

Addenbrooke's Kidney Patients Association NEWSFLASH

Issue 1 2011

No. 49

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

A MEMBER OF THE NATIONAL KIDNEY FEDERATION

Sarah's Garden Party has X Factor



Jo Beetlestone

Sarah Rook has organised a Garden Party in aid of AKPA at her home, Birdbrook Hall on the 4th June. A barbecue lunch will be served in the

grounds of the historic hall. The hall is situated in the idyllic village of Birdbrook 4 miles NE of Haverhill

The afternoon's entertainment will feature ITV's *X Factor* soul singer Jo Beetlestone, guitarist Ash Beetson and the cool funk of The Turkey Street Jazz Band.



Birdbrook Hall

Jo Beetlestone, from Saffron Walden, won the thumbs-up from all three judges on the ITV talent show. Her renditions of soul classics have won the acclaim of audiences and ensured a demand for her performances.



The Turkey Street Band

There will also be games, including a tennis competition and activities for children.

Tickets (numbers limited) £15; includes barbecue lunch and first drink. Children under 12 free.

Please come along and enjoy the food and the entertainment in beautiful surroundings. And help Sarah raise money for AKPA.

To reserve tickets please ring Sarah Rook on 01440 785253.

www.akpa.org.uk

Dates for 2011

4th June – Birdbrook Hall Party

11 June – Cambridge Street Collection – Collectors needed: 01842 815941

29 June – AGM 6.00 pm
David Dunn Suite Addenbrooke's

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WE NEED SOME HELP

Volunteers are needed for the following AKPA fundraising schemes.

- **Bric-a-Brac stall organiser**
To organise stalls in Addenbrooke's Outpatients entrance hall.
- **Christmas Card sales organiser**
To arrange purchase of cards and distribution to hospitals, clinics and charity card shops.

Own transport necessary, travel expenses and guidance supplied. Would suit active retired person, ideally in or close to Cambridge. If you can help please send details to: **AKPA Volunteers, PO box 608, Freepost RRKT-RBGX-AETR, Cambridge CB1 0GJ or ring 01223 353575** for more info.

Where the Money Goes: – In the Last Six Months

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

- Home Haemodialysis Machine **£16,078**

And provided comforts for patients:

- DVD players for West Suffolk Unit **£539**
- TVs for Dialysis Centre **£7,354**

We continued to provide support for patients by:

- Funding Addenbrooke's Renal Welfare Officer
- Welfare grants for sick and needy patients
- Trip to Thursford for West Suffolk and Kings Lynn dialysis patients
- Dialysis Patients' Christmas Parties

Tribute to Sam



Sam Wood

It is with deep sadness that we announce the passing of Samantha Wood, AKPA's newest committee member. Sam became ill in March and

was taken to Addenbrooke's Hospital where she died suddenly, aged 26, a tremendous shock to her family and all who knew her.

Sam first came to the attention of AKPA as a member of our 15-strong group that attended the NKF Roadshow at Hinckley Island last October. She enjoyed the event and was a fun, lively member of the group who was concerned to learn how little is done by NKF and AKPA for younger people. AKPA soon co-opted Sam onto the committee,

hoping to tap into her skills and enthusiasms for the benefit of our younger patients.

After the Roadshow Sam wrote to the NKF and so impressed their Executive Committee with her ideas that they invited her to join them and head up a new drive to attract young members. Sam knew that the key to success would be to capitalise on young people's interest in social networking – Facebook, Twitter, email and texting. She was responsible for setting up “young@nkf” on Facebook and was proud and excited about how membership is steadily growing, now numbering 128.

Sam will be greatly missed by AKPA and everyone who knew her. Sam's family, friends and colleagues wish to pay tribute to her in a more detailed article which will appear in the next edition of the *Newsflash*.

BKPA Opening Ceremony



AKPA member Myra Sankey is pictured here at the opening ceremony of new Offices of the British Kidney Patient Association. Myra who last year celebrated the 40th anniversary of her kidney transplant was featured in the Association's magazine.

From left to right: Councillor Willoughby, Myra Sankey, Nicholas Owen, Chief Executive Rosemary Macri, Chair Sally Taber, Damien Hinds MP, and Mrs Margaret Willoughby.

