worthwhile causes amounted to £16,563.

We funded Christmas buffets for patients in the Dialysis Centre, and Kings Lynn and Bury satellite units at a total cost of £400.

Reserves:

Over the last few years we have been very fortunate in receiving some generous legacies and donations, which increased our reserves. We are committed to using these reserves to fund important projects and services that patients and staff have been requesting and that had not been funded by the NHS.

The current level of our reserves will enable us to continue these projects and to confidently support the welfare of patients whose numbers are predicted to grow in the near future, and to carry out the objectives of the Association over the next year.

Spending Plans:

In the current financial year we are committed to funding urgently needed pieces of medical equipment, not funded by the NHS, for the Renal Department. These include a Urine analysis Machine for Transplant Unit, an Oxiometer for Clinic 12, blood pressure monitors for the Dialysis centre and ECG machines for Bury St Edmunds and Kings Lynn.

Also, we have long term commitments to fund an extra haemo-dialysis machine for the new Hinchingsbrooke satellite unit when it opens and a major contribution towards a new computerised dialysis monitoring system for the Dialysis Centre.

Administration Costs:

Despite the ever-increasing burden of financial regulation, insurance and form filling, our administration costs remain very low. At £3,813 they represent just over 7% of our total annual spending.

The Treasurer's job would be very difficult without the dedication and skills of our two paid, professional staff, Bookkeeper Polly Connell and Secretary Jenny Ridgeon. Thank you both.

Thanks to the continuing support of patients and their families, the charity is in a good financial position and we look forward to more achievements in the coming year.

Canterbury Weekend for West Suffolk Patients

Saturday 1st September

With the sun shining, 40 patients and relatives boarded the coach for Canterbury, and after collecting two more from Addenbrooke's we were on our way.

We were dropped off at our destination, the 15th Century, beamed, Falstaff Hotel close to Canterbury's Westgate tower. And after a buffet lunch, everyone had the afternoon at leisure to explore within the city walls, visit the Cathedral or indulge in retail therapy. For the less ambitious it was an opportunity to relax in the hotel lounge and courtyard.

Sadly, we discovered Canterbury was not the most disabled friendly of cities and the lack of vehicular access to the city caused some difficulties. However, with everybody's help none of the problems were insurmountable.

In the evening, after a three course meal in the Hotel restaurant, we set off for the Marlowe Theatre and 'A Gala Night at the Proms' with The Kent Concert Orchestra. The second half saw us

singing along to Land of Hope and Glory and Rule Britannia with Union Jacks waving. After a stirring evening we made our way back to the hotel and adjourned to the bar for a 'night cap'.

“Getting away from the normal routine does everyone good”

Sunday was bright and sunny, and after full English breakfast we had planned a leisurely carriage ride around Canterbury. Unfortunately there was only one carriage and the horse had gone lame! I had warned that this was the case, but everyone thought it was a joke – they soon found out it wasn't and I told them the alternative was a boat trip on the river. With much trepidation all agreed, it was a lovely morning and the rowing boats came complete with oarsman. Everyone had a thoroughly enjoyable time, although I was threatened with the 'ducking stool' on our return.

Then it was back to the coach for the short drive to Herne Bay, where we had

time for a walk along the front or to sit watching the sea before Sunday Lunch at The Ship Inn. After lunch it was time to re-board the coach and head for home.

We all had a lovely weekend with many amusing moments. I would like to thank Derek Varley for organising the coach. Also, Ron Fuller, who was tremendous in helping with all the arrangements, but who was unable to attend at the last minute due to ill health. My thanks also to all the patients and relatives who came along and made the weekend such a success.

None of this would have been possible without the tremendous support given to us by AKPA to finance the trip. Getting away from normal routine does everyone good, and I know that both patients and relatives benefited from the change.

