



Addenbrooke's Kidney Patients Association NEWSFLASH

Issue 2 2013

No. 54

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

A MEMBER OF THE NATIONAL KIDNEY FEDERATION

Open Garden at Alswick Hall



Annie Johnson (centre) meets some old friends

In April, Annie Johnson opened her gardens at Alswick Hall in aid of AKPA. The event was a big success raising over £3,000.

Despite the late spring there was a fine display of flowers and plenty of interest for everyone in the well planted and landscaped garden. The weather kept dry and bright, with food, refreshments and a hog roast making it a great day out for the many visitors.

Annie had a kidney transplant 35 years ago – in the early days of transplantation. Some members of the transplant team from that time visited the garden and met up with Annie. The photo shows Annie with Mary Nugent – Renal ward Sister and Audrey Campbell – Secretary to Prof. Calne, and just behind Mary, Gabsey Braun – medical researcher with Prof. Calne's team.

Our thanks to Annie and her family for a great event and a welcome boost to AKPA funds.

www.akpa.org.uk

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AKPA Christmas Cards

Please buy some AKPA cards, they are available from the following outlets:

Cambridge Cards for Good Causes, Visitor Information Centre, Peas Hill, Cambridge (Guildhall side entrance, opposite St Edwards Church and Arts Theatre).

Open Mon–Sat. 10.00am–4.45pm

Pearce's Farm Shop and Cafe, Buntingford, Herts.

www.pearcesfarmshop.com

Tel: 01920 821246

Open Mon. to Sat. 8.30am–5.00pm, Sun. 10.00am–4.00pm

Addenbrooke's Clinic 12 and Dialysis Centre

Satellite Dialysis Units at: West Suffolk Hospital, Bury St Edmunds

Queen Elizabeth Hospital, Kings Lynn and Hinchingsbrooke Hospital.

All proceeds go to AKPA; this year's designs can be viewed on the AKPA website www.akpa.org.uk – message in cards; "Season's greetings and best wishes for the new year".

**AKPA needs volunteers to help with fundraising.
Please can you help?
Contact Brian Wood:
Tel: 01223 353575 • Email info@akpa.org.uk**

Alswick Hall Gardens



Spring flowers around pond in the landscaped gardens of 16th Century Alswick Hall, opened in aid of AKPA.

Committee News

New Committee Members

The AKPA committee is very pleased to welcome two new members, Janet Man and Peter Constable who put themselves forward at the AGM.

Janet worked for the Cambridge Branch of Cats Protection since coming to Cambridge 18 years ago and was co-ordinator for over 11 years. She stepped down from this post because of the time required for dialysis. Five members of her family have had transplants (a nephew only recently) and so she is keen to help AKPA in any way that she can.

Peter has lived in Cambridge for nearly 50 years. He retired from banking in 1991 as a Director and CEO of Black Horse Agencies and has since worked mainly in the charitable sector, with a spell as chair of an NHS hospital and now as a volunteer for Abbeyfield.

He said that AKPA is not new to him as his own kidney disease was diagnosed over 30 years ago. He is now on haemodialysis and hopes to help others in similar circumstances.

Janet and Peter bring a wealth of experience to the AKPA Committee from their work in the charitable sector.

Thank You Tony

After serving on the committee for ten years, seven of those as Chairman, Tony Weaver announced his retirement from the AKPA committee at the AGM. Tony also acted as Publicity Officer, Collecting tin co-ordinator and frequently stepped in to support other AKPA activities.

Although retired from full time work, Tony is still involved in a host of activities. He said he “wants to slow down a bit” but he will still be acting as AKPA Collecting tin co-ordinator.

As Chairman Tony was very much hands-on, making himself known to staff and patients. And his committee meetings always managed to be good-natured affairs that nonetheless efficiently cracked on through the agenda. The committee expressed their appreciation of his work by presenting him with some of his favourite wine.

A big thank you to Tony for his work and dedication from everyone involved in AKPA.

David and Jayne

David and Jayne Wyatt have reluctantly, left the committee for personal reasons. All committee members are very sad to see them go and thank them for all their fundraising work, the 200 club, street and supermarket collections, and for all their support and camaraderie.

Thank you both.

Derek Retires

Long serving member Derek Varley, retired from the AKPA committee at this year's AGM.

Derek served on the committee for 22 years and was involved in organising social events and excursions for dialysis patients. Also, street collections, Christmas card sales and other fund-raising events in and around his home town of Bury St Edmunds.