RenalPatientView is coming to Addenbrooke's

Providing up-to-date medical information for patients and healthcare professionals

Renal PatientView **NHS**

Home Patient Details Patient Info About Me Enter My... Results Medicines Letters Contact Forum Help

RenalPatientView is a website which gives interested renal patients easy access to key parts of their medical records. Hospitals able to take part when the scheme first started use a computer system called Proton. Addenbrooke's uses a different system, but now new software is being written to allow Addenbrooke's to interface with the RenalPatientView system.



Dr Afzal Chaudhry

Dr Afzal Chaudhry, Trust and Renal Lead for IT and Consultant Nephrologist says, “RenalPatientView is well established in other parts of the UK and has been a considerable success. It is an excellent example

of enhancing a patient's involvement in their own care. The system takes information from a renal unit's computer system and links it to useful explanations about a patient's kidney condition and the relevant treatment. It shows blood test results and in some cases clinic letters and can show more. Patients, their GP and a limited number of staff from the renal unit have access to the information. Additionally, patients may share their password with anyone they wish. So it can be used to show information to relatives, friends, and to healthcare staff in other locations where renal notes are not available. It is entirely up to each individual patient as to whether or not they join the system and they are free to withdraw at any time.

The Renal Unit at Addenbrooke's would like to become a participating

PatientView centre. We feel that this would be to the benefit of our patients, and initially we plan to offer enrolment to dialysis and transplant patients. In the longer term we could also recruit interested pre-dialysis patients too.”

AKPA has funded the start-up of this new scheme, paying for the software modules and the initial IT development work needed. Dr Chaudhry pointed out that the start-up funding provided by AKPA has shown the strength of patient interest in this type of development. The Renal Unit will continue to fund maintenance and ongoing development costs.

Dr Chaudhry hopes that patient recruitment will start and Addenbrooke's will go ‘live’ with RenalPatientView before the end of the year. You can find out more about the scheme at:

<https://www.renalpatientview.org/help.do>

Alan Craig

In Time of Need

AKPA supports patients and their families who are experiencing real hardship because of kidney failure. We have done this continuously since our association was founded in 1975. We also fund a Renal Social Worker to help those patients

In order to do this we need to raise the money; from donations, raffles, 200 club, bric-a-brac stalls, Christmas card sales, collecting tins and other fundraising schemes.

Despite the hard work of our volunteers and sterling support from our members, the amount of money we raise this way has dropped over the last few years. At the same time

the number of patients requiring help has increased greatly.

Please can you help?

Donations

You can make one off donations through our website www.akpa.org.uk – or Justgiving.com (see page 4). Or send a cheque to our freepost address (page 8).

Regular donations by standing order from your Bank would be a great help to us. To arrange this please complete the enclosed Standing Order Form and return to us at the address on the form.

Gift Aid

Remember, if you also complete the Gift Aid form, we can claim tax back on your donations, increasing the value by over 20%.

Fundraising

In the last few years several of our long serving fundraisers have had to give up or have retired. We now urgently need volunteers to organise Christmas cards sales and to run bric-a-brac stalls in the outpatients area. (For details see advert on front page.)



200 Club is a Winner

Our 200 Club continues to be very popular and has grown in strength since the relaunch in 2009. During 2010, members raised £1,232 to help improve the lives of kidney patients.

Members also had a chance to share in the £1,232 paid out in monthly prize draws, which included the December Annual Grand Draw Prize of £122 paid to one lucky winner.

It only costs £12 per year for each share number, and individuals can have as many shares as they like, with half the proceeds going to AKPA funds and half to prize money.

Unfortunately a few subscriptions have not been renewed this year, so we would welcome new members to the 200 Club to help us to continue our valuable work for kidney patients.

You can join at anytime by filling in an application form which you can get from our website www.akpa.org.uk, clinic notice boards or by contacting: Jayne & David Wyatt
Telephone: 01842 815941
Email: 200club@akpa.org.uk

