

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

A MEMBER OF THE NATIONAL KIDNEY FEDERATION

MP Visits Dialysis Centre



Left to right: Val Slade, MP David Howarth. Tony Weaver and Sister Clare Daniels

David Howarth, MP for Cambridge visited the Dialysis Centre in June. He came at the invitation of the AKPA committee and was welcomed by AKPA Chairman Val Slade, Vice Chairmen Brian Wood and Tony Weaver, and Haemodialysis Sister Clare Daniels.

During his tour of the Centre he said he was impressed by the range and scale of the treatments available. He also

discussed with the staff and committee members some of the problems faced by patients and staff, such as lack of space, transport difficulties and the shortage of donor organs.

The visit was very successful and our thanks to David Howarth for taking time to visit the Centre. We are sure he gained a good understanding of the work done there and the need for increased funding from the NHS.

Dates for 2009

Oct.–Dec.

Xmas card sales – help needed, please contact Val Slade
01787 477070

20th, 21st, & 22nd November
Supermarket Collection
Sainsburys, Coldhams Lane,
Cambridge. Collectors needed
please contact Michael Moore
01223 244202

10th Nov. & 1st Dec. – Tuesday
AKPA stalls in Addenbrooke's
Outpatients entrance

9th December – Wednesday
Christmas Raffle Draw 1.00 pm
in the Dialysis Centre

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

Richard Retires

After many years serving on the AKPA committee as Chief Fundraiser and Patient Representative, Richard Fossey retired from the committee at this year's AGM.

As well as the mammoth task of organising two raffles a year, Richard has encouraged and supported a whole army of fundraising activities. Almost every fundraising event known to man Richard has somehow been involved. He also constantly concerned himself with the welfare of his fellow dialysis patients.

At the AGM, AKPA Chairman Val Slade made a presentation to Richard thanking him for his years of outstanding work for AKPA.

Val said of Richard that "when he came across a patient problem he has been like "a dog with a bone" never letting go until he had done all he could to bring it to everyone's attention."

Despite being on haemodialysis and having health problems of his own Richard worked tirelessly for the good of his fellow patients.

See Committee retirement, AGM Chairman's report page 6.



Above: AGM presentation to Richard. Below: Richard with some of his "conjured" raffle prizes



Richard; the Champion of Raffle Organisers

Richard was already a committee member when I joined some six years ago and in the time I have known him he has worked tirelessly and unselfishly for the benefit of his fellow patients.

He is indeed a champion of raffle organisers and never ceased to amaze us with the number of prizes he could conjure up from all his contacts.

The amount of money raised through all the raffles he has held over the years is legendary.

In addition he has been deeply involved as an informal Patient/Committee liaison officer and has clearly and carefully fought his and others' corner when things such as transport arrangements for patients have needed some pressure.

But most of all Richard has always impressed me with his cheerful disposition, he is always smiling and never minds if we gently take the mickey out of him.

He is a true gentleman and we will miss him immensely on the committee.

Tony Weaver

AKPA to Fund New TVs for Dialysis Centre

It is planned to replace the televisions in Addenbrooke's Dialysis Centre with up to date, flat screen, digital models. This should greatly improve the quality and range of entertainment for patients on dialysis.

A very generous legacy has enabled AKPA to fund this much needed update and it is hoped that the work will start in the near future.

Where the Money Went – 2008-09

Support for Addenbrooke's Renal Units

We funded medical equipment needed to treat kidney patients that was not funded by the NHS.

- An ACT (Activated Clotting Time) machine for the Hinchingsbrooke Satellite unit – £5,000
- A Dinomap machine for blood test monitoring in the Dialysis Centre – £450
- An ultrasound scanner for the Renal Ward – £500
- A home haemodialysis machine – £10,900.

Support for Patients

- Welfare and holiday grants to disadvantaged patients.

- Funding for Addenbrooke's renal welfare officer
- "Food for Thought" dialysis diet recipe book free to patients
- Third reprint of the *AKPA Skin Cancer Leaflet*
- NKF annual conference travel and conference fees

Social Events for Patients

- Summer picnic
- Albert Hall carol concert
- Patients' Christmas parties
- Transplant games

For more details see AGM financial report page 7.

“Dark Ages” Transplant



Douglas House, Addenbrooke's first Renal Unit

Retired Nurse Myra Sankey has celebrated the 39th anniversary of her kidney transplant – making it one of the longest lasting transplants.

Myra, aged 70, from Galleywood in Essex, had her transplant at Addenbrooke's in 1970. Talking to AKPA Publicity Officer Tony Weaver, she commented that it now seems as if she'd had her transplant in the Dark Ages. She added, “But I have been very lucky and have been healthy ever since. Once I had it done there was no stopping me and I had boundless energy.”

