



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

A MEMBER OF THE NATIONAL KIDNEY FEDERATION

## AGM Demo of New Scanner



Dr Eoin McKinney, Renal Specialist Registrar, is seen here demonstrating the scanner at the AKPA AGM in July, ably assisted by volunteer 'patient' Renal Nurse Specialist Nicky Moncrieff.

The purchase of the scanner was made possible thanks to an extremely generous bequest to AKPA from Miss Doris Sampson who sadly died at the age of 95 last year. Doris lived in Worthing but she had family contacts in this area and had been a keen supporter of AKPA for many years.



Miss Doris Sampson

Scanning 'Patient' Nicky Moncrieff

The Renal Team has recently taken delivery of a brand new ultrasound scanner, funded by AKPA. This state-of-the-art equipment will improve the speed and accuracy of two routine procedures in the department – inserting neck lines for haemodialysis patients and taking renal biopsies.

### Dates for 2006

October 3 – Tuesday  
AKPA Stall in Outpatient Entrance

October 13–15  
NKF Annual Conference

November 9 – Thursday  
AKPA Stall in Outpatient Entrance

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## Hinchingbrooke Satellite Unit – Serious Delays

The summer opening planned for the new Addenbrooke's satellite dialysis unit at Hinchingbrooke Hospital has been seriously delayed.

The logistical problems responsible for the delay have now been resolved and Dialysis Centre management are optimistic that the unit will be open in

early 2007. They report that negotiations with potential partners to run the unit are back on track.

Delays in opening the unit have meant more pressure on Addenbrooke's Dialysis Centre where a record number of haemodialysis patients are now being treated. The centre is coping with the

increased demand by using four dialysis machines set up on ward C5, the renal ward at Addenbrooke's.

Lack of available NHS funding means the unit will open one machine short of maximum capacity. AKPA have pledged to raise £15,000 to start the new unit off with the maximum number of machines.

# Marion Retires from AKPA Committee



*Presentation to Marion*

After serving more than fifteen years on the AKPA Committee Marion Cheetham has decided to take a break and retire from committee work, although she hopes to return at some time.

At the AGM Marion was presented with a magnificent floral bouquet by Vice-Chairman Val Long who gave a tribute to Marion's long and distinguished service to AKPA.

During her time on the Committee Marion held posts critical to the success of AKPA; starting as Committee Secretary, then Vice Chairman, followed by five years as Chairman and latterly Administrative Officer. Her knowledge and expertise enabled the committee to function smoothly and was vital to the successful completion of dozens of

important projects, such as the dialysis equipment appeal, dialysis centre televisions and air-conditioning appeal.

Marion was also involved in many important fundraising events including a Golf tournament jointly organised with her husband Michael, as well as many social events such as AKPA Christmas Parties and the Summer Barbecue.

Marion's personal and family experience of dialysis and transplantation gave her the insight into the needs and problems of Kidney patients. She led the AKPA campaign for transplant clinic nurses and the skin cancer screening programme.

The AKPA Committee will sorely miss Marion's knowledge, experience and enthusiasm and we hope she enjoys a well-earned break.

## Freemasons Provide Flying Start for Hinchingsbrooke Machine Appeal

Our appeal to raise £15,000 for an extra dialysis machine at the new Hinchingsbrooke Satellite unit got off to a flying start with a generous donation of £1,000 from The Province of Cambridgeshire's Charity Care and Relief fund.

This benevolent organisation is a branch of the Freemasons whose members are predominantly Cambridgeshire people who quietly support local charities and members of the community.

Our thanks to them for their prompt and generous help.