**Julia McCarthy – Senior Sister
West Suffolk Dialysis Unit**



Canterbury boating

NKF
Helpline



Tel. 0845 601 02 09

E-mail: helpline@kidney.org.uk

Website: www.kidney.org.uk

Helpline

National Kidney Federation

6 Stanley Street, Worksop

Notts. S81 7HX

Renal Diet Information

If you have any questions regarding your diet please contact the relevant dietician. Here's a who's who of the dieticians in our area:

Addenbrooke's – Cambridge

Elaine Corden – covers CAPD.

Clare Parslow – covers ward C5, nephrology clinic and haemodialysis.

Laura McGeeney – covers ward C9 and transplant clinic.

We can be contacted on 01223 216655.

Queen Elizabeth Hospital – Kings Lynn

Hannah Lodge – covers the satellite haemodialysis unit.

Contact on 01553 613861.

West Suffolk Hospital – Bury St Edmunds

Sara Volkert – covers the satellite haemodialysis unit.

Contact on 01284 713010

AKPA Christmas Raffle



Richard with the winning tickets

Richard Fossey has been organising AKPA raffles for over seven years now, writing hundreds of begging letters to get valuable prizes, and organising sack loads of tickets to select the winners. Richard's raffles are always popular and each one manages to raise around £2000 for AKPA. Our thanks to Richard and all the people who donated prizes and bought tickets.

Are You a Member of AKPA?

To join or receive more information about AKPA please complete the form below and return to: **AKPA, P O Box 608, Freepost RRKT-RBGX-AETR, Cambridge CB1 0GJ**

Name _____

Address _____

Telephone _____

Join AKPA

Please send information

Subscriptions are **optional**, the suggested amounts are £2 single or £3 family. They are used to pay for NKF membership, and printing *Newsflash*. We are very grateful if you can help us to cover these costs.

Benefits of membership are:

- NKF membership, which includes:
 - *Kidney Life Magazine*
 - Access to NKF helpline
 - NKF Conference

Plus eligibility for:

- AKPA holiday and welfare assistance
- Sponsorship for Transplant Games
- Sponsorship for NKF Conference
- *Newsflash*

AKPA CHRISTMAS RAFFLE 2007

Drawn on 12th December 2007 in
the Dialysis Centre, Addenbrooke's Hospital

List of Prize Winners

- | | |
|---|--------------------------|
| 1. £300 Cash | Page, Wickford |
| 2. £150 Cash | Buckle, Great Dunmow |
| 3. £100 Cash | Legate, St Ives |
| 4. Toshiba Photo Frame
<i>Kindly Donated By John Lewis</i> | P Smith, Bury St Edmunds |
| 5. Premier Food Hamper
<i>Kindly Donated By Premier Food Co.</i> | J Weaver, Saffron Walden |
| 6. £50 Tesco Vouchers | Hillary, Bedford |
| 7. £30 Tesco Vouchers | Baines, Peterborough |
| 8. Hamper
<i>Kindly Donated By Kevin, Royston Market Trader</i> | Leeson, Cambridge |
| 9. £25 M&S Vouchers | Clark, Felixstowe |
| 10. £25 Ridgeons Vouchers | Beau-Jensen, Bushey |
| 11. Hamper | Warwick, Bedford |
| 12. Scrumpi & Flasks | Jones, Little Dunmow |
| 13. £25 John Lewis Vouchers | Sturgeon, Market Raisin |
| 14. £25 Ridgeons Vouchers | Bonfare, Bushey |
| 15. £25 M&S Vouchers | Ward, Bourne |
| 16. £25 Tesco Vouchers | Haig, Northumberland |
| 17. £25 John Lewis Vouchers | Dobson, Boston |
| 18. Hamper | Burke, Bedford |
| 19. £20 M&S Vouchers | Shephard, Chertsey |
| 20. Pizza Set | Hubbard, Bury St Edmunds |
| 21. £15 Sainsbury's Vouchers | Rogerson, Hoddesden |
| 22. Mulled Wine & Cheese | G Smith, Great Bardfield |
| 23. Bells Whisky | Julia, Addenbrooke's |
| 24. £10 Tesco Voucher | Brady, Oundle |
| 25. £20 Tesco Vouchers | Pike, Waltham Cross |
| 26. Cutlery & Cook Set | Wilson, Northumberland |
| 27. Croft Original & Chocs | Cornish, Stevenage |
| 28. Roses Chocs & Wine | Everitt, Bury St Edmunds |
| 29. Bowl of Nuts & Wine | Heard, Sudbury |
| 30. Harry Potter Book | C Harris, Bushey |
| 31. £10 Garden Centre Voucher | Goodrum, Downham Market |
| 32. Quality Street & Wine | Billingham, Bedford |
| 33. £10 Voucher | Clark, Ipswich |
| 34. Biscuits & £5 Voucher | Game, Great Bardfield |
| 35. Piña Colada & £5 Voucher | Winwood, Perry |
| 36. £10 Tesco Voucher | Jefferson, Peterborough |
| 37. Shortbread & Wine | Taylor, Rampton |
| 38. Cuddly Hottie & Serv. | Camp, Saffron Walden |
| 39. Teddy Bear, Game, Camera | Walker, Radwinter |
| 40. 2 DVD's & £10 Tesco Voucher | Greenhalf, Birmingham |
| 41. Scarf & Gloves | Parris, Colchester |
| 42. Iron & £10 Voucher | Hill, Peterborough |
| 43. Wine & Voucher | Chappell, Melbourn |
| 44. Bowl of Nuts & Voucher | Van Pelt, Kings Lynn |
| 45. Lambs Navy Rum | Foster, Great Bardfield |
| 46. Travel Book | Beamish, Wootton |
| 47. £10 Garden Centre Voucher | Pearce, Royston |