The UK's first kidney transplant was carried out in Edinburgh in the early sixties. In the mid sixties Professor Sir Roy Calne started carrying out kidney transplants at the Old Addenbrooke's Hospital Renal Unit. This was situated in Douglas House, an annex of the hospital in Trumpington Road and the first primitive dialysis machines were used there to keep patients alive.

Myra, a long time member of AKPA, has now had two hip replacements as well as the kidney transplant but still enjoys an active life and last year celebrated her 70th birthday in Canada where her niece lives.

Kings Lynn; Tenth Anniversary – and More Capacity Needed

Kings Lynn satellite dialysis unit opened in 1999. And earlier this year, on March 17th, the unit celebrated its tenth anniversary with a party for patients and staff. The celebrations, which were organised by Unit Sister Viki Brindle had financial support from AKPA, and a good time was had by all.

The unit was built so that patients in the area did not have to endure the long journey to Cambridge or Norwich several times a week. But

it is now working at full capacity and new patients in the area are having to travel to Hinchingsbrooke for Dialysis.

Plans to expand the unit have been put on hold while a plan for future developments at the Queen Elizabeth Hospital is drawn up.

The AKPA Committee have written to the Hospital authorities recommending that expansion of the unit is given urgent priority.

AKPA Christmas Cards

AKPA Christmas cards will be on sale in *Cards for Good Causes* shops in the following places:

Cambridge

- Opens 16/10/2009
Unit 1–4 Cambridge Visitors Information Centre, Peas Hill (near Corn Exchange Entrance)

Bury St Edmunds

- Opens 14/10/2009
Tourist Information Centre, 6 Angel Hill

Saffron Walden

- Opens 6/11/2009
Saffron Walden Library, 2 King Street

Sudbury – Shop still to advise.

New 2009 designs also available by post. See enclosed leaflet.

Helpers needed to sell cards.

Please contact Val Slade
Tel: 01787 477070

Satellite Dialysis Unit for Cambridge?

Plans have been drawn up for a Cambridge Satellite dialysis unit in Trumpington, but it is unlikely to go ahead because of cuts to NHS budgets. However, it is hoped that reorganisation of the renal ward will provide more dialysis facilities at Addenbrooke's Hospital.

Richard's Great South Run



Transplant patient Richard Jarvis is planning to celebrate the fourth anniversary of his kidney transplant in style – by running the Great South Run. This is the first return to running for Richard since he was forced to pull out of the 10-mile race in 2004 because of his worsening health. His wife's donation of her kidney in 2005 means he is back to fitness and this year he is planning to raise money for Kidney Research in the hope of helping other people who are as ill as he was.

For more information about Richard's run or if you would like to sponsor him, please visit his online fundraising website at www.justgiving.com/Richard-Jarvis/

Sainsbury's Choose AKPA

The Sainsbury store in Brooks Road, Cambridge is giving much-valued support to AKPA this year.

First we were their Local Charity of the Month (for nearly two months in fact!), to which customers donate in wall-boxes near the checkouts. Staff at the store then supplemented this by fund-raising of their own; as a result a cheque for £150 was presented to AKPA outside the store on 14th June.

Our very friendly and helpful contact at the store has been Beverley Tumber, who explained that Sainsbury's are particularly interested in supporting charities with strong local connections. We have gratefully accepted the offer of an AKPA collection weekend from 20th to 22nd November, and there is talk of a possible Christmas raffle prize.

Our sincere thanks to Beverley and her colleagues.



From left to right, Richard Jarvis and Kacey Zinkambani (AKPA Committee members) receiving the cheque from Beverley Tumber (Store Administration) and Alan Bedwell (Store Manager).

Presentation to Eve



Richard Fossey and Eve Richardson

Eve Richardson has raised over four thousand pounds for AKPA by selling her paintings and organising fundraising events with her friends. She started seven years ago when her son, Philip was diagnosed with kidney failure and received dialysis at Addenbrooke's. Eve was recently presented with a certificate by Richard Fossey on behalf of the Committee in recognition of all her efforts.

Eve said that she couldn't believe she had raised that much money and felt quite proud. Adding that when she initially heard her son had kidney failure she thought there was nothing she could do to help. But then thought why not sell her paintings to raise money for Addenbrooke's Renal Department because there was always a need of some help.

Eve's son Philip received a transplant four years ago and now enjoys a full working life.

Bridget Runs Rome Marathon

Bridget Goldstone had a kidney transplant 18 years ago and as a thank you to her donor, and to raise money for AKPA, Bridget and her husband Baz ran the Rome Marathon in March this year.

