



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

A MEMBER OF THE NATIONAL KIDNEY FEDERATION

John O'Groats to Lands End on a Dialysis Machine



Barrie crosses the 'finishing line'

Addenbrooke's dialysis patient Barrie Mill, completed a long distance cycling challenge from Lands End to John O'Groats without leaving the Dialysis Unit.

Barrie, 64, from Saffron Walden pedalled the 878 miles on an exercise bike strapped to his dialysis chair. He said "I enjoy exercise and staying fit, and cycling from Lands End to John O'Groats was always a lifelong ambition. Doing it on dialysis is not quite the same as doing it for real but it is still an achievement. One day I would still like to do the journey on the road."

Research has shown that exercise while on dialysis can increase solute removal, shorten dialysis time, improve fitness and wellbeing and alleviate restless leg syndrome.

AKPA has funded twenty exercise bikes for Addenbrooke's patients and they should be available shortly.

Our congratulations to Barrie for an amazing achievement and thanks for the money raised through sponsorship of his ride.



www.akpa.org.uk

In this issue

- ▶ Blood Results Online 2
- ▶ Home Haemo Help 2
- ▶ Tough Mudder 2
- ▶ Fundraising 3
- ▶ AKPA People – Profiles 4-5
- ▶ 200 Club Winners 6
- ▶ Xmas 2011 Raffle Winners 6
- ▶ Register for E-mail Updates 8
- ▶ AKPA Contributions 8

Dates for 2012

- 14th June – Bric-a-Brac stall in Outpatients entrance hall
- 18th July – AGM – 6.00pm, David Dunn Suite, Addenbrooke's Hospital
- 21st July – Collection Tesco Newmarket Road Cambridge
- 11th August – Collection Tesco Fulbourn

Annual General Meeting

The AKPA AGM will be held in the David Dunn Suite, Addenbrooke's Hospital on July 18th at 6.00pm. Please come along. There will be a free buffet and refreshments followed by talks and presentations on subjects of interest to renal patients. A full programme will be distributed nearer the date.

Some committee members will be retiring over the next year. We also need volunteers to help with our work. Please let us know if you are interested.

Contact:
Tony Weaver
Telephone: 01799 525875

Blood Results Online – *RenalPatientView*

Addenbrooke's renal patients should soon be able to view their blood test results on their home computers.

RenalPatientView, the software that will enable them to do this, is well established in other parts of the UK and has been a considerable success.

The software takes information from the renal unit's computer and displays blood test results with explanations about the condition of the patient's kidneys. The patient, their GP and a limited number of staff from the renal unit can have access to this information on the patient's area of the *RenalPatientView* website.

AKPA have funded the work to link Addenbrooke's Renal Unit with *RenalPatientView*. It is now two-thirds completed and the final phases,

including testing, should be completed by the end of May.

Once the testing is completed Senior Nurses from the various areas (dialysis, transplant, renal genetics etc) will be approaching individual patients with regard to signing up.

Due to the number of patients who might wish to take advantage of this option, it is likely that the invitations to join up will be staged over time, but we envisage that the majority of patients will be contacted by the middle of July at the latest.

For more information about the system, view the *RenalPatientView* website www.renalpatientview.org

Dr Afzal Chaudhry

Home Haemo Help

Recently, an Addenbrooke's patient was unable to start home haemodialysis because no NHS funding was available for the cabin to house the dialysis machine. AKPA gave a grant of £3,300 to fund the Cabin so that the patient could start dialysis at home.

After a long decline, Home haemodialysis is seeing a revival. However NHS budgets are very limited and help is needed to support the increase in this service. In the last two years AKPA has funded two Home haemo machines because NHS money was not available.

Over the next few years we are expecting to be asked to give more support for the expansion of this service. Government guidelines have set a target for Addenbrooke's of 70 home haemo patients by 2015. But there is no NHS funding for the machines, which cost around £22,000 each.

Open Garden

Saturday 16th and Sunday 17th June 2012

Ring Farm
Holme Fen Drove
Colne
PE28 3RE

12 noon - 5 pm

Entrance £3.00 per person - accompanied children free

**A mature garden with traditional borders.
Kitchen garden with seasonal cutting flowers.
Swimming pool conversion to a natural pond.
Unique sculptures created by Peter Baker -
who will be at the garden on both days.**

Teas
Homemade Cakes and Scones
Plant Stall
Rose Sales
Raffle

Proceeds to the Dialysis Unit at Addenbrooke's Hospital.