The net income from this year's Christmas Raffle amounted to just under £2000.00 and also £216.00 was received in cash donations.

I most sincerely thank everyone for the generosity shown: those who donated prizes, bought and sold raffle tickets and those who gave cash donations. Special thanks to those who every year sell large numbers of tickets, the Allens again managed to sell over £300 worth.

Congratulations to the prize winners and a healthy, happy and peaceful new year to you all.

A very happy, healthy and peaceful New Year to you all.

Richard Fossey – Raffle Promoter

AKPA 200 Club Monthly Draw Winners

April

• £50
No. 237
R. Young, Bury St Edmunds

May

• £50
No. 67
M. A. Camp, Saffron Walden

June

• £50
No. 29
S. M. Winkles, Papworth Everard

July

• £50
No. 86
Myra Sankey, Chelmsford

August

• £50
No. 319
Ronald Fuller, Newmarket

September

• £50
No. 29
S. M. Winkles, Papworth Everard

Newsflash Contributions

We would love to hear from you, letters and articles for publication in *Newsflash* are always welcome. Send them to the editor: Brian Wood, address, phone, fax and e-mail see Committee Members list.

Renal Book Club

Books can be borrowed and listings obtained by return of post simply by making contact with me direct at:

**Bellevue, Foul Anchor, Tydd,
Wisbech, Cambs. PE13 5RF
Tel: 01945 420291**

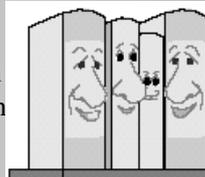
or by e-mail at
roger@anchor100.freeserve.co.uk

Books include:

Factual Information on Renal Failure, "in easy to understand language"

also Diet, Drugs, and the most Popular and requested.

"The Ultimate Gift" the Story of Britain's Premier Transplant Surgeon Sir Roy Calne.



Roger Ward

AKPA Committee Members 2008

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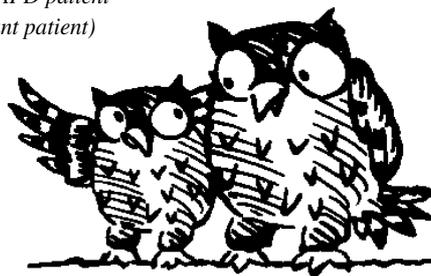
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January 2008