

# 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.

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## 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 Hinchingbrooke 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](mailto: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.