She says that despite hot windy conditions and over 11 miles of ancient cobble stones she completed the run in 4 hours 48 minutes. Her husband Baz finished in 4 hours 22 minutes.

Together they raised £177.63 for AKPA.

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She says that "Since my transplant I have enjoyed many new opportunities including getting married on skis on a mountain in Colorado, abseiling Addenbrooke's, representing Great Britain at the World Transplant Games and retraining as a sports therapist after 24 years in Banking." Adding, "I suppose what I am trying to say is life is good and I am very grateful for the Gift of Life".

Our thanks to Bridget and Baz.

Club Theo Donation

AKPA were selected to receive a donation of £50 from Club Theo. Theo stands for **To Help Each Other**. And it was set up to support and help bereaved people start a new social life.

Club member Mrs Moira Hunter of Great Cornard in Suffolk chose AKPA to receive the donation. Moira's late husband David was a transplant patient and they had both been involved with AKPA activities in the past.

Our thanks to Moira and Club Theo.

Howard and Veronica's Ruby Anniversary gift to AKPA



When transplant patient Howard Jarvis and his wife Veronica celebrated their 40th wedding anniversary with their friends and family in July this year, they asked their guests not to bring any gifts. Instead they asked for donations, which they wanted to share between two causes very close to their hearts: Breakthrough Breast Cancer & Addenbrooke's Kidney Patients Association.

The wonderful generosity of the people who came to celebrate with them means that these two causes will divide more than a thousand pounds between them.

Howard, who was a dialysis patient in both St Albans and Norwich before having a dialysis machine installed at home, was very keen that any money raised should go towards something that would benefit both the staff and other patients at Addenbrooke's.

He received a transplant there in 2006 and formed a strong relationship with many staff on the Transplant Ward. "I was made to feel like one of the family and received the most excellent level of care," he explained, "so I would love to be able to help make life better for both the staff and other patients who follow me through the ward. I hope that our families' and friends' generosity allows us to make that happen."

Chris Completes Another Gruelling Alpine Run for AKPA

"The longer the run, the more I enjoy it!"

When AKPA supporter Chris Law says these words, you really believe him.

At the age of 50-something, he recently took part in his 5th consecutive 'Bielerlaufstag'. Chris describes this event held near the Swiss town of Biel (or Bienne) as "the mother of all 100km runs." No, that's not a misprint; it really is that long! The course is extremely hilly and rises to 400 metres. About 4000 runners from all over Europe and Africa take part. The entries this year included two 76 year olds, a man and a woman. The 'off' is given at 10pm, and there are service and first-aid points every ten kilometres. This year Chris knocked nearly one hour off his last year's time. A steady pace is an important strategy, but making sure you have decent nourishment is also essential. Chris has got to know some British Army servicemen who also do this run, and declares that their bacon sandwiches and coffee are a great incentive.

Last year, Chris decided to raise funds to split equally between the MS Society in memory of his late father, and for AKPA in recognition of his own employer's long struggle with kidney disease. We



Chris Law (centre), with Robert and Moira Boughtwood who run the West View Marina Chandlery

were therefore delighted to receive a generous and unexpected donation; but this year Chris has been training even harder. As well as the Swiss run, he 'rowed' the equivalent of 100kms on a machine at the LA Fitness club in Huntingdon. That row took 11¼ hours!

To cap it all, Chris also organised a very successful raffle. The AKPA share of all this fundraising came to £665, and we offer Chris our warmest thanks for his dedication and generosity. He is already working on new physical and mental challenges for the future. He told us that on his days off from work at Westview Marina in Earith, he is most likely to choose to spend his time at ... the gym!

Cambridge Street Collection

AKPA's annual collection in the city centre again took place in late June. For the last few years the weather has been indifferent, and Saturday June 27th was true to form. Our collectors had an eye on the skies as well as on the passers-by, but in the end got by without much need for brollies or rainproofs.

People donated generously, so that our total was £294. This was almost the same amount as in 2008, so little sign of the credit crunch there! A further £81 was raised at a wedding party in Barbara Irving's family, for which our grateful thanks.

Thank you to our loyal band of collectors: the two Barbaras, Paul and Julie, Brian and Monica, Ron, Lib, Dorinda and Nicky, Jayne and Michelle, and Michael.



Jayne Wyatt, Michelle and Jenny

Beverly's Marathon

Beverly Padget of Great Cornard in Suffolk completed the Flora London Marathon in April this year and raised £432 for AKPA.

Our thanks to Beverly for an outstanding effort.

