



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

A MEMBER OF THE NATIONAL KIDNEY FEDERATION

The AKPA Great Grafham Event

www.akpa.org.uk



Completing the Full Circle

Many people so enjoyed walking or cycling around Grafham Water for this fundraising event on Saturday 15th July, that they suggested it should be held annually. Event organiser Graham Norton and committee member Martin Harnor signed in over 30 walkers and cyclists for either the Full Circle or Dam Stroll around the lake.

Apart from a slight rain shower the weather was fine and walkers and cyclists followed the well laid out paths through the varied scenery around the lake, arriving back at the cafe for drinks donated by Anglian Water.

The event raised £430 for AKPA – our thanks to Andrew, Martin, Anglian Water and all the participants.

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Dates for 2017

Mon. Nov. 6th, 6.00pm –
AKPA EGM
Cambridge Dialysis Centre

Sat. Dec. 2nd, 3.00pm –
AKPA & NKF Carol Service,
Great St Mary's, Cambridge

Fri. Dec. 8th, 6.30pm –
Philip Mead & Choir,
Cambridge Dialysis Centre

Wed. Dec. 13th, 2.00pm –
AKPA Raffle Draw,
Cambridge Dialysis Centre

Thurs. Dec. 14th –
AKPA Bric-a-Brac stall,
Outpatients Entrance Hall

Christmas Carol Service

Saturday 2nd December at 3.00 pm in
Great St Mary's Church Cambridge

Please join us for our annual Carol Service.

Again, Dr Rowan Williams (former Archbishop of Canterbury) will lead the service and give the address. St Augustine's Choir under their director Philip Mead with organist Cara Ellison will lead in seasonal carols interspersed with traditional bible readings and lighting of candles.

Refreshments will be served after the service, giving time to talk with friends old and new.

All welcome – we look forward to seeing you there.

Dialysis Garden Grows from Old Pallets

The entrance to the Addenbrooke's Dialysis Unit at Beadle's Way industrial estate has been made more interesting and beautiful this summer thanks to the kind hearts of two patients.

Stephen Wilson, together with **Ron Mackie**, were asked by Claire Joyce (Social Care Practitioner) if they would like to help plant flowers in the planters funded by **AKPA**.

Stephen being a resourceful fellow, thought that not only would he do this but he would also create a little allotment behind the bicycle sheds using pallets donated by Craig at the Pipe Centre, and seeds and plants he was going to throw away. Rather incredibly, every time he came for dialysis he would bring 5 or 6 bags of earth from home for the containers. Stephen says, **"It was created for the people by the people"**. And he is grateful for the support of AKPA who funded the garden benches as well as roses, tulips and primroses for the planters.

In the pallet containers our gardening duo planted seeds and seedlings that eventually grew into the most wonderful crop of broad beans, lettuce, garlic,

onions, peas and radishes, together with a note for patients and staff to **"Pick what you want, when you want"**.

Very sadly Ron Mackie has since passed away but not before he had helped to set up this wonderful allotment. Take a look amongst the greenery and you will find a rose dedicated to dear Ron nestling amidst the growth.

Stephen continues to work on the allotment, tending and watering the plants. He says, "Keep your eyes open for beetroot, cabbage and brussels (also, maybe some apples)".

I asked Stephen if he had any gardening advice for people who grow their own produce, "If you struggle with greenfly or caterpillars, soak one clove of garlic in water and then spray it over the plants, it's harmless to the environment and your plants will thank you".

Perhaps we could find a way to thank



The Dialysis Garden

Stephen – perhaps this is the kind of dedication that deserves an MBE?! Stephen says he'd rather just have a CDM (Cadbury's Dairy Milk)!

If you would like to help Stephen with the mini allotment please speak to Claire Joyce (Tel. 01223 400180) off the waiting room or look out for Stephen himself (P.M. Tues./Thurs./Sat.) often to be found by the puzzle table! He would urgently like some assistance.

Suzi Turton

Bringing Music to the Dialysis Centre



Philip Mead playing the new Dialysis Centre Piano

Cambridge Dialysis centre recently acquired a piano as a result of a donation and AKPA were pleased to fund the cost of moving and tuning it.

Gerrie Millar, Renal counsellor said: "We want to bring a little bit of live music to the Dialysis Centre. This can change the experience for patients especially when waiting to go on dialysis, or waiting for transport. We have been very fortunate that Philip Mead, a great pianist, has been willing to come and play to us on two occasions recently. The feedback from patients has been very heart warming with comments like: "this is wonderful, I feel very emotional," and "this is the happiest I have ever been in dialysis while waiting for my taxi to arrive." Patients have applauded Philip, and even cheered on occasions. The piano has brought real joy to the Centre."