## NKF Helpline



**Tel. 0845 601 02 09**

E-mail: [helpline@kidney.org.uk](mailto:helpline@kidney.org.uk)

Website: [www.kidney.org.uk](http://www.kidney.org.uk)

**Helpline**

**National Kidney Federation**

**6 Stanley Street, Workson**

**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.

**Gayle Loader** – covers ward C9 and transplant clinic.

**We can be contacted on 01223 216655.**

### **Queen Elizabeth Hospital – Kings Lynn**

**Kathryn Richardson** – 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**

# National Transplant Week *Takes to the Skies*



Wendy Smeeton and Paul Robinson



Mr Chris Watson, Consultant Transplant Surgeon

July's National Transplant Week was launched by Addenbrooke's Transplant Unit Staff with the message 'You don't have to be a hero to save lives!'

Wonderwoman (Wendy Smeeton) and Superman (Paul Robinson) launched three hundred balloons from Parker's Piece marking the start of a week's events.

Mr Chris Watson, Consultant Transplant Surgeon, supported the balloon launch and his presence was much appreciated by the staff and transplant patients there to give support. Mr Watson said, 'We want people to know that potentially anyone can save a life by signing up to the NHS Organ Donor Register. The week's activities are a great way to get this message across, so we would urge the public to come along to our displays and find out more about how organ donation can transform lives.'

The week of publicity celebrated the lives that have been saved by the gift of organ donation. Staff from the Transplant Unit organised an excellent photo display of patients enjoying leading normal lives after their transplant. The information stand was on view at the hospital and in the Grafton Centre, and transplant patients were on hand all week to chat to interested members of the public.

Alan Craig



The Information Stand in the Grafton Centre, Cambridge

*We must apologise for not including this touching story in our last edition. The newspaper cutting sent to us went astray but Carole's mother, Mrs Rosa Bates kindly provided us with these details.*

## Boys' Tribute to Their Mother

Two brothers, Daniel and Christopher Vinson raised over £300 for AKPA, in memory of their mother, Carole who died, aged 41 in September 2004.

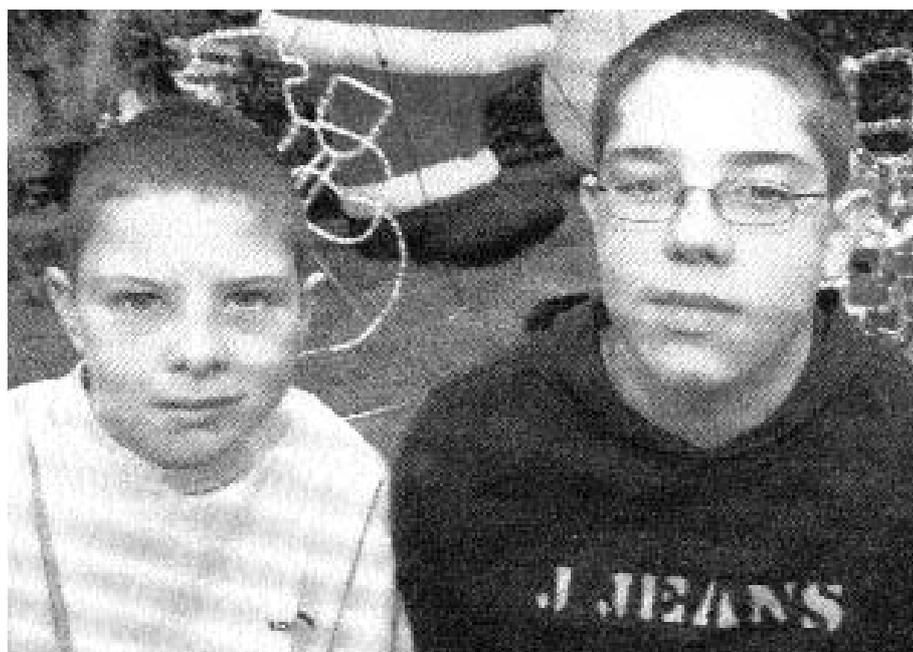
Daniel, 13 and Christopher 15, decorated their home in Littlebury with festive lights over the Christmas season and managed to raise £332 in donations from passers-by who stopped to admire the display.

