Ready for the Ball –
The Crown Appeal Committee

Amanda’s father who was a dialysis patient and Angela’s Mother, who suffered from cancer, both died recently. As a gesture of thanks for the help their respective parents had received from AKPA and Cancer Research UK the two friends decided to start an appeal to raise money for these two charities.

Ten of their friends volunteered to help and formed the committee with the name “Crown” derived from a combination of their parent’s surnames – CRoyden and BrOWN.

In total, they have raised an amazing £14,000, through a variety of events ranging from Princess Parties and Craft days to a Grand Ball, and they are currently organising another Ball for May this year. They plan to split the money raised equally between the two charities. Amanda recently presented AKPA with a cheque for £5000, which will go towards an ECG machine for the Kings Lynn dialysis unit where her father Eric Croyden received holiday dialysis.

Peter Hudson (right) with his son Michael presenting a cheque for £650 to Richard Fossey. Peter asked for donations to AKPA from friends and relatives celebrating his 60th birthday. A big thank you to Peter and all his friends and relations for their outstanding generosity.
High Flux Dialysis with New Water Plant

The much anticipated new water plant has been operating successfully at Addenbrooke’s Dialysis Centre since December 2006. The previous water plant was originally designed to supply only seventeen stations and over the seventeen years since it was installed the number of stations has grown to 27. The combination of age and overwork had taken its toll, and over the past two years this has meant the addition of filters to all the dialysis machines in order to guarantee the quality of the water supply. It has also meant that we have not been able to offer high flux dialysis to haemodialysis patients at Addenbrooke’s, which is something we have been doing for several years at the Satellite dialysis units. With the introduction of the new water plant, the quality of the water meets the most stringent biochemical and bacteriological standards and will allow the introduction of high flux dialysis in March 2007. It is hoped that this will lead to an improvement in the treatment that patients receive.

The process of introducing and commissioning the new plant has involved a lot of hard work from many people and I would like to thank all involved for their efforts. In particular I would like to thank all of the patients who have completed questionnaires which form a crucial part of monitoring the changes we have introduced.

Dr Nick Pritchard

Heather Retires

At the end of March 07 we will say a fond farewell to Sister Heather Foster, who after 27 years as Home Dialysis Sister has decided to hang up her surgical gloves.

Heather came to Cambridge in 1980 then Sister Heather Black, having qualified at The Hammersmith Hospital in London. She came to replace Sister Hazel Leeson who together with Sister Mary Nugent trained and looked after all the home dialysis patients.

Heather soon fitted into the team which at that time looked after well over 80 patients on home dialysis. The unit was then based at Douglas House in Trumpington Road and was directed by the late Dr David Evans.

Heather very quickly became involved in all the activities of the unit, and for a period of six years served on the AKPA committee as staff representative organising holidays for patients, and various trips to shows and sight-seeing in London, as well as being a sound link between the unit and the AKPA.

It was in 1989 that Heather became Mrs Foster having married Norman an Air Flight Controller at Luton Airport.

Over the years with the increase in successful transplants and the emergence of the CAPD programme the number of home patients has decreased significantly to a matter of only six at this present time. Heather’s role has had to change accordingly to a part time basis and become more involved in staff training and general unit activities.

Heather will be sadly missed by staff and patients alike, and I am sure I can speak on behalf of all the patients when I say we wish Heather a Long, happy and healthy retirement.

Bob Hinson

Antonio Says Goodbye

Antonio Ortiz left Addenbrooke’s Dialysis Centre to work in Australia last year. He sent this message for all his many friends and colleagues.

I want to let you know what a privilege it has been for me to work the last seven and a half years at Addenbrooke’s dialysis unit. To all those people receiving dialysis who knew me, I would like to say they have always been an inspiration. Also, I would like to give thanks to all my colleagues who helped me so much over the years.

Antonio

Urgent Need for Dialysis Computer System

For several years Addenbrooke’s Dialysis Centre has applied, without success, for NHS funding for a dialysis data logging IT system.

The current system involves manually entering patients dialysis data into computers. It is slow and time consuming, with valuable nurses time spent entering and checking data. With the introduction of high flux and other new kinds of dialysis, speedy and accurate recording of data from dialysis machines will become increasingly important.