We would welcome pianists who can play well to use the piano, whether patients, relatives or staff. If you know

anyone who might be interested please contact Gerrie on: **01223 400186** or email **gerrie.millar@addenbrookes.nhs.uk**.

There is a growing interest in live piano music in public places including hospitals, and over time we want to look at the benefits to patients of providing this.

On the 8th December from 6.30 to 7.30pm Philip is bringing a choir to sing in the Dialysis Centre. All patients, relatives and staff are welcome to come and listen.



Addenbrooke's Patients Selected for World Games

In June of this year 14 members of our Team Addenbrooke's were selected to represent Team GB & NI in the World Transplant Games hosted by Malaga in Spain. Seven of those being kidney recipients and seven liver recipients.

All 14 had trained hard and deserved the glory they received by bringing home at least one medal. Team GB & NI won overall: – it's official we have the best Transplant Sport athletes in the world!



Veteran Transplant Games Athlete Malcolm Souza-Lewis with his medals: gold in Javelin, Discus, Ball Throw and High jump, and silver in Shot Putt at the British Transplant Games in Lanarkshire.



Iain Maxwell and Andy McGarry with their gold medals for golf at the Malaga World Transplant Games

Shortly afterwards, in July, a small Addenbrooke's team (eight kidney recipients and five liver recipients) travelled to North Lanarkshire to compete in the British Transplant Games.

The opening ceremony was amazing with over 800 competitors attending. This opening ceremony enables us to show our appreciation of the Donor Family Network and the living donors for their generosity and support. And

to raise the profile of organ donation by celebrating the Gift of Life through sport. Every team member put 100% effort in, all winning medals and I'm proud to say even though we had a small team we came fourth overall.

The importance of these games is paramount in highlighting how transplantation changes peoples lives. Not only does it give recipients the opportunity to get active after their transplant, it opens doors to meet a network of people who have been through the same experiences, you cannot put a price on this. Transplant Sport really does change lives.

I would like to thank ACT, the Transplant Unit, AKPA and ALTA for their ongoing support. Without your help, team members would not be able to afford to attend Transplant Sport events, therefore reducing the promotion of our Transplant Unit and organ donation.

For more information go to the team's website: atgt.co.uk.

Nina Herbert
Team Manager

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. to Sat. 10.00 am – 4.45pm

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

www.pearcesfarmshop.com

Tel: 01920 821246.

Open: Mon. to Sat. 8.30am – 5.00 pm,
Sun. 10.00 am – 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
- Hinchingbrooke Hospital

All proceeds go to AKPA.

Message in cards; "*Season's greetings and best wishes for the new year*".

New Raffle Organisers

Ralph and Carol Slattery have kindly offered to take over running the AKPA Christmas raffle. Carol already organises and distributes AKPA Christmas cards throughout the hospital and will combine that with distributing raffle tickets.

Cards are on sale at various outlets and raffle tickets will be available in early November.

Thank you Sarah

After many years as a member of the AKPA committee Sarah Rook has decided to stand down due to family commitments. During recent years Sarah has achieved great results as organiser of the AKPA Christmas raffle and supported our events with some wonderful catering. Although she is leaving the committee, Sarah has kindly offered to supply the catering for this year's Carol Service.

Our thanks to Sarah for all her committee, fundraising and catering work, and best wishes for the future.

A Kidney Donated and a Parachute Jump – Sally and Daryl’s Story

When Sally Hayden became a live kidney donor by donating to her brother Daryl, she made a condition, that, when they were both back to full health they would do a tandem parachute jump to say thank you to Addenbrooke’s and the Broomfield Kidney Unit for all their care.



Sally and Daryl landing

Sally explained that, Daryl’s health was deteriorating due to a kidney condition and in 2014 he was told by the Broomfield Kidney Unit that he would need a Kidney transplant. At the time he was adamant it would be from a

deceased donor. But his family and friends had other ideas and began tests to find the best match.

By December Daryl started on Dialysis and was put on to the ‘transplant list’. Sally said, “The care he received from Broomfield was amazing, the Renal Team were with him every step of the way. The rest of us, were under the care of Addenbrooke’s; and the Live Donor Co-ordinators had their work cut out as two of us were very close matches. After lots of discussions, tears and consultations a live donor and date were set for the transplant. On the 9th April, after lots of deliberation and tremendous worry for those close to us, Daryl and I were prepared for surgery.”