AKPA Annual General Meeting July 2009

AKPA Chairman's Report – Val Slade

Our thanks to:

Our thanks to our medical colleagues who support our committee meetings, sharing their knowledge of patient needs and developments. To our Patron, Lady Susanne Walker who has given us much hands-on support, which we greatly value. And to Alan Craig our National Kidney Federation representative who keeps us in touch with national issues.

A big thank you to all our fundraisers. To Barbara Vining and her helpers running their craft stalls. To all those who help in the sale of Christmas Cards; the volunteers in the Cards for Good Causes shops; people who sell our cards in their own venues and a special thank you to Dorinda Ray who deals with our postal sales and stalls in the hospital.

To our professional staff; Jenny Ridgeon our committee secretary, without whom, I for one would be lost. It doesn't matter how many times we change our minds about dates and venues she comes back calmly with alternatives. Thank you also to Polly Connell who keeps our books and gives us a brilliant service, leaving our accountants with an easy task.

The Committee

Committee meetings are always well attended whatever the weather or distance people have to travel and I appreciate the support of such a brilliant group.

Tony Weaver took on the post of Vice Chairman and publicity and we have had good coverage on both TV and in the newspapers during the past year.

Jayne and David Wyatt revived the *200 Club* and have worked very hard to get it back to full strength.

Michael Moore continues to encourage us to shake a collecting tin and find new venues to collect, despite a busy year with family business. He was also the driving force behind the new patients' handbook.

Brian Wood continues to do sterling work as our Treasurer and still finds time to produce our *Newsflash*.

Richard and Lorna Jarvis are continuing to build and update the website. It is not difficult to impress me when it comes to IT skills, but I do believe they are doing an exceptional job.

Andrew Collins our Deputy Treasurer has been sorting out Gift Aid and has now taken on the job of Company Secretary.

A special thank you to all the committee members.

Welfare

For me our patient welfare role is one of the main reasons I serve on the committee. And I must thank **Barbara Irving** our Renal Social Worker for doing a wonderful job. It is on her advice that we give welfare and holiday grants to patients and their families. We have recently increased the level of our grants as in the current financial climate need for help may increase.

Some Events of the Past Year

Tony and I attended the opening of the new Hinchingbrooke unit and were greatly impressed with what we were shown. We have already funded some equipment for this unit.

We also funded essential medical equipment needed by the Renal Department. (details of equipment purchases appear in the financial report)

In June we were able to show David Howarth our patron and local MP around the unit here. It gave us an opportunity to discuss the perennial concerns around hospital transport and the cost some patients incur with prescription charges. Unit staff explained the different processes of dialysis and he met patients and asked many questions.

We distributed a dialysis cookery book "Food for Thought" to all dialysis patients. And reprinted the AKPA "Skin Cancer leaflet" which continues to be in great demand.

We funded West Suffolk and Kings Lynn dialysis units trip to the Albert Hall Carol Concert and funded patients' Christmas parties in all the units. Again, we supported patients taking part in the UK Transplant Games.

Fundraising and Donations

We had a very profitable Christmas raffle and sold our Christmas cards in CFGC shops and other venues. I have ordered cards for the next two years and would be most grateful if anyone can suggest any additional selling points. Do encourage your friends and families to purchase them; they not only make us money but also keep us in people's minds.

We have benefited this year from many legacies and donations in memory. I would like to take this opportunity to express our gratitude for the selfless way people consider as at such difficult times. Their support forms the mainstay of our finances. Thank you always feels inadequate, but we are always most grateful.

Committee Retirement

Sadly, Richard Fossey has decided it is time to retire from the committee. We will miss him greatly. When he came across a patient problem he has been like "a dog with a bone" never letting go until he had done all he could to bring it to everyone's attention. I have been in awe of the way he has selflessly turned up at meetings regardless of his health or the weather. He received and answered so many letters and had so many useful contacts.

Of course he was best known for the sterling work he put into running the raffles; two a year until recently. He has a persistent way about him that makes it difficult to refuse when he asked for donated prizes, that together with his hard work, charm and down to earth approach to things makes him irreplaceable. I can only guess at the amount of money he has raised over the years, but many people have reason to thank him. The committee will be losing a good friend and we are sad to see him go.

We cannot mention Richard without mentioning his wife Josie, we owe her a debt of gratitude for supporting Richard's AKPA work, for housing raffle prizes and folding endless raffle tickets. Thank you both.