A dialysis patient at the West Suffolk satellite, Derek has always worked for the well-being and comfort of his fellow patients.

Our thanks and best wishes to Derek and his family.

Two Silver Jubilees



Malcolm on crutches after knee replacement

Malcolm Souza-Lewis recently celebrated two 25th anniversaries. In 2012 his triple bypass, and this year his second kidney transplant. To mark the occasion he presented AKPA with a cheque for £250.

Malcolm has been part of the Addenbrooke's athletics team since moving to Kings Lynn in 1998, regularly winning medals in the British and World Transplant games. In last year's British Games he won 5 medals but was unable to compete this year because of the knee replacement.

Malcolm said that his wife Valerie has been a great help and support and kept him going all these years. Next year they celebrate their Ruby Wedding Anniversary.

He is hoping to be fit for the next Transplant Games. Fingers crossed but not the knees – the operation scar is still too sore.

Our thanks to Malcolm and Valerie.

Rampton Motors, another regular AKPA supporter, recently sent us a cheque for £80. Money donated by their customers.

Our thanks to Trudi Butler and the customers of Rampton Motors.

Help Us Raise More – Fundraise on *JustGiving*

AKPA has joined *JustGiving*, the online fundraising and sponsorship website, to make raising money quicker, easier and more effective.

You can set up your own personalised *JustGiving* fundraising page to tell everyone what you are doing and why you are raising money for AKPA. The *JustGiving* team then gives you everything you need to reach more sponsors faster.

You can also make a one-off or regular donation to AKPA via *JustGiving*.

Also, *JustGiving* will collect Gift Aid from any eligible donors, enhancing any gift by up to 28%. The donation is a 100% secure, spam-free experience. They will never sell or share your personal details and won't try to sell you anything.

To start raising money for us on *JustGiving*, please visit www.justgiving.com/akpa



Bric a Brac Stalls

In July Sue Oates and Monica Taylor ran another Bric a Brac stall in Addenbrooke's Outpatient's Hall. The stall was well stocked with items donated by friends and supporters and raised £344 for AKPA.

Sue and Monica are planning to hold another stall in the same venue on November 28th and would welcome donations of good quality bric a brac to sell. Items (clearly labelled) can be left in the Dialysis Centre.

Our thanks to Sue and Monica and all the people who donated items.

Virgin Media Fundraising

Virgin Media recently raised £1,946 for AKPA in an online fundraising raffle.

Virgin Unite, the social and fundraising arm of Virgin Media, chose AKPA to be their East Midlands charities of the year. AKPA was selected randomly from four charities nominated by staff in that region.

Our thanks to the staff and fundraisers at Virgin Media.

Internet Fundraisers

Thanks to all the people who have raised money through the **JustGiving** and **Charities Trust** web sites. Sorry that we don't have details of all internet fundraisers. If you let us know by writing or emailing we would be very pleased to publicise your fundraising efforts.

Thank you all.

Remembering Simon

Friends and family of Simon Costigan held a fundraising event at their local pub in his memory and raised £1,180 which they donated to AKPA.

Our thanks to Debbie, Paul, Ross and all Simon's friends and family.

Regular Supporters

Regular AKPA supporters, **Bassingbourn Bingo Club** recently donated another £50 raised by their members.

Our thanks to all the members for their generosity.

Glen's 30th Anniversary Publicises World Kidney Day



Glen Smith

Transplant patient Glen Smith used the 30th anniversary of his kidney transplant to publicise World Kidney Day.

In an article published in his local Essex paper, Glen said that members of the public still seem to believe transplantation is just a short term solution – but his had worked for thirty years. His GP recently told him that his kidney is probably working better than her's. Glen believes there is a lack of knowledge about organ transplantation and not enough donors.

Fifty three year old Glen, who runs his own business, Avanti Travel Insurance, lives life to the full, skiing, biking, playing tennis, and rock climbing.

World Kidney day, was in March this year, and is organised by the Kidney Alliance to promote better treatment for kidney patients across the UK.

Hospital IT Problems Slow RPV

Testing of Renal Patient View (RPV) – the software system that allows patients to view their blood results – has been delayed by problems with the Hospitals IT system. It is hoped to resume testing shortly.

Many patients are keen to use the system, which is being used by several other hospitals and AKPA are funding development and testing at Addenbrooke's.

Holiday Dialysis

This year's holiday season is over but next year's holiday brochures are already dropping through the letter box. For dialysis patients it's useful to find information about holiday dialysis units before you start planning.