AKPA 200 Club Monthly Draw – Winners

2010

AUGUST

First prize £51 • No 28, Janet Davies

Second prize £26 • No 91,
Mrs S Griffin

Third prize £15 • No 298,
Mrs Jean Richards

SEPTEMBER

First prize £51 • No 24,
Mrs Ann Seaton

Second prize £26 • No 88,
Michael & Cynthia Turner

Third prize £15 • No 152,
Penny Olesen

OCTOBER

First prize £51 • No 73,
Mrs Elizabeth Olive Evans

Second prize £26 • No 204,
Mary Balmer

Third prize £15 • No 125,
Mrs V Massingham

NOVEMBER

First prize £54 • No 86, Mrs Myra Sankey

Second prize £27 • No 114, Mr M Hale

Third prize £16 • No 33, Stacey Pratt

DECEMBER

First prize £54.00 • No 128, Mike Baldock

Second prize £27 • No 257,
Daryl & Wendy Palmer

Third prize £16 • No 156, Ryan Finch

Annual Grand prize £122.00 • No 333,
Mrs M H Reid

2011

JANUARY

First prize £49 • No 4,
Margaret & John Thompson

Second prize £25 • No 215,
Helen Ingram

Third prize £15 • No 10,
Margaret & John Thompson

FEBRUARY

First prize £49 • No 42,
Mrs C J Heavingham

Second prize £25 • No 138,
Mr G A Dickerson

Third prize £15 • No 30, Tracey Griffin

MARCH

First prize £51 • No 221, Jean Weaver

Second prize £25 • No 196,
Mr John Vining

Third prize £15 • No 16, Simon Pitts

Clavering Swings to the Sixties Beat – Again



The Swinging Sixties dance in aid of AKPA is becoming an annual event in the village hall of Clavering in Essex.

In September last year the hall rocked to a sell out crowd when the sixties band *Highly Strung* performed there.

Everyone had a fabulous time and in the process raised £930 for AKPA.

The evening was organised and run by Geoff, Eileen and Wendy with a team of helpers on the evening.

Our grateful thanks to them and to the band *Highly Strung*, of which Geoff is a member.

Following the huge success of last year's event another dance has been organised for this year.

Saturday September 24 2011, Clavering Village Hall, Swing to the Sixties Beat with *Highly Strung*, again, in aid of AKPA.

Myra's Coffee Morning Raises Funds

A coffee morning organised by AKPA member Myra Sankey at her local Heritage Centre raised £137 for AKPA. The event was very well attended with a raffle, cake sale and sales of seed mats and children's books produced by Myra's niece Jane Finch.

Our thanks to Myra, Jane and all their friends and neighbours for such generous support.

Christmas Cards Sales

Despite the dreadfully bad weather, sales of AKPA Christmas Cards did very well, bringing in a total of £4,800 over the Christmas period.

The cards were on sale in Cards for Good Causes Shops in Cambridge, Bury St Edmunds, Saffron Walden and Sudbury. They were sold in the Hospital Dialysis Centre, Clinics and

Satellite Units. And in the Concourse from Margaret Johnson's charity stall.

Dorinda Ray continued to to run the mail order service and Barbara Vining sold cards from her stalls. Again Peace's Farm Shop in Buntingford sold an amazing amount of cards.

Val Slade again organised the distribution of cards to all the outlets



and recruited volunteers for the CFGC shops.

Our thanks to everyone who helped to sell our cards.

Help Us Raise More – Fundraise on JustGiving

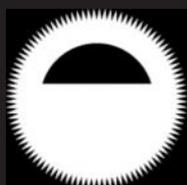
AKPA has joined up with *JustGiving*, the online fundraising and sponsorship website, to make raising money quicker, easier and more effective.

Whether you are celebrating a transplant, running a marathon or taking donations for a birthday or wedding anniversary, 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. It only takes 60 seconds! 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



JustGiving™

The A-Team Braves a Chill Wind to Mark World Kidney Day!



In March, AKPA members marked World Kidney Day with a successful street collection in Cambridge. Rain held off but a chill wind kept everyone stamping their feet during the six-hour-long event which raised a brilliant £248.92.

Pictured above are Wendy Craig, David and Jayne Wyatt, Barbara Irving and Tony Weaver. Also collecting were Alan

Craig and Michael Moore. Thanks go to everyone involved, especially David and Jayne who have recently taken over organising collections, and did a marathon six-hour stint themselves. Our collections are held two or three times a year, sometimes in shopping centres, sometimes at supermarkets. If anyone can offer the occasional hour to help, please contact David and Jayne, phone number as below.

Annual Cambridge Street Collection – June 11

The Annual Cambridge City Street collection will take place on June 11 2011. From 9.30 am to mid afternoon. Volunteers are needed to collect. Please come along and help.