AKPA Annual General Meeting July 2009

AKPA FINANCIAL REPORT 2009

Income:

Our income for 2008/09 totalled £52,489; slightly less than last year but in line with other recent years. Again, a large proportion came from legacies and 'in memory' donations, with income from these sources totalling £17,476. This represents around a third of our total income and reflects the sad fact that we have lost more of our loyal supporters, some of whom were involved in the very early days of this organisation. However, many of those donations represent a "thank you" for the dialysis and transplants that extended and enhanced their lives.

The majority of our income still comes from the hard work and generosity of our dedicated fundraisers who are mostly patients and their families. This income, totalling over £22,000, comes from raffles, Christmas cards sales, craft stalls, bric-a-brac sales, collecting tins and donations and enables us to provide support for patients and their families who are experiencing real hardship as a result of renal disease. Without this regular source of income it would be impossible to continue with these commitments. Thank you to everyone who raised money for us.

Expenditure:

Our total expenditure was £45,067, again less than last year.

£17,488 of this was funding for essential medical equipment needed by the Renal Department and not supplied by the NHS. This included funding an ACT (Activated clotting time) machine for the new Hinchbrooke Dialysis unit at a cost of £5,000, a Dinomap machine to improve monitoring of blood test results in the Dialysis Centre at a cost of £450, a handheld Ultrasound

scanner to improve the placement of fistulas in the Renal ward at a cost of £500 and a Home Haemodialysis machine at a cost of £10,900. We also funded comfortable chairs for dialysis patients' training sessions in the Dialysis Unit at a cost of £258.

We printed a new AKPA handbook for patients and their families with information about renal disease and treatment, and re-printed our nationally acclaimed Skin Cancer leaflet at a total cost of £1,078. Also, in order to inform and educate patients, the Association sponsored patients to attend the annual National Kidney Patients conference in Warwick with grants totalling £200, and supported contestants in the National Transplant Games with grants totalling £1,225.

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 provide funding for the Renal Social Worker, a service that is highly valued by staff and patients, and continued to give welfare and holiday grants to sick and needy patients and their families. Our total expenditure on these worthwhile causes amounted to £16,000.

We also gave a grant of £512 for a trip to the Albert Hall Christmas Carol concert for dialysis patients treated at the West Suffolk satellite dialysis unit and a grant of £200 for a patients' party to celebrate the 10th anniversary of the opening of the Kings Lynn Unit

Spending Plans:

In the 2009/10 financial year, the committee proposes to fund the purchase of a completely updated television system for Addenbrooke's

Dialysis Unit to better provide entertainment for patients undergoing long haemodialysis sessions; the present system is outdated and unreliable. We estimate this will cost between £20,000 and £30,000.

We have also offered to provide £4,950 part funding for intravenous pumps for renal patient treatment in the new Patient Day Centre.

Due to more generous funding by the NHS during the last year we were not called upon to provide as much funding for medical equipment as we expected. The computer monitoring system for Haemodialysis machines and the Ultra sound scanner both mentioned in last year's report, were funded from other sources. The combination of lower than expected funding requirements and the receipt of several large legacies means that our reserves are still fairly high and we will be actively seeking other projects to fund in the current financial year.

Administration Costs:

Despite the ever-increasing burden of financial regulation, insurance and form filling, our administration costs remain very low. At £4,689 they represent only 10% of our total annual spending.

The Treasurer's job would be very difficult without the dedication and skills of our two paid, professional staff, book keeper 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.

Brian Wood, AKPA Treasurer

Following two pages contain reports given at the AGM of exciting new developments in medical treatment at Addenbrooke's.

Annual General Meeting Medical Updates

Gene Genie – It Could Be You

Prof Fiona Karet, Renal Geneticist

About 12% of all patients attending Nephrology outpatient clinics at Addenbrooke's have a primary renal genetic disorder – meaning that it can be inherited and this may raise the possibility of family members being at risk of the same problem.

We know quite a lot about some of these conditions – such as polycystic kidney disease, Alport's syndrome and Gitelman syndrome – but in the rapidly expanding era of gene discovery, more are being identified. For example, what was once recognized only as 'chronic kidney disease with small (or shrunken) kidneys' may sometimes be due to mutations in a recently discovered gene called UMOD. A mutation in UMOD can be passed on to children in the same way as PKD can be inherited.

Here at Addenbrooke's, we have a more-or-less unique clinic in national terms, the Renal Genetic and Tubular Disorders (RGTD) Clinic. This is dedicated to the care of patients with both known inherited conditions and

also those that seem to run in families but where the diagnosis is unclear.

It's a one-stop shop where you will receive both renal care and genetic advice. If you have familial kidney stones you can also see a urologist at the same visit. Where we can, we will offer to perform genetic testing. This is not yet possible for all disorders, but we're expanding the list of available tests, and also doing research to try and discover more genes that cause kidney diseases. If there is an inherited condition in your family, we can also see other family members for investigation, care and/or advice.