Proceeds from the rose sale to be shared equally between
Colne Village Hall and Earith Village Association.

Guide dogs only

For more information please call 01487 841382

Tough Mudder



On May 12th in the grounds of Boughton House, Kettering, eight men from 15 Squadron RAF Regiment based at Honington, ran through mud and water: jumped, crawled and slithered through a variety of unmentionable obstacles and ended one of the toughest endurance races ever by running through dangling live wires.

The course, over 12 gruelling miles, was devised by British Special Forces to include probably the worst obstacles compared to any other event.

These brave or possibly mad men did all of this to raise money for the RAF Benevolent Fund and AKPA. Our thanks to them all.

For more information see www.toughmudder.co.uk

Soul Songs for AKPA

Eight piece soul band Superstition raised £500 for AKPA with a charity concert in Thaxted last November. Fronted by vocalist and transplant patient Adrian Weaver the band stormed through hits spanning six decades, including songs by Rose Royce, James Brown, Wilson Pickett, Barry White and the Beatles.

Lead singer Adrian has performed with top local groups over many years despite undergoing two transplants and periods on dialysis. The band included



Superstition

some of the finest musicians from London and Cambridge with a wealth of experience including playing in West End shows.

Our thanks to Adrian and the band.

Haig Court Bring & Buy

For the second year running the residents of Haig Court Chesterton have supported AKPA by donating the proceeds of their Bring and Buy sale. The sale, held in November last year raised £191 for our charity.

Our thanks to House Manager Adrian Livermore and all the residents for their generosity.

Bric-a-Brac Stalls

Sue Oates and Monica Taylor ran another Bric-a-Brac stall in the Out Patient's entrance in March. The stall was well stocked with items donated by friends and supporters, which sold very quickly and raised £272 for AKPA.

Sue and Monica are planning more stalls in the same venue and would welcome donations of good quality bric a brac to sell. Items can be left in the Dialysis Centre.

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

World Kidney Day Collection

Nurses in Addenbrooke's Dialysis Centre organised a collection to mark World Kidney Day, 8th March. They managed to raise the magnificent sum of £664, which was divided equally between AKPA and the National Kidney Federation.

Our thanks to all the nursing staff and to all those patients who generously donated.

Richard Fossey

Eve's Paintings

Eve Richardson has been selling her paintings and donating the proceeds to AKPA for many years.

She recently donated another £100 from sales and we estimated that over the years she has raised over £4,500 for AKPA in this way.

Eve's regular donations over the years have helped AKPA to continue providing support for kidney patients at Addenbrooke's.

Our thanks to Eve for her dedication and hard work.

Supermarket Collectors Needed



David and Jayne Wyatt have arranged two Supermarket collections at Cambridge branches of Tesco later this year. On the Saturday July 21st at the Newmarket Road store and Saturday August 11th at the Fulbourn store.

Collectors will be needed and we would be very grateful for any help. If you can come along, even for an hour or so, please contact: David and Jayne Telephone: 01842 815941.

Christmas Card Sales

Sales of AKPA Christmas cards did well again last year raising over £2,000 for AKPA.

They were sold in various hospital outlets including the Dialysis centre and Clinic 12. Our thanks to all who helped sell our cards in Addenbrooke's and the Satellite Units.

Cambridge Cards for Good Causes shop raised £538 and Pearce's Farm Shop in Buntingford sold an amazing £705 worth. Our thanks to Monica Taylor for her hard work in the Cambridge card shop and to all at Pearce's Farm shop for their brilliant contribution.

New designs are planned for next Christmas but we urgently need someone to organise card sales and volunteers to help in the Cambridge card shop. **Phone 01223 353575**

Winter Warmers at City Fair



Mill Road Winter Fair has become a very popular annual event in Cambridge and Mr and Mrs Raj Gharv, owners of the Lallys News used the Fair to raise funds for AKPA.

They set up a stall outside their Mill Road shop selling delicious Indian snacks to the crowds thronging the street, and donated all the proceeds to AKPA. Their bhajis and curry were a great success and raised a total of £380 for AKPA.

Our thanks to Mr and Mrs Gharv for this brilliant fundraising effort and for all the full collecting tins from their shop that they regularly deliver to AKPA.