A bespoke system, designed to record data from the existing machines is available at a cost of around £60,000. And although there are none currently installed in dialysis units in the UK, twelve systems are running successfully in Holland. Dialysis technicians and medical staff have seen the system in operation and are very impressed with it.

The system will enable the staff to quickly make crucial decisions about the quality and quantity of dialysis each patient needs; to treat more patients on the same machine with slightly shorter dialysis times and improve the planning of patient appointments and transport.

It appears unlikely that funding will be available in the foreseeable future and AKPA have been approached to help fund this project. The Committee are very keen to support a project that will improve the wellbeing of dialysis patients and are considering ways to help, including a fund raising campaign.
Kidney Exchange – The Netherlands Experience

In October I attended the annual symposium of the International Transplant Nurses Society in Rotterdam. A significant proportion of the 3-day meeting was devoted to living donor issues, particularly kidney exchange and altruistic donation programmes.

As Newsflash readers may be aware, the law in the UK has recently been changed to allow exchange of kidneys between pairs of donor-recipient couples who are unable to donate to each other directly because of blood group or tissue-type incompatibility.

As yet we have still to do the first such swap in this country, so I was particularly interested to hear of the experience of other countries.

The Netherlands started a similar scheme at the beginning of 2004 and although a much smaller country than the UK, 112 pairs registered in the first two years. Half of those pairs have so far found a compatible pair and been transplanted. We would hope that the UK would have a potentially bigger ‘pool’ of incompatible couples and so more opportunities to find suitable matches.

The Netherlands have also performed several dozen transplants from anonymous ‘altruistic’ donors. In some cases these have been combined with incompatible pairs to allow even more transplants to take place.

Several other countries presented on their exchange programmes, and they also reported significantly increased numbers of living donations, with excellent success rates.

Although there are many details of the scheme to be finalised, not least the logistics of carrying out several simultaneous sets of live donor operations, we expect that over the coming year Addenbrooke’s will start to make use of these new opportunities to continue to increase the number of transplants performed.

I would like to thank AKPA for their assistance in attending this extremely useful meeting. If anyone would like more information, or to discuss any aspect of living donation, please call the living donor office on 01223 596177 or 586979.

Jim O’Sullivan
Living donor transplant co-ordinator

A Brave and Caring Lady

The photo shows Teresa Pritchard with her mother Mrs Ann Butler presenting a cheque for £1,125 to AKPA outside the Dialysis Centre last October. It is with great sadness that we have to report that Teresa died early this year.

Teresa had been on dialysis for many years following a failed transplant, and she sadly developed cancer in 2006. But that didn't stop her fundraising efforts and in September last year Teresa and her mother held another Golf Day, raising a total of £2,250 that was divided between AKPA and the Hospice at Home Appeal.

The money will go towards a plasmapheresis machine to provide treatment that should enable some patients who have suffered rejection of a transplanted kidney to quickly receive a second transplant.

Dialysis Petition on PM’s Website

Some of you may already be aware of the National Kidney Federation’s campaign to increase the amount of dialysis available in the UK. Many units are working at maximum capacity and it is often not possible to arrange dialysis when travelling either for holidays or work.

Timothy Statham OBE, Chief Executive of the NKF has started a petition on the Prime Minister’s website arguing for increased Dialysis Capacity to enable Kidney Patients to dialyse away from their home units for holiday or work.

He asks patients, their families and friends to please visit the website and sign his petition.

The address is http://petitions.pm.gov.uk/Dialysis/

The short name of the Petition is Dialysis and there is a ‘more detail’ button on the petition to read the full wording.

Sally Reynolds, seen here with transplant Surgeon Chris Watson and Transplant Co-ordinator Jim O’Sullivan, presenting a cheque for £8,300 to the Transplant Unit’s Antibody Removal Programme.

Sally raised the money by running the London Marathon and organising other fundraising events.

The money will go towards a plasmapheresis machine to provide treatment that should enable some patients who have suffered rejection of a transplanted kidney to quickly receive a second transplant.

We offer our deepest condolences to Teresa’s family.
The NKF Annual Conference was held last October at Chesford Grange Hotel in Warwickshire. A full conference report now features in the Spring 2007 issue of *Kidney Life*.