New committee member Janet Man has used holiday dialysis units in many parts of the UK and has recommended three.

They are: Norfolk and Norwich University Hospital, Kendal dialysis unit – Lancashire teaching hospitals and William Harvey Hospital Ashford Kent.

She reported that she used all three this year and all were excellent. They can all be found on the UK Renal Units website.

The National Kidney Federation (NKF) and the British Kidney Patients Association (BKPA) also provide information and advice about dialysis holidays. Their websites have lists of holiday dialysis centres in the UK.

NKF – Holiday Pages
(www.kidney.org.uk/holidays)

BKPA – Holidays
(www.britishkidney-pa.co.uk/holidays)

If there are any units you would like mentioned please let us know.

Help for Kidney Patients and Carers

The National Kidney Federation (NKF) Helpline provides assistance to patients, carers, family, friends and medical professionals. Seek advice, obtain literature, get help, all from the one Helpline number (details below). It is open for calls from 9am to 5pm, Monday to Friday.

To obtain NKF Information Leaflets go to www.kidney.org.uk

Tel: (0845) 601 02 09
(charged at Local Call Rate, UK only)

E-mail: helpline@kidney.org.uk
Address: Helpline
National Kidney Federation
The Point, Coach Road, Shireoaks
Worksop, Notts S81 8BW

The Helpline also provides access to the NKF Advocacy Service.

Are You a Member or Friend 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*

AKPA Annual General Meeting July 2013

Presentations

Skin Surveillance and Screening

Gill Matthews, Renal Transplant Specialist Nurse

Gill gave an update on skin surveillance, including some new findings. A patient survey carried out in 2011 involving 200 post transplant patients reported that 88% were aware of the increased skin cancer risk associated with transplantation, 75% of the patients regularly assess their skin and report findings and 65% said they had increased sunscreen use and sun avoidance since their transplant.

This survey proves that patients' understanding of skin-related risks has greatly improved over the years and the AKPA funded skin cancer leaflet has been very useful in helping spread the word. It is given out both pre- and post-transplant and is well used at Addenbrooke's and also at other units around the U.K.

Gill also spoke about the potential risks of skin cancer in patients and ways to minimize these.

There is an increased risk of skin cancer after a second transplant, particularly if there was damage with the first transplant, and this often occurs in the first year of the second transplant, which is attributed to a second load of immunosuppressants. Patients in their 60s to mid-70s are more prone to skin cancer in the first year post transplant, possibly because this age group was not used to using sunscreen and maybe would get skin cancer.

Sun avoidance is the best way to decrease risk.

Sirolimus, an immunosuppressant, is thought to have skin cancer sparing properties, and can be used in place of Cyclosporine, although some patients suffer side effects from this.

Gill thanked AKPA for providing a wonderful leaflet and for their on-going support and grants to attend national conferences.

Patient and Carer Support – Home Therapies Workshop

Gerrie Millar and Gillian Chumley, Renal Counsellors

Gerrie and Gillian reported on the Home Therapies Support Workshop. This was arranged for patients and carers to better understand home based patient care, to discuss problems and issues, and change practice as needed. Nineteen patients and carers were invited, most already on home haemodialysis. A large group of staff was also represented to cover all disciplines and respond to concerns.

Patients and carers were divided into separate groups enabling each to express concerns more freely. Both groups were keen to talk and share personal information. The patient group was asked about any concerns for their carer, and carers were asked about the implications of being a carer.

“patients and carers saw many advantages from home care”

The workshop revealed that patients and carers saw many advantages from home care including flexibility – the ability to change the time and frequency of dialysis. Reduced travel was also important as was enjoying being at home rather than in the hospital. Although some patients reported missing the camaraderie of nurses and other patients.

Discussions about concerns and feelings revealed that equipment and needles can be a bit overwhelming. However, practical advice was offered and future plans suggested, including clearer dialysis machine guidance and involving patients and carers in writing the guidance.

Advocacy

Sandy Lines, NKF Advocacy Officer

Sandy explained the job of NKF Advocacy Officer, which is to support

renal patients and their carers. She gave examples of issues that arise such as: transport problems, carers feeling isolated, home Haemo patients wanting to go back to the unit for camaraderie, air conditioning temperature control and obtaining correct state benefits. A recent problem is the “bedroom tax” which can make life difficult for some renal patients.