Genetic testing is nothing to be afraid of – it can firm up a potential diagnosis; allow us to provide more tailored medicines and management; and may be useful for donor assessment in living related kidney donation. Your DNA is obtained from an extra tube of blood when you have your routine blood tests. Of course it's stored safely and confidentially. DNA is already used for tissue typing.

We are also undertaking research through the RGTD clinic, because we don't know as much as we could about even common conditions like PKD – for example, why does some people's kidney function deteriorate rapidly while others are only mildly affected? We may therefore ask your permission to look at notes, blood and urine. It won't mean any extra visits to hospital!

If you think your kidney disorder affects other members of your family, feel free to ask for an appointment with us if we don't already know you. Alternatively we may be able to come to you if you are an Addenbrooke's haemodialysis patient.

Contacts – Phone :

**Sister Caroline Robinson, on 01223 348745
or Sara Horncastle (PA) on 01223 256318**

Email: caroline.robinson@addenbrookes.nhs.uk

Blood Pressure – How Low Should We Go?

Dr Laurie Tomlinson, Renal Specialist Registrar

Dr Tomlinson described her research work on blood pressure in Chronic Kidney Disease (CKD).

She began by explaining that Chronic Kidney Disease (CKD) mainly affects older people. Around one quarter of people aged 70–80 are affected; a study involving one million people in the USA showed that as kidney function reduces, the risk of heart attack or stroke goes up, even after taking into account age, diabetes and smoking.

What Can Be Done?

She listed actions that can be taken to alleviate this, such as; early detection;

specific therapies; treatment for risk factors such as heart disease and strokes at an early stage. Blood pressure treatment is very important but she explained there are different measurement methods and guidelines.

Which BP Matters?

Research showed that high blood pressure affects people in different ways and results may differ between home and clinic. Twenty four hour ambulatory blood pressure taken at home may differ from measurements at clinic, also controlled blood pressure is more common at home.

Blood pressure can be low enough to cause health problems such as fainting and dizziness and it is important to treat this to avoid complications.

Blood Pressure Study

A study is currently being carried out to establish:

- How patients feel about blood pressure treatment?
- Are side effects common?
- Will patients feel better if their blood pressure treatment is based on home readings?

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Please let Dr Tomlinson know if you would like to be involved in the study – the time commitment is minimal.

Dr Laurie Tomlinson

Clinical Pharmacology Unit
ACCI, Level 3, Box 110
Addenbrooke's Hospital
Cambridge CB2 2QQ
01223 336 806

Questions

- Q** GP checks – how useful?
- A** GPs are now being targeted to look at kidney function when treating high blood pressure.
- Q** Self checking at home- how useful?
- A** Checking blood pressure at home can be useful – make sure your blood pressure monitor is checked

by the hospital or GP, and ensure the cuff is always positioned above the elbow.

- Q** Are researchers interested in blood pressure post transplant?
- A** It would be useful to add to the study. If there have been long standing problems there may be changes to blood vessels which could affect the patient.

Developments in Living Donation

Jim O'Sullivan, *Transplant Co-ordinator*, – gave us an update of developments in the living donation kidney transplant programme at Addenbrooke's.

Jim opened by explaining that in the UK Living donor transplants have gone from 589 in 2005–2006, to 910 in 2008–2009 and now represent more than one in three of all kidney transplants. Over forty living donor transplants were performed at Addenbrooke's last year and the renal department now has three living donor transplant co-ordinators.

Living donation is an increasingly important option when seen against the background of falling numbers of cadaveric donations and a rising waiting list.

With the aid of graphs and slides Jim went on to explain the procedures for living donation. The risk to the donor must be low; they must be fully informed; their decision must be entirely voluntary; there must be a good chance of a successful outcome.

The donor has to undergo testing in order to establish suitability, starting with an assessment to establish they have two healthy kidneys and are fit for a major operation. Then tests for medical conditions that will prevent donation. For example, CJD, HIV, diabetes, obesity, high blood pressure or major heart or lung disease.

Blood Group and Tissue Type

He then explained that one of the main factors for successful living donation is achieving compatible blood groups and tissue types. There is a 36% chance that any two individuals are blood group incompatible and even more variations can occur in tissue types.

This is further complicated by the fact that many patients awaiting transplants have been sensitised and have developed

antibodies against transplanted tissues. This sensitisation can be due to such things as blood transfusions, previous transplants or pregnancy.