**Complete Conference Talks and Discussions Now Available on the Web**

This year, NKF have made an exciting addition to their website for members who were unable to attend the annual conference – go to [www.kidney.org.uk](http://www.kidney.org.uk) and click on **NKF Conferences then 2006 Positive Thinking** for the chance to hear audio recordings of all talks and panel discussions!

*Just click on the LISTEN AGAIN! button – the subjects and speakers you can listen to are:*

### Welcome and Opening of the Conference

The conference was opened by Dr Evan Harris, Member of Parliament for Oxford and Abingdon, and Chairman of the Commons All Party Parliamentary Kidney Group. Dr Harris, who has been a staunch supporter of the NKF for many years, extended a hearty welcome to all delegates, speakers and the conference sponsors Genzyme.

### PKD – New Developments in Diagnosis and Treatment

Dr Albert Ong is Reader in Nephrology & Hon. Consultant Nephrologist in Sheffield. Dr Ong gave a fascinating overview of recent research into polycystic kidney disease, a common cause of kidney failure world-wide. He painted a promising picture of what the next ten years might bring in the quest for new treatments.

### PKD from the Patient Perspective

Janice Parkes told a moving story of how this hereditary condition has affected four generations of her family. In spite of all their problems, Janice’s family have managed to keep their sense of humour, and their positive determination. Janice showed a happy photograph of a recent family wedding which brought together all eight surviving transplants!

### Positive Phosphate Control – Why You Should Sign Up For It

Dr Elizabeth Bailey is Associate Specialist Renal Medicine at the Royal Preston Hospital. She explained how healthy bones rely on healthy kidneys and gave an informative and persuasive argument for patients playing an active role in controlling their phosphate levels.
The Role of Chronic Kidney Disease Management Programmes

Dr Kevin Harris is the Clinical Director of Renal Services & Urology at Leicester General Hospital. Dr Harris explained how GPs are now increasingly involved in the early detection of chronic renal failure, with much better long-term outcomes for patients.

Pain Control

Christine Price is Clinical Nurse Specialist in Acute Pain at the John Radcliffe Hospital in Oxford. Christine’s insight into the depressing and debilitating effects of pain touched many patients and their carers, and they found her advice on coping strategies extremely helpful.

Climbing Mountains

Tony Ward gave an inspiring talk on his life as a professional mountaineer, and how his positive outlook has helped him to come to terms with his illness. After many years of dialysis and continuous health problems, he was able to benefit from his brother’s persistence and generosity which led to a successful live donation.

Life on Dialysis and the Transplant List

Charlene Henry is a 17 year-old kidney patient at the Royal Victoria Infirmary in Newcastle. Charlene gave a moving account of the frustrations of life on haemodialysis and the uncertainties of waiting on the transplant list. Charlene’s story wound up happily with a generous live donation from her half-sister Allison.

Conference delegates from all around the country visited AKPA’s conference display which, once again, was expertly created and arranged by Alan Craig. AKPA Chairman Tony Weaver enjoyed fielding their questions and receiving many complimentary comments on the quality of our display.

This year, AKPA’s seven-strong delegation comprised Allan & Gillian Collins, Paul Cookson, Alan & Wendy Craig, Rodney Morris, and of course Tony Weaver.

Left: AKPA member Allan Collins and AKPA Chairman Tony Weaver looking at the AKPA Conference display. The display included photos of Allan’s wife Gillian and son Andrew, both transplant patients.
Ralph’s ‘50’ Raises Funds

Ralph Slattery, of Cambridge, celebrated his 50th birthday in October last year by holding a party for friends and family. Amazingly there were exactly 50 people at the party. And as Ralph had requested that (apart from Family) all monies that guests would have spent on presents should be donated to AKPA, a brilliant £295 was raised. Ralph has been a kidney patient since 1980. He began peritoneal dialysis in London in 1983 and moved to Cambridgeshire in 1986, becoming one of the first PD patients at Addenbrooke’s. He received a kidney transplant on 1st October 1987 and it is still working fine. He was really looking forward to his 50th Birthday. And when asked why he was so excited about this sometimes daunting milestone he said “at 30 I was on dialysis, so reaching 50 and being as healthy as I am today was only a dream”. Our thanks to Ralph and all his friends who gave so generously.