Carole had kidney failure in 1985 and received a transplant in 1986; sadly the transplant failed after ten years and Carole had to return to dialysis.

The boys' grandmother Mrs Rosa Bates thanked everyone who donated, saying that 'people's support for the lights was fantastic; I think Carole would have been very proud of her sons they said they would do this and they kept their promise.'

A weeping silver birch tree was also planted by the Littlebury Recreation Committee in memory of Carole who was well known and very popular in the area.

Our thanks to Daniel, Christopher and Rosa.



## Sally's Marathon Pays Off

Months of training and dedication paid off for Sally Reynolds when she completed the London Marathon in April this year. Sally was running to raise funds for Addenbrooke's Transplant Unit's Antibody Removal Programme.

Antibody removal is sometimes necessary when patients need a second transplant after failure of their first. However, the treatment is not yet available at Addenbrooke's through lack of funding.

Sally donated a kidney to her son Ollie when he was 12, now ten years later Ollie is back on dialysis and needs a second transplant. His father Peter has offered to donate a kidney this time, but first Ollie needs the antibody removal treatment to stop him rejecting the new kidney.

AKPA supported Sally's run and Richard Fossey helped to organise sponsorship at the Dialysis Centre. The total raised was **£8,300**.

The appeal to support the Antibody Removal Programme is being co-ordinated by Transplant Surgeon Mr Chris Watson and funds are still needed to get it underway.



*Sally Reynolds competing in the London Marathon*

## Cambridge Street Collection

A record number of collectors turned out for the annual Cambridge Street Collection on the 24th June and despite early drizzle and the disruption of the major construction work in the city centre, they managed to collect £345.

Once again the street collection not only raised money but also provided a good public relations exercise, with many people stopping to chat about friends and relatives with kidney problems and finding out about the work of AKPA.

The collection was again organised by Michael Moore and our thanks to him and all the collectors:

Anne-Marie Moore, Mary Gibbs, Brian Wood, Monica Taylor, Michele Satchwell, Malcolm Peck, Jayne and David Wyatt, Brian Martin, Barbara Irving, Janet Mann and Barbara Webb.



*Sally Reynolds being presented with a certificate by Tony Weaver at the AGM in recognition of her achievements*

## Glaxo Tops Up Appeal Fund

We were very pleased to receive a donation of £2000 from the Glaxosmithkline *Making a Difference* charity award scheme.

We were chosen to receive the award because the three cyclists who completed the Lands End to John O'Groats charity cycle run for us were employees of Glaxo. Their company supported the cycle run and judged our Dialysis Chairs Appeal a cause worthy of extra funding.

Our thanks to Glaxo and to Jamie, Simon and John for recommending our appeal.

## Barbara's Stalls

A big thank you to everyone who supported Barbara Vining's stall in outpatients on May 11th by buying, donating or helping on the day. The stall raised £209 for AKPA.

Don't forget there are two more stalls coming up on Tues. Oct. 3 and Thurs. Nov. 9th, if you are in the area please take a look.