AKPA People

Committee



Tony Weaver

Tony Weaver – Chairman

Tony joined the committee some years ago persuaded by one of his sons who had kidney failure.

After 5 years as Chairman he then became vice Chair for a couple of years but is now Chairman again.

Tony lives in Saffron Walden and is now officially retired (but working part time) after finishing his ‘proper’ working life as Maintenance Manager for Christ’s College in Cambridge.

He will be standing for the Committee again this year if needed, but confirms that it will be his last year.



Brian Wood

Brian Wood – Newsflash Editor and Treasurer

Brian is 69 and lives in Cambridge.

He is now retired, following a long career as Technical

Officer in Cambridge University.

Brian’s wife Jill had a successful transplant in 1993. Jill had several roles in AKPA including Treasurer.

It was through her involvement that Brian took on the role of *Newsflash* Editor. After her death he also took on the role of Treasurer and is responsible for the day to day financial operations of the charity.



Andrew Collins

Andrew Collins – Deputy Treasurer

Andrew is 49 and married to Lisa. They live in Cherry Hinton and are both from Cambridge. He

works in Bury St Edmunds as the accounts manager for a small family run firm.

Andrew suffered kidney failure in 1992 and was on haemodialysis for 11 years before receiving a transplant in 2003.

He is responsible for completing the gift aid claims, charity commission returns & all statutory forms required by Companies house for the AKPA.



Alan Craig

Alan Craig – NKF Representative

Alan is 65 and recently retired from education training. He lives in Stotfold, Beds. with his wife

Wendy, close by to his two daughters and new granddaughter. Alan was lucky to have an early diagnosis of polycystic kidney disease and he has had a successful kidney transplant for 23 years.

After a long period in various committee roles Alan is standing down from the AKPA Committee as our Representative to the parent organisation, the National Kidney Federation (NKF). His role involved liaising between the two organisations, mainly by email, informing the committee of national patient-related issues and attending twice yearly NKF Council meetings.

David and Jayne Wyatt – Vice-Chairman and Fundraising



David Wyatt



Jayne Wyatt

David and Jayne joined the committee in 2008 and began by reviving the 200 Club, they have since taken on Street and Supermarket Collections. Both of these are very important and lucrative fundraising schemes for AKPA. David has also taken on the role of Vice-Chairman.

Jayne started CAPD in 1998 following chronic renal failure and after two unsuccessful transplants received a successful transplant in 2004. David became a live donor in 2005 when he donated a kidney to their daughter Michelle. All three are now doing very well.



Nicky Moncrieff

Nicky Moncrieff – Staff Representative

Nicky is married with 2 children aged 18 and 21. She has worked at Addenbrooke’s

renal unit for over 25 years, first as peritoneal dialysis sister for 20 years and now as Renal Nurse Specialist for pre-dialysis patients.

She has been on the AKPA committee since 1987 and acts as liaison between AKPA and the unit, guiding appropriate expenditure and helping with queries.



Richard Jarvis

Richard Jarvis – Website

Richard is a 37-year-old transplant recipient who designed and maintains the AKPA website.

He has also set up internet fundraising schemes for AKPA with JustGiving.com and easyfundraising.

Following a brief spell on dialysis in 2005 he received a kidney from his wife Lorna. They have subsequently had two children and the family lives in the Fenland idyll of Shippea Hill where Richard divides his time between staying fit and healthy, looking after his children, running a company with his brother installing home cinema systems and computer networks and trying (and mostly failing) to squeeze the rest of his life in the diminishing gaps in between!

AKPA People

Derek Varley –
Bury St Edmunds Patient Representative, and Social Event Coordinator

Derek is one of the longest serving committee members and represents AKPA at the West Suffolk Hospital satellite unit where he dialyses. He is involved in the organisation of social and fundraising events in the unit.

Jenny Ridgeon –
Committee Secretary

Jenny has been providing invaluable support to the committee for many years. She books venues, takes minutes, deals with correspondence, updates mailing lists and generally keeps the whole show on the road.

Co-opted Committee Members

Barbara Irving –
Renal Welfare Officer

Barbara has been providing welfare advice to Addenbrooke's renal patients for over twenty-five years and has also been a co-opted committee member and fundraiser for all that time.

Her role is to help needy patients. She will help patients to complete DLA and Attendance Allowance forms and will apply for grants from AKPA and other charities on behalf of patients with financial and benefit problems.