“Just over a year later, Daryl is living life to the full, I am fully recovered and meet up with my left kidney often! From my point of view “That’s what little sisters are for”, as I had a spare and we came out of the same mould then there was never any doubt in my mind that we could share my kidneys.”

“We jumped on the 23rd July 2016 from the North London Parachute club and were lucky enough to have 6 close family and friends to jump with us. A



Sally and Daryl’s Dad

big thank you to our amazing dad who jumped 4 days before his 75 birthday and our mum for being there supporting us and dreading every second until we all landed safely.”

Our thanks to Sally, Daryl, their family and friends. They raised over £3,000 to be split between Addenbrooke’s and the Broomfield Kidney unit.

Race Night in Memory of Michael

A Race Night held at Moreton Hall Community Centre in Bury St Edmunds raised £1,600 for AKPA. The event on the 25th August was organised by Paul Webb in memory of his brother-in-law Michael Chudley.

Michael, who had been on dialysis for 18 months was born with kidney problems and had many operations throughout his life, with only his close family knowing he had any health problems. He was due to have a kidney transplant donated by Paul’s wife Lorraine, who was found to be a match for her brother. Sadly, before the date could be set for the transplant he was taken ill and died. His funeral was on 30th September last year on what would have been his 33rd birthday.

Paul and his family wanted to do something positive to mark the first

anniversary and to help others. Paul said, “Seeing where the money is to be used has inspired us to make this an annual event and we have booked another night on Saturday 15th September next year and set up a new Just giving page.”

Our thanks to Paul and his family.



Bric-a-Brac Stalls

During the spring and summer Sue Oates and Monica Taylor’s bric-a-brac stalls in the Outpatient’s hall raised £544 for AKPA. In October Carol Slattery and Monica ran a card stall in the same venue selling old stock AKPA Christmas Cards at reduced prices and raised £107.

Sue and Monica are planning to hold another bric-a-brac stall on the 14th December and would welcome donations of good quality bric-a-brac. Our thanks to Sue, Monica and Carol.

AKPA needs volunteers to help with fundraising.
Please can you help?
Contact: Janet Man
Telephone: 01223 660312
Email: fundraising@akpa.org.uk

AKPA Annual General Meeting June 2017

This year's AGM was held in the Cambridge Dialysis Centre and began with the traditional buffet and refreshments.

AKPA Chairman, Peter Constable welcomed everyone thanking them for their support.

AGM Talk

Peter then introduced Stephen Bond, Transplant Co-ordinator Team Leader who gave a talk on the work of Transplant Co-ordinators in Addenbrooke's.

Stephen began by talking about waiting lists and the risk of dying before getting a transplant, adding "It doesn't have to be that way". He continued by outlining the work of the team, describing the specialist care and advice they provide for patients being assessed for kidney transplantation and for those who have received a transplant.

Stephen then spoke about paired kidney exchanges and the possible advantages of having an "Opt out" organ donation scheme as in Wales. Ending with answers to questions from the audience.

Chairman's Report

Peter updated the meeting on the *Dialysis Exercise Project* funded by AKPA. The outcome was particularly good for patients and it was hoped to resume it very soon. He then described a recent project where artefacts from Cambridge Museums were displayed to patients during dialysis, creating interesting discussions.

He continued with the news that Philip Mead, a distinguished pianist and choir master, (who was present) had offered to arrange a musical event at the dialysis unit with members of the St Augustine Singers. Peter thanked Philip and the Choir for their wonderful performances at the AKPA Carol services.

Peter drew the attention of the meeting to the recent report by the British Kidney Association and UK Renal Registry on "Patient Experience of Kidney Care". This report showed Addenbrooke's as being in the middle of the spectrum of the dialysis centres, and our patients were reported as being

reasonably happy with the transport arrangements.

He ended by thanking all our fundraisers, committee members, and supporters.

Financial Report – Year Ending 31st March 2017

AKPA Treasurer Brian Wood reported another good year with income totalling £50,268. Enabling us to continue providing support for renal patients at Addenbrooke's Dialysis Centre, satellite units and transplant wards.

Our fundraisers achieved great success and donations via websites such as **JustGiving** and **easyFundraising**, plus regular contributions provided a good source of income.

Donations in memory and legacies continue, and we are very grateful that members and their families remember us in this way, and support our work at a sad time for them. But sadly, it reflects the fact that we have lost loyal supporters.

Our total expenditure in this financial year was £51,456 making an excess of spending over income of £1,188. This was expected as a result of our continued funding of the Dialysis exercise project, and taken from our reserve funds.