Please contact David and Jayne Wyatt on 01842 815941

"I'm Back!", says Rod 'Rambo' Lenette

Rod Lenette, British Arm Wrestling Champion, has returned to the sport following his successful kidney transplant. Rod, a former haemo patient at Addenbrooke's, was transplanted in Nov 2008. Before his health problems Rod was eight times British Arm Wrestling Champion. After intensive post-transplant training he has returned to the sport and regained his British title.

Rod's enthusiasm for his sport, and the impact his transplant had on his life led to him making a short documentary film promoting transplantation. This was premiered at Bedford Cineworld in January and hopefully will be shown on TV later this year. Prof. Andrew

Bradley and Prof Steve O'rahilly feature in the film, and Rod plans soon to arrange a viewing at Addenbrooke's which both Profs can attend, together with dialysis and transplant staff and any interested members of AKPA.

Rod hopes that the film will inspire people not to give up on what they love doing. There is a trailer on YouTube: <http://armwrestling.forummotion.com/t2304-i-m-back-trailer-a-documentary-of-rod-rambo-lenette>

Rod sees this film event very much as a payback venture. He is grateful to the staff of Addenbrooke's for his excellent care, but he also feels a debt of gratitude to AKPA. During his illness before the transplant he was unable to

Thank You Michael



AKPA wishes to pay a particular tribute to Michael Moore pictured right, for his sterling work as the previous Collections

Organiser, and thank him for turning out to help the A-team with this WKD event.



Rod Lenette, pictured with his son at the Bedford Premiere of "I'm back"

work and he really appreciated the financial support given to him and his family. Rod invited AKPA to collect at the Bedford premiere and his generous audience donated over £120.

Rod and his business partner Dave O'Neill are hosting the British Grand Prix & Fitness Expo at the Excel Centre in London this spring. AKPA wishes them the best of luck.

World Kidney Day exists to raise awareness about the importance of our kidneys. Treating kidney disease early could help reduce deaths from heart disease, and this year's theme is "*Protect your kidneys, save your heart*".
Dr Richard Fluck, President-Elect of the British Renal

Society, says: "Screening for kidney disease is extremely simple, requiring a blood test to measure kidney function, as well as a test to measure the amount of protein in the urine, as increased levels indicate kidney damage. People at high risk of CVD, such as those with diabetes or high blood pressure, should be screened routinely."

When?

The second Thursday in March every year

Why?

To raise awareness of the importance of healthy kidneys

Where?

- Everywhere!
- Over 100 countries celebrate World Kidney Day
- Local activities are taking place all over the UK

Who?

- People with kidney disease
- Relatives and friends of people with kidney disease
- People at risk of kidney disease
- Healthcare professionals
- Researchers
- Health policy makers and healthcare commissioners
- Governments

Kidney Disease is common, harmful & can be treatable

Kidney disease is often 'silent', causing few symptoms, especially in the early stages. If left unchecked the disease can progress or lead to kidney failure. It can severely impact on quality of life and ultimately can cost lives. Very often it comes along with other health threatening conditions such as cardiovascular disease and diabetes.

WKD Reception at the Houses of Parliament



Each year the Kidney Alliance hosts a reception at the House of Commons to encourage government support of World Kidney Day. All MPs and key Ministers are invited and have the chance to meet kidney patients and senior professionals in the kidney community.

Star speaker this year was Ciaran Hill who has the distinction of being the youngest self-managing home haemo patient in Europe, starting when he was 13 years old. When Ciaran was only 2, his dad donated a kidney, and Ciaran had ten successful years before needing haemodialysis. More than a few tissues were pulled out as Ciaran enthralled everyone with his moving story. He wound up by describing how his first few months on home haemodialysis are making a tremendous impact on his independence, his time with family and friends, enabling him to catch up with schooling, and above all improving his health and fitness.



Richard Fluck (President-Elect of the British Renal Society), Alan Craig (AKPA), Rosemary Macri (BKPA Chief Exec.), Fiona Loud (Kidney Alliance Chair).



Anne Milton MP, Parliamentary Under Secretary of State for Public Health



Donal O'Donoghue, National Clinical Director for Kidney Care



Ciaran Hill fooling around with TV Chef Lawrence Keogh.