She reports to the AKPA committee about patient welfare grants and liaises (in confidence) with two committee members with responsibility for approving welfare grants. She also distributes AKPA information to new patients at Pre-Dialysis meetings.

After a long and dedicated career both helping Addenbrooke's renal patients and raising funds for AKPA, Barbara is retiring this year.



Angela Green

Angela Green –
Senior Sister

Angela is in charge of the newly merged Home Therapies, which incorporates peritoneal dialysis and home haemodialysis across the region. At present they are supporting 45 PD patients and twenty Home Haemo patients in the community. Angela serves on the AKPA committee as patient advocate



Julia McCarthy

Julia McCarthy –
Sister at the West Suffolk Satellite Dialysis Unit

Julia has served on the AKPA committee for many years representing the West Suffolk Unit. She advises the committee on patient needs and organises regular social and fundraising events at the unit.

AKPA Patient Reps.



Richard Fossey

Richard Fossey –
Addenbrooke's Patient Representative

Richard lives in Bedford with his wife Josie. He has been on haemodialysis for many years and has been involved with AKPA for a good proportion of that time. He recently retired from the committee after a long and distinguished career as Raffle Organiser and Fundraiser.

Richard is now the AKPA patient representative in the Dialysis Centre, reporting to the Committee on patient issues; distributing information about AKPA and encouraging fundraising and membership.

Email: rd.fossey@ntlworld.com
Tel: 01234 213546



Geoff & Cilla Gidley

Geoff and Cilla Gidley –
Hinchingbrooke Patient Representatives

Geoff and Cilla are both retired, they have three married children and four grandchildren.

Cilla became a haemodialysis patient at Hinchingbrooke Dialysis Centre in April 2009.

Soon after they had come to terms with the impact of this on their day-to-day lives, Geoff became an Addenbrooke's Volunteer at Hinchingbrooke. Whilst he is nominally 'tea-boy' the role offers scope to work with the unit manager, and her staff helping to maximise the positive aspects of patients' experience.

Geoff and Cilla have now taken on the role of AKPA reps. reporting to the Committee on patient issues; distributing information about AKPA and encouraging fundraising and membership.

Email: Geoff@geoffgidley.co.uk



Colin Gant

Colin Gant – Kings Lynn Patient Representative,
Colin, who lives near the Kings Lynn dialysis unit, was involved with AKPA from the earliest days, serving as Vice-Chairman and Publicity Van Organiser, he was also

involved in the Transplant Games. Although he retired from the committee some years ago he has maintained an interest in AKPA.

Colin was a haemodialysis patient who received a successful transplant in the 1980s. When his transplant failed four years ago he returned to haemodialysis at the Kings Lynn Unit. He renewed his connections with the AKPA committee after attending the NKF conference and is now Kings Lynn Patient Representative.

Email: colin@gant5366.freemove.co.uk
Tel: 01553 828600

A Fond Farewell from Addenbrooke's Dialysis Centre

In November we said goodbye to our young "tea lady", Julia who left our family to go for further education to learn English having originally come from Eastern Europe.

We, the patients on Haemodialysis regard all involved from Nephrologists, Doctors, Nursing staff, Technicians and all support staff as well as those suffering from renal failure as part of One Big Family.

Our uniqueness being on dialysis is that mostly everybody spends three days a week receiving treatment and sharing each other's company for many hours together.

It must be said that the quality of the nursing staff who are daily taking care of us, the patients, is very high and the majority here treat their work as a vocation and doing it efficiently does not need a University qualification (in my opinion).



Dialysis Staff Say Goodbye to Julia

Both staff and patients bid Julia a farewell for pastures new and presented her with leaving presents from all of us

to show our appreciation and wish her every success and happiness.

Richard Fossey

Thanks to AKPA for Funding Staff Development

I would like to take the opportunity to thank the AKPA for funding my course in Preparation to Teach in the Lifelong Learning Sector or PTTLs (pronounced petals) as it is affectionately known.

This course allowed me to expand and explore the teaching aspects of my job as a Renal Nurse Specialist. A large part of my role involves developing the skills of haemodialysis staff nurses, so this course has proved instrumental in my planning and delivering their study days and training courses.

The other part of my job involves teaching and educating pre-dialysis patients about their treatments and plans. And I know that this course has given direct benefits on several fronts for the patients we all care deeply about. Many thanks.