Antibody Incompatible Transplantation

Over the last few years procedures have been developed to allow sensitised potential recipients to be transplanted. Desensitisation is a process by which pre-formed antibodies are removed from the recipient as a prelude to transplantation. This is normally done by Plasma Exchange, – a filtering process similar to dialysis, plus early immunosuppression with Rituxmab and other drugs. These processes are not suitable for everybody. It takes longer to prepare for the transplant with more chances of complications. Out of the sixteen desensitised patients transplanted at Addenbrooke's so far, one has failed but the rest are still working. Eighteen more are planned.

Paired Donation

This is another method to increase the success of live donation. Where a close relation, friend or partner is healthy and able to donate an organ but is not well matched to the potential recipient, that couple can be matched to another couple in a similar situation so that both people in need of a transplant receive a well-matched organ. Pooled Donation is a similar arrangement between more than two couples.

A logistically complex National scheme, which relies on setting up simultaneous transplants has been running for three years. Matching runs every 3 months and Hospitals are notified of matched pairs. Cross-matching is performed and Human Tissue Authority assessment and approval obtained. Recipients are then suspended from the deceased donor list; an operation date is agreed with

transplants scheduled simultaneously. Jim ended with recent statistics from the scheme – as follows;

**UK Paired Donation
Jan 07 – April 09**

- 29% of 226 enrolled patients identified for transplant (Limited by high levels of sensitisation and few A, AB blood group patients listed)
- 44% identified transplants did not proceed
- 26% of patients removed from scheme
- 81% due to other transplant
- 26 (12%) of enrolled patients transplanted (all 2-way exchanges)

**Addenbrooke's Paired Donation
Jan 07 – July 09**

- 22 pairs involved in the scheme
- 6 recipients transplanted (27%)
- 1 currently in planning
- 9 recipients received other transplant – cadaveric or desensitisation

Questions

- Q** Why suspend patients on the paired programme?
- A** They are only suspended when it is confirmed to be going ahead. If they remain on the list one person might get a kidney which will break the chain.
- A** Is there an age ceiling for donors?
- Q** Each case is decided on its own merits. Older donors donate to older recipients. It is possible to start the process then take a biopsy before transplantation, but there is no reason not to use kidneys from older donors.

Charities Fund Conference Delegates

Addenbrooke's nurses Stephanie Smith and Zoe Toombs attended the British Transplant Society Conference in April this year with joint funding from AKPA and ALTA.

Their report contained several subjects of interest to kidney patients such as the **Ethical debate on Organ Donation** with Mr David Mayer and Mr Chris Rudge. In this debate challenging ethical scenarios experienced by Donor Co-ordinators were put to delegates and the ethics debated by all in the room.

Situations debated mainly concerned donor families only agreeing to donation if certain demands were met. For example, one family would only give consent if the donor co-ordinator could guarantee their relative's organs would only be transplanted into a white recipient.

In another a relative of the deceased, who was on the transplant waiting list and would only agree to donation if he received his son's kidney and others could receive the rest of the organs.

This debate produced a great deal of interest and highlighted the ethical dilemmas faced by Transplant co-ordinators.

Safety first – critical dose drugs in transplantation symposium discussed possible therapeutic differences between different brands of the same drug. Before approval new brands must be tested to prove they are bioequivalent to existing brands. However, the speaker suggested that many brands that are technically bioequivalent can still produce different levels within the blood.

Many things affect the bioavailability of a drug – these include the types of inert additives used such as sweeteners and colours. Whether a tablet is taken with or without food and the type of food or drink it is taken with.

At present we do not have many different brands of immunosuppression in the UK and at Addenbrooke's only Neoral (cyclosporine) and Prograf/Advagraf (tacrolimus) are used.

However, there are several different brands in the USA so it is possible new brands will be approved here.

The speakers were not promoting one brand over another; rather they were suggesting that switching between brands or mixing brands could result in unstable levels of immunosuppression. Also, that GPs, patients and pharmacists should be aware of these risks and brand specific (rather than generic) immunosuppression should be prescribed and dispensed.

Just to note, the symposium was sponsored by Astellas and Novartis so the speakers may have been a little biased towards brand specific prescribing!

These conferences provide valuable insights into the developing world of transplantation and ensure staff are kept abreast of the latest developments.

Stephanie and Zoe both thanked AKPA and ALTA for their support.

Important Information About Your Medication

The National Kidney Federation (NKF) has advised AKPA of recent cases of patients being offered Advagraf instead of Prograf (or vice versa) in error by GPs or pharmacists. This highlights the importance of patients ensuring that changes to their medication should only be made by their Transplant Surgeon or Consultant Nephrologist.