# AKPA SUMMER RAFFLE 2006

**Drawn at the AGM, 7.00 pm – 28th June 2006  
in the David Dunn Room at Addenbrooke's Hospital**

### List of Prize Winners

- |                                      |                            |
|--------------------------------------|----------------------------|
| 1. Cash £300                         | Read, Newmarket            |
| 2. Cash £150                         | Waspe, Needham Market      |
| 3. Cash £100                         | Tigue, Kings Lynn          |
| 4. Tesco vouchers £30                | Clark, Felixstowe          |
| 5. Premier food hamper               | Neil, Addenbrooke's porter |
| 6. Mini hob                          | Lucas, Dialysis            |
| 7. M&S vouchers £25                  | Ogden, March               |
| 8. Tesco vouchers £20                | Maniscallo, Dialysis       |
| 9. Two mugs                          | Rignall, C9                |
| 10. Bottle of wine and £10 voucher   | Owen, Brandon              |
| 11. Garden centre voucher £10        | Humberstone                |
| 12. Brut and truffles                | Brady, Oundle              |
| 13. M & S vouchers £15               | Morris, Dialysis           |
| 14. Oils, candles, cards and voucher | Cooper, Tiptree            |
| 15. Sainsbury voucher £10            | Warbey, Dialysis           |
| 16. Garden centre voucher £10        | Fawcett                    |
| 17. Two mugs                         | Whitmarsh, Winchester      |
| 18. Mickey Mouse                     | Bacon, Ely                 |
| 19. Tesco vouchers £20               | Falvey, Thornbury          |
| 20. Gardening pack and wine          | Anderson, Kings Lynn       |
| 21. Car accessories and wine         | Knight, Saffron Walden     |
| 22. Toiletries                       | Falvey, Thornbury          |
| 23. Carrier bag and £10 voucher      | Hill, Peterborough         |
| 24. M&S voucher £10                  | Graves, Saffron Walden     |
| 25. Wooden farm and sherry           | Bowdidge                   |
| 26. Vodka                            | Morris, Dialysis           |
| 27. Wine and chocolates              | Bell, Sawston              |
| 28. 21" television                   | King, Bedford              |
| 29. Lady's shawl and belt            | Owen, Brandon              |

**The raffle net surplus amounted to £1100 and was accompanied by donations totalling £400. Congratulations to the winners. Thank you to everyone who contributed, bought tickets or donated prizes. Thank you all.**

*Richard Fossey – Raffle Promoter*

# Another Successful PKD Information Weekend

The PKD Charity is an organisation set up recently to help patients with Polycystic Kidney Disease. On July 1st and 2nd Susan Mealing, Peter Last, and Alan and Wendy Craig from AKPA attended the third annual PKD Information Weekend held at Southmead Hospital Centre for Medical Education in Bristol.

Tess Harris, PKD Charity Chairman, warmly welcomed everyone to the weekend and explained the aims and achievements of the charity. The PKD Charity is the only charity in the UK dedicated to the concerns of people affected by Polycystic Kidney Disease – the world's most common life-threatening genetic condition. The Charity's aims are to:

- Provide information, advice and support to those affected by PKD.
- Fund research into determining the causes of PKD, discovering treatments and a cure.
- Raise awareness of PKD, providing information about PKD to patients, the public, the medical community and the media.

The conference was opened by Dr Anand Sagggar, Consultant in Clinical Genetics at St George's Hospital, whose talk entitled 'More than a kidney disease' set the scene for the weekend with a detailed overview of Polycystic Kidney Disease. Later, Dr Sagggar gave a second talk 'The Genetics of PKD', which included DNA testing and genetic counselling.



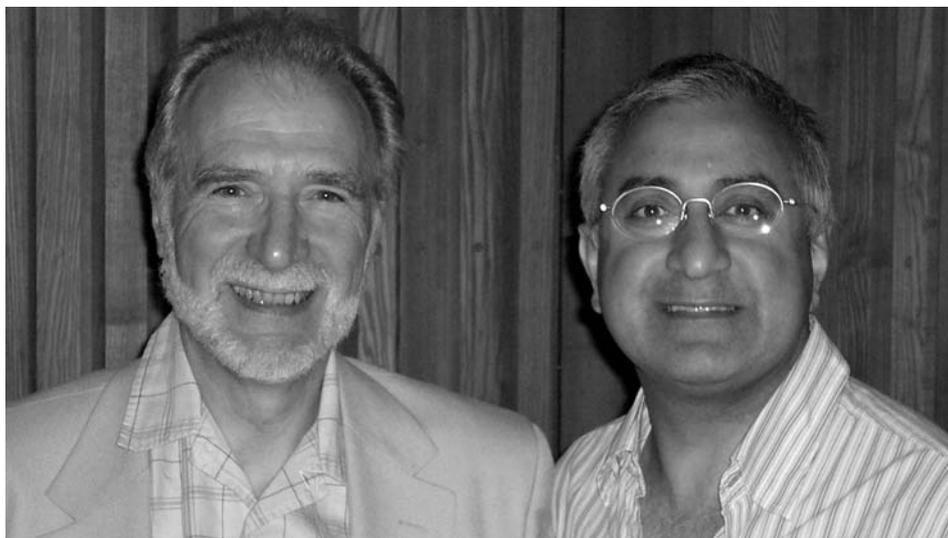
*Southmead Hospital Centre for Medical Education, Bristol*