Our regular support for patients included welfare and holiday awards to sick and needy patients.

And in conjunction with Addenbrooke's Liver Transplant Association (ALTA) we funded relaxation therapy to assist patients' recovery following transplantation. Further help to patients included Christmas buffets for patients receiving treatment over the Christmas period and funding patient comforts for the new Cambridge Dialysis Unit.

We sponsored patients to attend the annual NKF patients' conference, and supported participants in the National Transplant Games. We also funded nursing staff to attend a conference. Our funding for the Dialysis Exercise project continued and we funded materials used in a transplant research project.

Despite the ever-increasing burden of financial regulation, insurance and

form filling, our administration costs remain very low.

Future Developments:

We are currently negotiating with Dialysis Medical staff and Addenbrooke's Charitable Trust to continue supplying Dialysis Exercise facilities for patients on dialysis.

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.

Where the Money Goes

Over the last six months, beside our regular welfare support for sick and needy patients, our funding has included:

- Water cooler and scales for Ward C5 (Addenbrooke's in-patient dialysis ward) at a cost of £400.
- Medical Alert wristbands for patients with fistulas at a cost of £456.
- Piano for Cambridge Dialysis Unit at a cost of £315.

We have also approved funding for:

- Two wheelchairs for the Kings Lynn satellite dialysis unit at a cost of £650.
- The purchase of 40 pressure relief mattresses for Cambridge Dialysis Centre at a cost of £5,967.
- Six months interim salary for a Band 7 nurse to administer a new drug therapy for Polycystic Kidney Disease at a cost of £11,370.
- An ultra-sound scanner to examine the performance patient's fistulas at a cost of £36,520.

We are still in discussions with medical staff about re-starting the Dialysis Exercise programme. Funding has been agreed by AKPA and ACT and we are hoping for staffing and equipment arrangements to be agreed shortly.

Who's Who in the Dialysis World – Informal interviews with Suzi Turton

Claire Joyce is a full time Social Care Practitioner at Addenbrooke's, giving people advice on benefits, debts, housing, grants and psychological support, as well as acting as an advocate for patients and their families. Besides Cambridge, she also helps patients at the three satellite renal units. Claire said, "The staff and patients know they can come to me and get quick support and advice. I'm always available, patients' have my direct contact details so they don't need to go through other people." Claire is very approachable so feel at ease to contact her if you need any support, on 01223 400180.

Now let's get to know Claire a little better!

Name: Claire Joyce.

Where did you grow up? In West London, a place called Hounslow which was very close to Heathrow Airport.

Tell us something about your childhood or where you grew up? Our house was directly on the flight path of Concorde so when it was taking off we would run outside to watch it fly over and wait for the sonic boom, it was so loud we would have to put our hands over our ears.

Position of responsibility? Renal Social Care Practitioner.

How long have you been doing this job? Four years.

What do you enjoy about your job? The fact that I am able to be creative in my role in giving patients advice and guidance, helping them through some very difficult times.

Is there something you'd like to change about your job? I would like to be able to spend more time at the satellite units.

Any other jobs you've done in your past? I have been an occupational therapist assistant, social work assistant in mental health and older people's teams – these were based in the community. I then moved to the NHS about fifteen years ago to work at Imperial University Hospital as a Renal Social Support Officer for ten years, until I started working at Addenbrooke's for the Renal Team here.

Any hobbies? I love art and craft. I have a City and Guild's in sugar craft so I also love to decorate cakes such as for wedding and birthdays.

Favourite meal? Whilst on holiday this year I had grilled octopus served with green beans in a tomato sauce, it was the most delicious meal I had ever had.

What was the happiest moment in your life so far? Not just having my two wonderful children but being able to help and watch them grow into two independent happy and lovely people.

What would you do if you won the lottery? Make sure that all my family were financially stable, give some money to charity and then set up a tea room which had a ceramic workshop and art gallery attached.

Any phobias you wish to share? I really hate wasps!

What is the most daring thing you've ever done? When in Vietnam we went on a boat trip along the Mekong delta. The boat was not very big and we had to keep jumping on and off the boat to get onto little islands. We were told that we needed to be careful as the water had lots of water snakes and conga eels in it!

Where have you been in the world where you would like to return to and why? I have been very fortunate and have been to many places, Singapore, Vietnam, America, Europe. This year I went to Crete for the very first time, I now want to travel to more of the other Greek Islands .

Your favourite thing to do in Cambridge? To just walk around and take in the sights especially along the river Cam.