AKPA XMAS RAFFLE 2010

1.00 pm – 15th December 2010 in the Dialysis Centre

List of Prize Winners

1. 1st Prize £300.00 Cash – Barry Moody, Uxbridge
2. 2nd Prize £150.00 Cash – Mrs K Law, Newport
3. 3rd Prize £100.00 Cash – Mrs W Winstone, Brandon
4. £300 holiday vouchers – Mrs Pilgrim, March
5. Hamper – Mrs F Cross, Fornham All Saints
6. Hamper – G Pattison, Great Bardfield
7. £50 – N Franklin, Cambridge
8. £50 – T Henderson, Dane End
9. £50 – Shani Searle, Great Barford
10. £50 – Miss V Bean, Hatfield
11. £50 – Overton, Brightlingsea
12. £50 voucher M&S – Steve Owens, c/o Gt Bardfield
13. MOT voucher – Ben Winters, Ely
14. MOT Voucher – Michelle Bailey, Ely
15. MOT voucher – J Irish, Great Bardfield
16. £10 voucher – Ray Godby, Abbots Ripton
17. £10 voucher – Jeremy Nowing, Bristol
18. £10 voucher – David Brooke, Hartford End
19. £10 voucher – E Meen, Livermere Rd
20. £10 voucher – H Brady, Oundle
21. £10 voucher – G Parrish, Litlington
22. Family Ticket – Mrs Hillyard, Eaton Ford
23. Bottle Whisky – Simon Price, Haverhill
24. Box miniature Jams – E J Rees, Bedford
25. Tin Champagne – Tom Walker, Thaxted
26. Box Tea – Tim & June Colebrook, Gamlingay
27. £10 voucher – Jarman, Cambridge
28. Slow Cooker – Mrs Massingham, Doddington
29. Irish Liquer – Elizabeth Freeman, Sutton
30. Car Valet – Jane Hood, Ashdon
31. Meal for 2 – Ron (nurse green room), Dialysis Unit
32. Scotsdale Voucher – Mrs Hayhoe, Bury St Edmunds

The raffle, organised by Sarah Rook with help from Richard Fossey did very well. The net result raised £2,620 for AKPA. Thanks are due to Sarah and Richard for their hard work.

Donated prizes included £250 for five £50 cash prizes.

Several people sold large amounts of tickets; Jon and Angela Allen sold £366 worth.

Our thanks to everyone who participated, those who bought and sold tickets and those who generously gave prizes.

Renal Diet Information

If you have any questions regarding your diet please contact the relevant dietician. Here's a who's who of the dieticians in our area:

■ Addenbrooke's – Cambridge

Elaine Corden – covers CAPD.

Clare Parslow – covers ward C5, nephrology clinic and haemodialysis.

Laura MGeeney – covers ward C9 and transplant clinic.

We can be contacted on 01223 216655.

■ Queen Elizabeth Hospital – Kings Lynn

Hannah Lodge – covers the satellite

haemodialysis unit.

Contact on 01553 613861.

■ West Suffolk Hospital – Bury St Edmunds

Sara Volkert – covers the satellite

haemodialysis unit.

Contact on 01284 713010

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

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,
Freeport 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*

NKF Helpline



Tel. 0845 601 02 09

E-mail:
helpline@kidney.org.uk

Website:
www.kidney.org.uk

Renal Book Club

Books can be borrowed and listings obtained by return of post simply by making contact with me direct at:

**Bellevue, Foul Anchor, Tydd,
Wisbech, Cambs. PE13 5RF**

Tel: 01945 420291

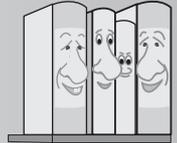
or by e-mail at
roger@anchor100.freeserve.co.uk

Books include:

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

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

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



Roger Ward.

HELP

ADDENBROOKE'S KIDNEY PATIENTS

Help

Addenbrooke's
Kidney Patients
when you shop

on-line –

visit [www.akpa.org.uk/
easyfundraising](http://www.akpa.org.uk/easyfundraising)
for more information.

Our website address is:

www.akpa.org.uk

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

You can e-mail us at:

info@akpa.org.uk

For general enquiries to the AKPA.

fundraising@akpa.org.uk

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

questions@akpa.org.uk

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

webmaster@akpa.org.uk

For suggestions, comments or requests for the website. Remember we are happy to advertise your fundraising event if you can supply us with a photo.

Newsflash Contributions

We would love to hear from you, letters and articles for publication in *Newsflash* are always welcome.

Send them to the editor:

Brian Wood

newsflash@qkpa.org.uk