Eve Raises £275

Eve Richardson with Wendy Clark

Once again by the sale of her paintings and the generous help of her friends, Eve Richardson has raised money for AKPA. Her latest efforts raised £275 and she is seen here presenting the cheque to Wendy Clark. Over the past few years Eve, from Raunds Northants, has raised a total of £2775 for AKPA in grateful appreciation of the care received by her son Philip who is a PD patient at Addenbrooke’s. A big thank you to Eve and all her friends.

Barbara’s Stalls

Barbara Vining ran several very successful stalls in the outpatients reception area last year. The stalls sold craft items, bric-a-brac, cards and gifts, most of which were kindly donated. They raised a total of £1026 and the money was used for patient welfare and support for clinic 12. Barbara and the committee would like to thank everyone who donated items, helped with the stalls or who purchased goods from them. They are a brilliant way of raising funds and publicising our work. Thank you all.

Collectors needed for street collection – Sat. June 30
Please contact: Michael Moore 01223 244202

Robinson College Bring and Buy

A great way to recycle and raise money for charity.
Staff at Robinson College Cambridge raised a grand total of £921 for AKPA with their annual Bring and Buy sale. The sale, which was held in October last year by the Housekeeping Department, is an annual event where items left behind by outgoing students are sold to incoming students and all proceeds are donated to charity. The organisers choose a different charity every year and this year they chose AKPA on the recommendation of Gary Hollis, who works at Robinson College and is the husband of Dialysis Unit Sister Jane Hollis. Our thanks to Gary Hollis, Housekeeper Angela Coyle and all involved in this sale.
AKP A

CHRISTMAS RAFFLE
2006

Drawn 15th December 2006 in
the Dialysis Centre at 2pm

List of Prize Winners

1. £300.00 Cash  D. Brooks, Gt Bardfield
2. £150.00 Cash  Collins, Bury St Edmunds
3. £100.00 Cash  Arnold, Saffron Walden
4. £50.00 John Lewis Vouchers  Fuller, Dialysis
5. £30.00 Tesco Vouchers  A. Smith, Dialysis
6. Premier Food Hamper  Spencer, Peterborough
7. £25.00 John Lewis Vouchers  Gray, Bury St Edmunds
8. £25.00 John Lewis Vouchers  Clark, Ipswich
9. Xmas Hamper  R. Levitt, Dialysis
10. Ornate Chess Set  P. Smith, Gt Bardfield
11. £25.00 John Lewis Vouchers  C. Scoley, Hertford
12. Xmas Hamper  R. Buckle, Gt Dunmow
13. £25.00 John Lewis Vouchers  P. Pratt, Ipswich
14. Xmas Hamper  Lewis, Bedford
15. £20.00 Tesco Vouchers  Burton, Car. Disp.
16. 2 Teddy Bears  Braston, Thaxted
17. £15.00 M&S Vouchers  Ayres, Godmanchester
18. Whisky and Hip Flasks  Harrison, Peterborough
19. CavA & £10.00 Voucher  Weegart, Gt Bardfield
20. £15.00 M&S Vouchers  Watson, Kempston
21. Mickey Mouse  Day, Gamlingay
22. European Car Kit  Collins, Saffron Walden
23. Cadbury’s and Candle  Jones, Peterborough
24. Cider, Glass & Voucher  Longyear Wootton
25. Singing Reindeer  Bunnage, St Neots
26. £10.00 Voucher  Warwick, Bedford
27. £10.00 Sainsbury Voucher  Adams, Ely
28. £20.00 Garden Centre Voucher  Calley, Bury St Edmunds
29. £10.00 Voucher  Waspe, Ipswich
30. Xmas Cake & Chocs  Roger, Saffron Walden
31. Port & Sherry  M. Andrews, Dialysis
32. £10.00 Tesco Voucher  Carr, Preston
33. Bath Accessories  Day, Gamlingay
34. Kitchen Knives  Fuller, Dialysis
35. Water Whirl  A. Johnson, Pckrg
36. Toiletries  Bunnage, St Neots
37. House Plant & £5.00 Voucher  Parkin, Gt Bardfield
38. 2 Bottles Bucks Fizz  Ingram, Wisbech

The net income from this year’s Christmas Raffle amounted to just under £1700.00 and also £420.00 was received in cash donations.

I most sincerely thank everyone for your generosity: those who donated prizes, bought and sold raffle tickets and gave cash donations and congratulations to the prize winners.