Professor Terry Feast, Clinical Director at the Richard Bright Renal Unit in Southmead Hospital followed with 'Signs and Symptoms', describing early warnings for PKD patients. Professor Feast went on to give a progress report on 'Renal Patient View', an exciting project which provides online information about diagnosis and treatment, and gives

patients direct access to their latest test results. Renal Patient View is at present only available from UK renal units which use 'Proton' IT system, and unfortunately Addenbrooke's is not one of these. Up-to-date information about Units coming on line with Renal Patient View can be found at [www.renalpatientview.org](http://www.renalpatientview.org).

Tess Harris gave a fascinating talk about Diet & PKD, with lots of practical tips and clear guidance, stressing the importance of controlling blood pressure and regulating salt intake. Tess's tips on 'no-salt seasoning' are available in the current PKD Charity Newsletter, and notes from her talk and will be reproduced on the website.

The Sunday programme included two talks by Dr Richard Sandford, Wellcome Trust Senior Fellow in Clinical Research and Genetics Consultant at Addenbrooke's Hospital. The first, entitled the 'Renal Patient Pathway' outlined the complex and diverse routes PKD patients sometimes have to follow before they eventually arrive at treatment.



*Professor Terry Feast, Clinical Director (left) and Dr Anand Sagggar, Consultant in Genetics (right)*



Tess Harris (left) and Dr Richard Sandford (right)

Dr Sandford went on to describe an exciting new Renal Genetics Clinic set up last year at Addenbrooke's Hospital with two years' funding from the Department of Health. The Renal Genetics and Tubular Disorders Clinic, unique at present, brings together medical and nursing specialists from nephrology, medical genetics, urology and clinical biochemistry, and also offers genetic counselling and genetic testing. New patients with inherited kidney disease should find that this one-stop-shop approach leads to better, more efficient care.

In his second talk, Dr Sandford gave an update on treatments available, drug trials and current research.

Martin Wilkinson, whose wife Tina has PKD, gave a moving talk entitled 'Dancing in the Dark'. Martin described his experiences as a carer, and the impact of PKD on their family life. On the Sunday, Martin also ran a workshop for partners, families and carers on developing strategies for managing the emotional impact of the disease. Here he is seen using a grapefruit and a melon to graphically illustrate the size of Tina's polycystic kidneys!

All information weekend sessions were excellent and gave plenty of opportunities for interaction and questions. Full details of the presentations will be made available on the PKD Charity website.



Martin Wilkinson

Conference-goers enjoying a coffee break (see pic. below) – one of the most valuable benefits of attending gatherings such as this is the chance to meet other patients and find out things that the books, the websites and sometimes even the doctors don't tell you!

To receive the PKD Charity's Newsletter or order free copies of their excellent information leaflets, register on the website at [www.pkdcharity.org.uk](http://www.pkdcharity.org.uk) or phone the PKD Helpline on **01388 665004**.

Alan Craig



# AKPA Annual General Meeting June 2006

## Recent Developments in the Renal Department

### Dr John Bradley

Dr Bradley began by saying that although there had been some exciting new developments in the department it has also been a tough year.

## Increased Demand

Demand for dialysis has continued to grow and delays to the new Hinchingsbrooke satellite unit have meant bed spaces on Ward C5 being used for haemodialysis. A record number of patients were now receiving Haemodialysis at Addenbrooke's despite the satellite units at Bury St Edmunds and Kings Lynn putting on extra shifts.

