

Addenbrooke's Kidney Patients Association

NEWSFLASH

Issue 2 2024

No. 75

Your local association — Run by patients for the benefit of patients. Serving patients in Cambridge, Kings Lynn, Hinchingsbrooke and West Suffolk Hospitals

We Need Your Support More Than Ever Before

We are a local charity run by volunteers. We rely entirely on your support, and on your donations and fundraising to continue our vital work of supporting local kidney patients and their families.

We would be very grateful for any donations you can give, if possible regular donations of any amount to support our work.

Please see enclosed donation slip.

Also, we desperately need committee members and volunteers to help run the charity.

Examples of the roles that we are struggling to fill with our current committee:

- NKF Representative
- Christmas Cards Management
- Raffle Management
- Data Protection
- Publicity & Communications

We will be 50 next year. Can you help us into our 50th year and beyond?

The future of AKPA relies on people who are prepared to give their time to help fellow patients.

If you think you could help in these or any other areas, or if you know someone who is willing to help, please contact us:

Paul Smyth, email: paul51.smyth@gmail.com or
Brian Wood, email: brianwood389@gmail.com

www.akpa.org.uk

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Dates for 2024

Sat. December 7th - 3.00pm

AKPA Carol Service

Great St Mary's Church, Cambridge

Great St Mary's
THE UNIVERSITY CHURCH CAMBRIDGE

Please join us for a
**Christmas
Carol Service**

in Great St Mary's Church, Cambridge
**Saturday 7th December 2024
at 3.00pm**

Traditional Carols and Christmas Music
The St Augustine's Singers directed by Paul Jackson will accompany traditional carols and give solo performances.

We will be welcoming the wonderful Ely College Choir under the direction of Kate Arnold, who will give a joyful performance.

ALL WELCOME TO THIS FREE EVENT

AKPA ADDENBROOKE'S KIDNEY PATIENTS ASSOCIATION

Where the Money Goes

AKPA purchased a much needed ultrasound scanner for King's Lynn at a cost of £5,460.

There is continuing demand for our welfare support to sick and needy patients due to current economic conditions and we have paid £2,700 in welfare grants over the last six months.

We continued our support for the Addenbrooke's Transplant game team by helping to fund their travel and accommodation expenses at a cost of £1,852.

We also continued funding phones for staff at a cost of £195 per month.

AKPA Vice President

We are very sad to announce the recent death of *AKPA Vice President Janet Evans*. Janet has always been a strong supporter of AKPA. Her late husband Dr David Evans was a pioneer of dialysis in the UK and together they were very involved in the the creation of AKPA. She will be sadly missed.

"Very sad news. I am sure AKPA would not exist without David and Janet's support in its early years, and beyond."

Prof. John Bradley (President AKPA)

Fundraising • Fundraising • Fundraising • Fundraising

Stretham Feast 2024

The organisers of Stretham Feast, which took place on the 19th May this year, chose AKPA as one of their charities to support.

Donna Cornwell, lead of the Feast Working Party wrote, "Stretham Feast parade was probably held for the first time in 1897 and the collection from the parade has supported Addenbrooke's Hospital over the years. It is always held on the third Sunday in May and is a firm local favourite. The marching bands as well as old and new vehicles are a highlight. But for the children riding in the trailer dressed up to complement the theme of the year, lasting memories are made. This year's theme was 'Books' and was chosen by the WI as well as the chosen charities of AKPA and ReadEasy."



The Fancy Dress Children's Trailer

Commemoration Day for Professor Sir Roy Calne

11th July 2024 at Trinity Hall College, Cambridge

This was a celebration of a remarkable life: the story of a brilliant surgeon who revolutionised organ transplantation and who was dedicated to saving lives, often by solving problems considered impossible by others. The Commemoration was held at his old college.

In her presentation, titled “Where there is a Will” transplant patient Angela Dunn, told the story of her transplant, performed 54 years ago by Sir Roy Calne at RAF Halton.

Angela says of the Commemoration:

I was very honoured to be asked to speak at the celebration for the life and work of Sir Roy. Somewhat daunted as well, particularly when I discovered that almost every other speaker was a professor.

My worry that the talks would be above my head – I’m only an amateur nephrologist – or very serious, were unfounded. I enjoyed all of them, particularly the man who followed me who was very funny, though I did struggle with Menna Clatworthy’s Future for Immunosuppression.

Listening to the people who had worked with Prof over the years, I realised that we the patients had only

seen one side of him. To us he was the head of the department, a constant presence even when he wasn’t there, and the best surgeon any of us could have wished for.

“He wanted to provide the best outcome for us.”

But for all his career he had to fight for his ideas to be accepted. And often against fierce opposition in the hospital. Transplantation wouldn’t work. Immunosuppression wouldn’t work. There’s no theatre space. There aren’t any beds.

But he was persistent, driven, and above all patient focused. He wanted to provide the best outcome for us.

Every speaker spoke of him with affection, respect and a certain amount of “awe!”



Angela and her French Nephrologist Prof. Rostaing, who she meets annually for lunch when he and his family holiday nearby

Angela is probably the longest surviving kidney transplant patient. She spoke via a Zoom link from her home in France. At the end of the Commemoration Day the audience were asked to vote for best talk, and Angela’s won!

“Why Can’t It Be Done?”

Amongst the presentations there were many from those who had worked with him over the years, beginning with fellow surgeon Peter Friend who spoke about Sir Roy’s early years at Guy’s Hospital. And how in the 1960s, after receiving a travel award to visit the USA, he met researchers investigating organ transplantation – his question was: “Why can’t it be done?”.

Bill Wall spoke about the early years of transplantation and trials of early immunosuppressants. And Neville Jamieson recounted how “The Cyclosporine Revolution”, changed the outlook for organ transplantation, and allowed Sir Roy to expand his transplant programme.