James Perry – Renal Nurse Specialist

AKPA 200 Club – Monthly Draw – Winners

2011 SEPTEMBER

First prize £50 • No 19,
John Rook
Second prize £25 • No 176,
Arthur Muir
Third prize £15 • No 45,
Richard & Lorna Jarvis

OCTOBER

First prize £50 • No 129,
Nick Crocker
Second prize £25 • No 32,
Mrs Janet Day
Third prize £15 • No 53,
Beverly Wilson

NOVEMBER

First prize £51 • No 327,
Mrs Pauline Linwood
Second prize £25 • No 82,
Mr A K Baker
Third prize £15 • No 266,
Paul Owens

DECEMBER

First prize £50.00 • No 27, Monica Taylor
Second prize £25 • No 140,
Sue & Byron Harvey
Third prize £15 • No 349,
Mr & Mrs Tom Ballantyne
Grand prize £120 • No 203,
Andrew Collins

2012 JANUARY

First prize £45 • No 11,
Mrs Bridget Brady
Second prize £23 • No 33, StaceyPratt
Third prize £14 • No 166,
Sue & Byron Harvey

FEBRUARY

First prize £45 • No 242, Ann Parker
Second prize £23 • No 22,
Mrs Barbara Irving
Third prize £14 • No 85,
Mrs Margaret Hill

MARCH

First prize £47 • No 31,
Mrs Gladys Rogerson
Second prize £23 • No 102,
Mr A Newby
Third prize £14 • No 22,
Mrs Barbara Irving

APRIL

First prize £47 • No 192,
Tim & Pam Ayres
Second prize £23 • No 81,
Mrs Pauline Linwood
Third prize £14 • No 348,
Tim & Pam Ayres

New Members welcome,
contact David and Jayne Wyatt
Tel: 01842 815941

AKPA XMAS RAFFLE 2011

2.00 pm – 12th December 2011
in the Dialysis Centre

List of Prize Winners

1. 1st Prize £300 – Mrs S May, Braintree
2. 2nd Prize £150 – Iain Drane, Braintree
3. 3rd Prize £100 – Ronald Markham, Cambridge
4. Hamper – Mr Rodgeron, Melbourn
5. Hamper – Shani Searle, Great Bardfield
6. £50 M&S Voucher – Mr Finch, Bacton
7. £50 Restaurant Voucher – Marivic, Dialysis Unit
8. £50 Restaurant Voucher – Arlyn, Dialysis Unit
9. Box Rioja Wine – Mrs F Smith, Claydon
10. Christmas Cake – Geoff Gridley, Rushden
11. £10 Tesco Voucher – Mrs Heavingham, Brandon
12. £20 Tesco Voucher – Irene McCartney, Cambridge
13. £10 Tesco Voucher – Charlotte Blunham, Bedford
14. £10 Tesco Voucher – Mrs J Man, Cambridge
15. £10 Tesco Voucher – Tony Sawyer, Bishops Stortford
16. £10 Tesco Voucher – Simon Pitts, Bishops Stortford
17. £10 Tesco Voucher – C Holland, Northumberland
18. £10 Tesco Voucher – Muriel Bond, Fressingfield
19. Bottle Irish Crème – Gaynor, Green Room
20. 4 Bottles Wine – Mrs White, Fulborn
21. £10 John Lewis Voucher – Alan Carr, Saffron Walden
22. £5 Tesco Voucher – P Ellis, March
23. Scotsdale Voucher – Sue Oates, Cambridge
24. John Lewis Voucher – Anne Whitmarsh, Winchester
25. Set Mugs – J A Day, Gamlingay
26. Tesco Voucher – Laria Sell, Melbourn

The raffle, which was organised by Sarah Rook was a great success and raised £2,276 for AKPA. Thanks are due to Sarah for all her hard work.

Several people once again sold large numbers of tickets with Jon and Angela Allen selling an amazing £400 worth.

Our thanks to everyone who generously donated prizes and to all those who bought and sold tickets.

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*

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

AKPA News Online

To receive news updates from AKPA please register by e-mailing your name and address to members@akpa.org.uk.

Contributions to *Newsflash* always welcome. Send to editor at above e-mail address or post to Brian Wood, e-mail for address details or check back page of *Newsflash* in Committee Members List.

NKF Helpline



Tel. 0845 601 02 09

E-mail:
helpline@kidney.org.uk

Website:
www.kidney.org.uk

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



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@akpa.org.uk