Sandy is one of eight NKF Advocacy officers covering the UK, and has been in post since November 2012, covering East Midlands and the East of England. She is gradually getting round the area, already visiting King's Lynn and Addenbrooke's

NKF Advocacy officers work in partnership with the BKPA to promote grants where there is hardship. They also provide information and advice via the large range of leaflets and books, including a very popular renal recipe book, produced by the NKF.

Dialysis Holidays and Unit Update

Maddie Seeley, Senior Clinical Nurse for Renal Services

Maddie began by discussing holiday dialysis options; advising patients to consult their nephrologist before planning a holiday and saying holidays are not recommended within six months of starting dialysis.

She explained that holiday dialysis is available in many UK resorts, and that more, some at short notice, is available abroad. An EHIC card will entitle patients to free or reduced cost hospital treatment in the European Economic Area (EEA), but additional travel insurance is also required.

She continued by reviewing the many new developments in the unit over the last year, and discussed the potential new Cambridge Dialysis centre. A new unit with 36 stations has been requested and although some potential sites have been considered, access and transport issues are proving to be a problem, as patients and staff will need to travel between sites.

AKPA Annual General Meeting July 2013

Chairman's Report –

After welcoming everyone, Tony began his report by saying that the Association was in the best financial position it had been in for many years. Although, as he emphasised, we were still desperate for help on the Committee, especially for anyone with skills in publicity, fund raising or chairing meetings.

He had included “chairing meetings” he said, “because this will be my last meeting.” After ten years he was sad to go, but felt it was important that new energy and enthusiasm was injected into the organisation.

He considered it an immense privilege to be part of AKPA and had enjoyed working with some great and good people in a very worthwhile cause, saying; “it is patently obvious that Addenbrooke’s Kidney Patients Association is a very large, strong family that includes not only Patients but Hospital Staff, Surgeons, Doctors, Transplant Coordinators, Counsellors, Admin. Staff, Technicians, Drivers, People who serve refreshments, Cleaners – and I’m sorry if I’ve left anyone out.”

Reviewing the year, he said; “our most significant funding was of four home dialysis machines, enabling the home dialysis programme to grow in strength.”

“We also continued funding Welfare Grants, which I personally feel (and your Committee feels) are very important to ease hardship. I know some other KPA’s refuse to make grants to individuals but I feel we are doing exactly the right thing. The letters of thanks, and the relief expressed, are obvious confirmation that this system is a triumph for our Association.”

Turning to fundraising, he said: “We have had some wonderful money raising events this last year: Staff Nurse Jenny Jennings ran yet another 10K and raised a further £388.00. I think this is her ninth or tenth run. She has raised in excess of £2,000 and is to be



Retirement presentation: David Wyatt (left) hands Tony the committee's token of thanks

congratulated and warmly thanked for her efforts.

In April, Annie Johnson kindly opened her garden at Alswick Hall near Buntingford to raise funds for AKPA and as a result presented us with a magnificent donation of £3,013. Annie, we can't thank you enough for your support and generosity.

In addition we were blessed with some very generous legacies, including £7,000 from Myra Sankey who had a transplant for over 40 years and was a long time supporter of AKPA. Other unexpected legacies gave our funds an amazing boost, resulting in our good financial position.

AKPA is keen to fund new projects in the coming years. Exercise for dialysis patients has been discussed and talks are ongoing about a research project into physiotherapist input on dialysis wards. And this will almost certainly need some financial input from AKPA.

We have welcomed two new committee members. Ralph Slattery, has taken on the NKF Representative job following Alan Craig's retirement from the Committee last year and Scott

Devereux has been co-opted to assist Richard Jarvis with the website, communications and mailing lists.

As we advised last year, our dear Barbara Irving is retiring as Renal Welfare officer. However, she has stayed on until a new person is appointed to the post, which the British Kidney Patients Association has agreed to fund for three years.

Once again our very grateful thanks to Barbara for her unstinting service and loyal support for so many years.

Finally, last year we spoke about Satellite Patient Liaison representatives and I am pleased to be able to thank Richard Fossey who fills this position in Cambridge, Geoff Gidley who looks after Hinchingsbrooke and Colin Gant who is in post at Kings Lynn. Unfortunately we are still trying to persuade someone to take up the post at West Suffolk unit.

I think I have probably said enough, except to say, thank you all very much for your support and help over the last ten years and especially the Committee who really are the best.”