Current drugs are very complex and, even though one make of drug may appear to contain the same or similar drug to another (in the above case the drug being tacrolimus) the formulations can be very different and very harmful if taken wrongly.

The NKF states very clearly that if the drug you have been prescribed or are given is not identical to the drug you usually take DO NOT TAKE IT without getting advice from your own Renal Consultant. This applies even if the person is your GP, pharmacist, nurse or other physician.

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 MGeeney – 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 200 Club Monthly Draw – Winners

FEBRUARY

First prize £37 • No 79
R Buckle, Lindsell

Second prize £18 • No 352
Mr & Mrs R Burton, Weeting

Third prize £11 • No 120
L Hackman, Yaxley

MARCH

First prize £40 • No 151
J Finch, Bacton

Second prize £20 • No 164
G L Rose, Cromer

Third prize £12 • No 124
G A Dickerson, Gamlingay

APRIL

First prize £41 • No 340
T Angliss, St Neots

Second prize £20 • No 160
R Fossey, Bedford

Third prize £12 • No 320
J Maniscalco, Peterborough

MAY

First prize £44 • No 215
H Ingram, Wisbech

Second prize £22 • No 317
T Weaver, Saffron Walden

Third prize £13 • No 190
V Walker, Thaxted

JUNE

First prize £44 • No 324
P Burton, Huntingdon

Second prize £22 • No 90
R Ward, Wisbech

Third prize £13 • No 145
L Viner, Gt Dunmow

JULY

First prize £48 • No 172
J Dilley, Baldock

Second prize £24 • No 144
R Cookson, Cambridge

Third prize £14 • No 197
A K Baker, Huntingdon

AUGUST

First prize £48 • No 226
E Howes, Colchester

Second prize £24 • No 348
T & P Ayres, Godmanchester

Third prize £14 • No 122
J Wyatt, Weeting

SEPTEMBER

First prize £49 • No 127
Aylmer, Penrith

Second prize £24 • No 99
Ribnell, Wisbech

Third prize £15 • No 209
Tosic, Malden

A big thank you to all those taking part in the *200 Club*. Numbers of shares sold have steadily increased since the restart in January, we only need 6 more to hit the magical 200. Hopefully we can carry on and increase the numbers even more, don't forget, the more shares sold, the more money raised to help kidney patients and the greater the prize money. In addition to the monthly prize draws the Annual Grand Prize Draw is well on the way for one lucky winner to win over £100 in December.

You can join at any time by downloading an application form from the website, picking one up from AKPA notice boards in the clinics and dialysis centres, e-mailing 200club@akpa.org.uk or contact
Jayne & David Wyatt,
7 Castle Close, Weeting, Brandon, Suffolk, IP27 0RG

New AKPA Raffle Promoter

Committee member Ron Cookson has taken over running the AKPA Xmas Raffle. As usual there are generous cash prizes plus many excellent prizes donated by local businesses.

The draw will take place at the Dialysis Centre on 9th December.

Tickets are enclosed with this *Newsflash*.

Please support AKPA by buying as many tickets as possible and selling some to friends and neighbours.

For more tickets please contact:
Ron Cookson – Tel: 01223 233631

NKF



Helpline

Tel. 0845 601 02 09

E-mail:

helpline@kidney.org.uk

Website:

www.kidney.org.uk

Are You a Member of AKPA?

To join or receive more information about AKPA please complete the form below and return to
**AKPA, PO 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*

Donor Charities Merge

Recently formed *Brightside of Life* charity have merged with The British Organ Donor Society (BODY). And from July this year have taken over the Organ Donor Bus which will be available for bookings at organ donation and transplantation events.

For more information do not hesitate to contact:

Mr Ray Pearson

E-mail: thebrightsidecharity@googlegmail.co.uk. Tel: 07833 976834.

Our website address is:

www.akpa.org.uk

It contains a large amount of information about AKPA and many other topics of importance to renal patients.

You can e-mail us at:

info@akpa.org.uk

For general enquiries to the AKPA.

fundraising@akpa.org.uk

For help with your fundraising event or to have an AKPA sponsor form sent to you.

questions@akpa.org.uk

For questions relating to kidney disease – we will try to forward these to somebody who can help you.

webmaster@akpa.org.uk

For suggestions, comments or requests for the website.

Remember we are happy to advertise your fundraising event if you can supply us with a photo.

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 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

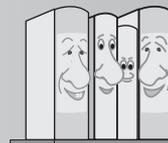
or by e-mail at roger@anchor100.freeserve.co.uk

Books include:

Factual Information on Renal Failure, 'in easy to understand language'.

Also, diet and drugs books, and the most popular and requested:

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



Roger Ward.

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