## Satellite Delayed

Plans for the Hinchingsbrooke unit ran into serious problems when the original site proved unsuitable. After much re-planning contracts have at last gone out to tender, but the unit is now not expected to open until the end of the year at the earliest.

However, there has been a slight decrease in the number of patients on peritoneal dialysis and the number of transplants performed per year is being maintained at the 80 to 90 level with a strong living donor programme.

## Clinics

The recently developed specialist clinics for renal patients are proving successful with patients seeing specialists more quickly for underlying problems such as vasculitis, diabetes and genetic diseases.

The Low Clearance Clinic deals with the problems of Pre-dialysis patients.

The system of annual checks for patients in the transplant clinic is going very well, although the transplant clinic is also under pressure with sometimes over 100 patients being seen in a morning session.

There is now a very strong base of specialist clinics both before and after dialysis.

## Referral Guidelines

National guidelines have now been established for the identification,

management and referral of kidney patients, this should ensure more accurate diagnosis and treatment for people with kidney problems.

## Research in Cambridge

Dr Bradley went on to explain that research was now his major focus. Also, that the organisation of health research was due to undergo dramatic changes in the next few years with Addenbrookes and Cambridge University being short listed as a centre of excellence for research into transplantation, and causes of kidney disease such as infection and genetics.

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*“The recently developed specialist clinics for renal patients are proving successful with patients seeing specialists more quickly”*

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## Progress Report – The New Renal Genetic and Tubular Disorders Clinic

Deborah Spencer, Renal Genetics Specialist Nurse – gave an update on her last year's AGM report about this important new clinic.

A significant proportion (around 12%) of kidney disease is caused by an underlying genetic disorder and referrals to several different specialists are often required to establish the best course of treatment. Patients attending this clinic are able to see different specialists such as Nephrology Consultant, Geneticist, Neurologist and Bio-chemist during one visit.

Patients with primary renal disorders are referred to the clinic and while on the waiting list are asked to establish whether any family history of renal problems exists. Urine and blood tests are done to identify specific disorders and sometimes new tests are developed for rarer diseases, particularly with regard to stone formation.

Patients are encouraged to discuss possible genetic diseases with their families, but nobody is forced to have genetic testing.

There is a need for genetic counselling, but the current shortage of counsellors, Deborah has also taken on this role.

The department of Health provided a two-year grant to set up the clinic, and it is now being evaluated. However, a recent patient satisfaction survey produced 190 responses – with over 70% rating the clinic as 'excellent'.

## CHAIRMAN'S REPORT Tony Weaver



Tony Weaver

Looking back over reports and minutes of the last year, it occurred to me that one of the dangers of presenting a Chairman's report each year is that it could become rather repetitive and boring. But then I realised,

to give a report that highlights the successes and achievements of an Association such as ours (and it is ours) is a real pleasure.

As a Committee we may have shortcomings, but I can assure you that the people who serve on this Committee work endlessly and tirelessly to bring about those achievements and successes. And on behalf of AKPA Members, and kidney patients and their families throughout the region, I applaud every one of them.

On a sad note, as you are probably aware, we lost our dear Colleague, Julie King in October last year. Julie worked with immense energy and enthusiasm for AKPA for many years and she is sadly missed. Julie was particularly interested in helping young patients and was instrumental in getting the NKF Young Patients magazine up and running. She also spent many hours building our website.

Another long standing committee member, Marion Cheetham, has decided to retire from committee work for a while. Our very grateful thanks and best wishes to Marion.

However, we are fortunate in that people express an interest in joining us and we welcome Clare Williams who joined the Committee in May.

A word about our Patrons; – we are pleased to welcome Lady Suzanne Walker this evening. Lady Walker, I'm pleased to say, is very hands on and regularly attends Committee meetings. Our thanks also to Amanda Goodman, who continues to support us, and we are grateful to have secured David Howarth MP who replaces Anne Campbell.