Tony Weaver, July 2013

AKPA
Annual General Meeting
July 2013

AGM Financial Report

The Year to March 2013

Income:

Our income this year was considerably boosted by legacies totalling £127,612, making our total income much higher than recent years at £172,625.

We are very grateful to members and their families who remember us in this way. But sadly, it reflects the fact that we have lost more of our loyal supporters.

Our hardworking fundraisers, mostly patients and their families, raised over £23,000 with the Xmas Raffle, 200 Club, bric-a-brac stalls, collecting tins, collections and other fundraising events. Thank you to everyone involved.

Donations and fundraising through websites **JustGiving.com** and **easyfundraising**, often given anonymously, have become significant sources of income, as have regular Standing Order donations. Thank you to all the people who raised funds and donated by these methods.

This income will enable us to continue our work of providing support for patients and their families who are experiencing hardship, and enable us to fund major projects in the coming years. Thank you to everyone who has donated and raised money for us.

Expenditure:

Our total expenditure was £73,462; considerably more than last year's £37,961.

We funded four reconditioned Haemodialysis machines at a cost of £18,482 for the Home Therapies unit. Funding for this equipment was not available from the NHS and our support enabled four patients to start haemodialysis at home.

We also funded medical alert bracelets for patients with dialysis fistulas. These have proved very popular. Also, a trial exercise machine for dialysis patients and video players for use at the West Suffolk dialysis unit.

We gave a total of £21,686 in funding for the Renal Social Worker and welfare and holiday grants for sick and needy patients. This service is highly valued by staff and patients and an important part of our charitable activities.

We funded four reconditioned Haemodialysis machines which enabled four patients to start haemodialysis at home.

Also, in conjunction with ALTA (Addenbrooke's Liver Transplant Association) we funded relaxation therapy to assist patients' recovery following transplantation. Further help to patients included £744 for Christmas buffets for patients receiving treatment over the Christmas period in the Dialysis Centre, and satellite units.

We funded nursing staff to attend conferences in order to update medical knowledge. And in order to inform and educate patients, the Association sponsored patients to attend the annual National Kidney Patients conference. We also helped publicise organ transplantation by supporting participants in the National Transplant Games.

The combination of lower funding requirements and the receipt of large

legacies means that our reserves are again higher than expected. However, we have plans and commitments for funding projects in the 2013/14 financial year.

Future developments:

In order to improve the health of dialysis patients, we intend to fund an exercise research project and part time physiotherapist for the Dialysis Centre. We will also continue to fund the development of Renal Patient view software, which we hope will be fully working in the near future.

A new Renal Welfare Officer post has been created, which will be funded by the BKPA. However, AKPA will fund any extra costs associated with this post. We will also support an extension of patient counselling services to satellite units.

We also expect to fund other equipment and patient comforts not funded by the NHS in the near future.

Administration Costs:

Despite the ever-increasing burden of financial regulation, insurance and form filling, our administration costs remain very low. At £4,262 this represents a very small proportion 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.

Brian Wood (Treasurer)

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.

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

To submit letters, articles and photos for publication in *Newsflash*

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.

Postal Address:

PO box 608
Freepost RRKT-RBGX-AETR
Cambridge
CB1 0GJ

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 see Committee Members list.

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, haemodialysis, Hinchingsbrooke dialysis, low clearance clinic.
Alice Lunt – wards G5/F5, renal transplant, home haemodialysis.
We can be contacted on 01223 216655.

■ **Queen Elizabeth Hospital – Kings Lynn**

Hannah Gilbert – Contact on 01553 613861.

■ **West Suffolk Hospital – Bury St Edmunds**

Sara Ennew – Contact on 01284 712920

AKPA Patient Representatives

Local contacts for information about AKPA, also AKPA Christmas cards and raffle

Addenbrooke's Dialysis Centre – Richard Fossey

E-mail: rd.fossey@ntlworld.com Telephone: 01234 213546

Kings Lynn – Colin Gant

E-mail: colin@gant5366.freerve.co.uk Telephone: 01553 828600

Hinchingsbrooke – Geoff and Cilla Gidley

E-mail: geoff@geoffgidley.co.uk

AKPA Committee Members 2013

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Assistant Treasurer

Tel: 01223 574951

Peter Constable

Scott Devereux

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CAPD Sister

Dialysis Centre

Box 118

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Website

Tel: 01353 675066

Janet Man

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Hardwick Lane

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Tel: 01284 712920

Nicky Moncrieff

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Hills Road

Cambridge CB2 0QQ

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