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

Richard Fossey – Raffle Promoter
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

AKPA Committee Members 2006–2007

<table>
<thead>
<tr>
<th>Name</th>
<th>Position</th>
<th>Details</th>
</tr>
</thead>
<tbody>
<tr>
<td>Tony Weaver</td>
<td>Chairman</td>
<td>9d Radwinter Road, Essex CB11 3HU, Tel: 01799 525875</td>
</tr>
<tr>
<td>Val Long</td>
<td>Vice-Chairman</td>
<td>2 Lodge Cottage, Wimbish, Nr Saffron Walden, Essex CB10 2XR, Tel: 01371 830711</td>
</tr>
<tr>
<td>Brian Wood</td>
<td>Treasurer &amp; Newsletter Editor</td>
<td>48 Montague Road, Cambridge CB4 1BX, Tel: 01223 353575, Fax: 01223 562165 (for many years)</td>
</tr>
<tr>
<td>Andrew Collins</td>
<td>Deputy Treasurer</td>
<td>55 Tamarin Gardens, Cherry Hinton, Cambridge CB1 9GQ, Tel: 01223 574951</td>
</tr>
<tr>
<td>Richard Fossey</td>
<td>Summer &amp; Xmas Raffles</td>
<td>92 Arundel Drive, Bedford MK41 8JE, Tel: 01234 213546 (Unit haemodialysis patient)</td>
</tr>
<tr>
<td>Michael Moore</td>
<td>Collecting Tins</td>
<td>103 Queen Edith’s Way, Cambridge CB1 8PL, Tel: 01223 244202</td>
</tr>
<tr>
<td>Michele Satchwell</td>
<td>Publicity Officer</td>
<td>101 High Street, Cambridge CB3 0QQ, (Formerly haemodialysis patient now transplant patient)</td>
</tr>
<tr>
<td>Sister Nicky Moncrieff</td>
<td>Staff Representative</td>
<td>Dialysis Centre CAPD, Addenbrooke’s Hospital, Hills Road, Cambridge CB2 2QX, Tel: 01223 217823</td>
</tr>
<tr>
<td>Peter Russell</td>
<td>200 Club</td>
<td>12 Sheerwater, Peterborough PE2 6YW, Tel: 01733 230238, Fax: 01733 236200 (home haemodialysis patient)</td>
</tr>
<tr>
<td>Derek Varley</td>
<td>21 Smithy Close</td>
<td>Staningfield, Bury St Edmunds, Suffolk IP29 4RH, Tel: 01284 828463 (Unit haemodialysis patient)</td>
</tr>
<tr>
<td>Jenny Ridgeon</td>
<td>Minutes &amp; Membership Secretary</td>
<td>Dialysis Centre, Addenbrooke’s Hospital, Hills Road, Cambridge CB2 2QX, Tel: 01223 217830</td>
</tr>
<tr>
<td>Co-opted Committee Members</td>
<td></td>
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<tr>
<td>Barbara Irving</td>
<td>Renal Welfare Adviser</td>
<td>Social Services Dept, Tel: 01223 714425</td>
</tr>
<tr>
<td>Wendy Clark</td>
<td>Dialysis Centre Manager</td>
<td>West Suffolk Dialysis Unit, West Suffolk Hospital, Hardwick Lane, Bury St Edmunds, Suffolk IP3 2QZ</td>
</tr>
<tr>
<td>Sister Julia McCarthy</td>
<td></td>
<td>West Suffolk Dialysis Unit, West Suffolk Hospital, Hardwick Lane, Bury St Edmunds, Suffolk IP3 2QZ</td>
</tr>
<tr>
<td>Clare Williams</td>
<td>Dialysis Centre</td>
<td>Addenbrooke’s Hospital, Hills Road, Cambridge CB2 2QX, Tel: 01223 217830</td>
</tr>
<tr>
<td>Richard &amp; Lorna Jarvis</td>
<td></td>
<td>58 Cambridge Road, Ely, Cambs CB7 4HT, Tel: 01353 615026</td>
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Are You a Member of AKPA?

To join or receive more information about AKPA please complete the form below and return to:
AKPA, 48 Montague Road, Cambridge CB4 1BX.

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

Newsflash Contributions

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

Registered Charity No. 277236

Addenbrooke’s Kidney Patients Association is a member of the National Kidney Patients Federation

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