Who would you most like to meet, famous or otherwise? I would love to meet the Dalai Lama.

Your favourite nibbles (should patients want to treat you!)? Crisps or savoury snacks are my nemesis.

Your favourite inspirational quote? "Our prime purpose in this life is to help others, if you can't help them at least don't hurt them." Dalai Lama

The best piece of advice you've ever been given? "Just go out there and be yourself, try your best, then everything will be ok."

Suzi Turton, September 2017

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, 46 Cherry Hinton Road, Cambridge CB1 7AA.**

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*

Patient Survey Gives Prevention, Early Detection and Curing as Research Priorities

Kidney Research UK's survey of 2,158 kidney patients in October last year suggested that discovering a cure for kidney diseases, prevention, early detection and finding new sources for organ transplants, should be the focus for future renal research. This was the third nationwide patient survey carried out by the charity and the results will help inform its future research priorities.

The survey was open to all UK kidney patients and was sent to renal units across the UK with additional patients completing the survey by email and social media. Respondents were asked

to choose their top seven priorities out of 20 renal research topics and to rank them according to importance.

Kidney Research UK's Director of Research, Elaine Davies, said: "Patients are at the heart of our research, and it is by actively engaging and listening that we understand what research matters most to them. This survey outcome will influence how we review and set the strategic direction of our future programmes."

www.kidneyresearchuk.org

Name Change for National Charity

The former **British Kidney Patient Association**, a national kidney charity with a long history of supporting kidney patients has recently changed its name to **Kidney Care UK**. (Website: www.kidneycareuk.org)

The charity said that the change was the result of talking to around a thousand patients, family members and health professionals. Feedback from these showed some confusion about the various kidney charities and what they did. Also, it was felt the old name didn't adequately describe the purpose of the charity, so change was needed. As a result the charity has been renamed Kidney Care UK in order to reach and support even more kidney patients and their families in the future.

They added that the name change will not effect their work and they will continue to offer all the support services they currently provide, as well as developing new ways of helping, continuing to improve health and care services and campaigning for change.



Help Us Raise More – Fundraise on *JustGiving*

You can set up your own *JustGiving* fundraising page to say what you are doing and why you are raising money. The *JustGiving* Team will give you all you need to reach your sponsors and will also collect Gift Aid for us. Donations are secure and spam free. They won't sell or share your details or try to sell you anything. Please visit www.justgiving.com/akpa



NKF Helpline

Tel. 0845 601 02 09

E-mail: helpline@kidney.org.uk

Website: www.kidney.org.uk

Help Addenbrooke's Kidney Patients when you shop on-line.

Visit:

www.akpa.org.uk/easyfundraising
for more information.

200 Club – Winners

MAY 2017

First prize £86 • Lionel E Young
Second prize £51 • Mrs Janet Wilson
Third prize £34 • Mr Neil Burton

JULY 2017

First prize £86 • Mike Ruggieri
Second prize £51 • J Thompson
Third prize £34 • M Taylor

SEPTEMBER 2017

First prize £86 • S Pitts
Second prize £51 • S Pitts
Third prize £34 • Wendy Palmer

Thank you to all 200 Club Members for another year of valuable support.



For more information contact Janet Man:
Tel: 01223 660312 • Email: fundraising@akpa.org.uk



AKPA Extraordinary General Meeting

An EGM was arranged by the Trustees to be held on Monday 6th November.

This meeting was convened for two reasons:

To present the inspected accounts for the year ended 31/3/2017, which was needed because the accounts were not available for the AGM.

To change the number needed for a quorum at a General Meeting. The number of 25 as stated in the Articles of Association had become increasingly difficult to achieve and it was proposed to reduce this to ten.

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

fundraising@akpa.org.uk

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

Postal Address:

AKPA, 48 Montague Road,
Cambridge CB4 1BX

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, Hinchingbrooke 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 – Suzi Turton

Kings Lynn – Colin Gant

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

West Suffolk Hospital, Bury St Edmunds – John Smitherman

E-mail: j.smitherman110@tiscali.co.uk

AKPA Committee Members 2017

Andrew Collins

Assistant Treasurer

Richard Jarvis

Website

Hannah Alexander

Minutes & Membership Secretary

Peter Constable

Chairman

Mike Ruggieri

Collecting Tins Coordinator

Ralph Slattery

NKF Rep. & Raffle Organiser

Scott Devereux

Nicky Moncrieff

Staff Representative

Brian Wood

Treasurer & Newsflash Editor

Angela Green

Staff Representative

Janet Man

Fundraising

Martin Harmor

Fundraising



October 2017