I really don't want to go into too much detail about funding and finance in this report as most of it will be presented to you in the Financial report, but suffice to say this has been a successful year.

As we have heard, Sally Reynolds raised £8000 plus for her marathon, the front page of the *Newsflash* tells you about the mammoth bicycle ride which raised £3400 plus £2000 from Glaxo Smith Kline who employ the three gentlemen who did the ride.

There have also been many hundreds of pounds of smaller donations in memoriam, also from fundraising functions and straightforward donations.

We have also received or had promised a couple of substantial legacies, one of which exceeded £25,000 and another which we believe will be in the region of £10,000.

Add to this, income from the raffles, the 200 club and the stalls and street collections and we now have a sound financial position which has allowed us to commit to buying the Ultrasound Machine you have seen earlier this evening, pledge money for a portable ECG machine for Kings Lynn and to begin a fund for a Dialysis Machine for the proposed Hinchingsbrooke dialysis unit. All of this, as well as regular welfare grants, mean that our patients and their families can be assured that we are continuing to do our best with the funds available.

Our sincere thanks go to all who have helped in any way to either raise money, raise the profile of AKPA or donated funds and of course we hope that we will continue to have your support in this.

In conclusion can I offer my warmest thanks to this great Committee for their continued efforts and enthusiasm on your behalf.

And of course my thanks to all of you for coming this evening.

## AKPA Financial Report – Brian Wood, Treasurer

### Income:

Our income for 2005/06 totalled £77,223, rather higher than most recent years, mainly due to a large legacy of £27,313. We were very fortunate in receiving this legacy at the same time as a request to fund an Ultra-sound scanner for the renal team on Ward C5 and with the approval of friends of the deceased, £24,000 has been used to purchase the scanner in the 2006/07 financial year.

Income from regular sources including raffles, 200 Club, Christmas card, craft and bric-a-brac sales and collecting tins all continue to do well. Our fund-raisers, who beaver away year after year provide our only source of 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 £59,471. Around half of that came out of Restricted Funds, money donated for specific purposes and held in our reserves. A total of £28,660 was used to fund the spending plans outlined at last year's AGM.

This included the purchase of five more Dialysis Chairs at a total cost of £9,230, completing the renewal of all the reclining dialysis chairs in the HD department well ahead of our original estimates.

We also funded the installation of air-conditioning in the PD department to improve the comfort of patients and staff at a cost of £14,342.

£5,088 went to fund the transplant clinic nurse post through the Jill Wood Award. Both of the transplant clinic nurse posts, campaigned for and initially funded by AKPA, are now being funded by the Trust.

### Social Support:

Our support for welfare and holiday grants to needy patients continues and we spent £16,000 on this important service. 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. The amount spent on this includes funding for the Renal Social Worker, a service that is highly valued by staff and patients.

We funded Christmas buffets for patients in the Dialysis Centre, and Kings Lynn and Bury satellite units at a total cost of £400. We also sponsored patients to attend the annual National Kidney Patients Conference in Blackpool with grants totalling £980 and supported contestants in the National Transplant Games with grants totalling £625.

### Reserves:

Over the last few years we have been very fortunate in receiving some generous legacies and donations, which increased our reserves.

In accordance with our spending plans outlined last year, we have used cash from our reserves to fund important projects and successfully provide services that patients and staff have been requesting for some time 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:

With the unprecedented expansion of renal services we are still receiving requests to fund services and equipment not funded by the NHS.

We have been asked to fund an extra haemo-dialysis machine for the new Hinchingsbrooke satellite unit at a cost of £14,000. We are also contributing to the fundraising for the Antibody Removal Programme for the transplant unit.

### Administration Costs:

Despite the ever-increasing burden of regulations and form filling, our administration costs remain very low. At just under £4000 they represent less than 5% 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.