In “The Multinational Family”, Surgeon Ignazio Marino told of Sir Roy’s regular teaching sessions, ensuring organ transplantation was taken up in hospitals across the world. Ending with a quotation from Nelson Mandela **“It always seems impossible until it’s done”**.

Allan Kirk continued this theme with “Sir Roy’s Impact Abroad” listing 648 collaborators across the world, and

21,000 citations. He produced a slide of Sir Roy’s connections resembling a giant spider’s web spanning the world, showing surgeons who were taking up Sir Roy’s work and using it to save lives.

“His paintings showed his great humanity and feeling for his patients.”

A very different aspect of Sir Roy’s life was illustrated by John Sheeran in “The Gift of Life Paintings”. John recounted being asked to curate an exhibition of paintings by Sir Roy. John and his wife had recently set up an art curating business – and were reluctant to exhibit an amateur artist. However, after meeting Sir Roy and seeing his work they agreed to arrange a short exhibition in London. It was so successful, it ended up touring world wide! John explained how Sir Roy had been inspired and taught by John Bellany, an established artist. John said his paintings of patients and hospital scenes showed his great humanity and feeling for his patients.

Prof. John Bradley recalled “Life at Trinity Hall” with Prof. Calne’s regular

tutorials to medical students from all over the world.

Professor Meena Clatworthy spoke about “The Way Ahead and the Future of Transplantation”. She quoted Sir Roy as saying that the most important aspect of his work was immunosuppression. “Without immunosuppression there would be no transplants. Tolerance is the Holy Grail of transplantation but we have not achieved it yet”.

She went on to explain “prope” tolerance and his work using Campath 1H. Ending with illustrations of her work in building on that legacy.

In the concluding remarks Peter Friend announced that a memorial fund had been set up in Sir Roy’s name to encourage young surgeons.

There was agreement amongst all attending that this had indeed been a fitting celebration of a remarkable life.

It’s still possible to view the *Commemoration Day* on YouTube. If you haven’t done so it’s well worth watching. This is the link:

www.youtube.com/playlist?list=PLajEIQ BmQs8HXw1b5jSWDs7sqYLy_ywyw

AKPA Annual General Meeting 15 October 2024

Our AGM This Year –

At the Quaker Meeting House, Hartington Grove, Cambridge

This has proved an ideal venue, spacious, comfortable and with facilities for refreshments, and Zoom communications.

Although the AGM is partly formal, it is also a social event, with snacks, meeting the committee, chatting to members and medical staff – discussing our work and our fundraising. AKPA is about patients supporting patients.

We also welcome guest speakers. This year it was **Chris Talbot** of the *National Kidney Federation (NKF)* whose presentation described the role of the NKF and how they can support patients.

See bottom of page 5.

Chairman's Report

Paul opened the meeting and welcomed those attending in person and by Zoom.

He continued, saying; "I am not going into any details on the finances. Andrew will cover that. However, I will state that throughout the year we have sought to support all requests that we have received that fell within our charity's aims and objectives.

An important point this year, that Andrew will expand on, is that our expenditure has again significantly exceeded our income. This reflects the inevitable ebb and flow of income and requests for our help. We remain able to absorb this variation as a result of generous legacies received in recent years. If our current rate of excess expenditure were to be maintained then we would drain our reserves in five years or so.

As commented last year, we are aware that AKPA's visibility remains inconsistent across the dialysis units and Addenbrooke's. Your committee has developed a re-branding including a new logo and has sought to improve communication. We have invested in a new website and created a presence on Facebook. Any suggestions that you may have to improve any of these areas are welcome. Please, join our Facebook group and share your thoughts.

We are seeking to ensure that all patients are fully aware of AKPA and what it might be able to do to help them. Sadly, we anticipate a continuing greater need for welfare support as the cost of living continues to rise and winter fuel payments for pensioners are reduced. If any of you

are aware of a patient who needs our help, but is unaware of what we can offer, please get in touch with us.

AKPA just like any other organisation depends on its people. Not just the trustees or the full committee but all our members and supporters. Currently, we have 6 trustees who were re-elected at last year's AGM, namely:

Andrew Collins – *Deputy Treasurer*

Martin Harnor

Suzi Peers

Laura Tilbrook

Brian Wood – *Treasurer, Newsflash Editor* and myself, **Paul Smyth** – *Chair Person*

Our small committee is ably assisted by our co-opted members:

Adella Charlton – *Minutes Secretary*

Aimee Robinson – *NHS*

Gill Chumbley – *NHS*

Karen Dahlsveen – *NHS*

Malcolm Souza-Lewis – *King's Lynn*

Patient Representative

Tarsem Paul

Whilst this may seem a large number, you need to consider how overworked all NHS staff are; our two youngest committee members are seriously ill and it is remarkable that they manage to contribute at all and our retired members have limited energy. As I requested last year, if any of you feel able to further help AKPA in any way, then please contact myself or another committee member. We will be happy to discuss any ideas that you may have.

We are always keen to welcome people with new ideas to our committee. I would particularly request any patients who are members to consider if they have any healthy close friends or relatives who recognise the importance of supporting you and would be able to help AKPA continue to do that.

Examples of the roles that we are struggling to fulfil with our current committee:

- NKF Representative
- Christmas Cards Management
- Raffle Management
- Data Protection Officer
- Publicity & Communications Officer
- Events Management

A reminder of our annual carol service on 7th December. Please, support this service. Not only is it a very appropriate part of our Christmas preparations. It is also an opportunity to meet up with the committee and each other. Suzi has once again organised an inspiring event, however, she will need plenty of help on the day including volunteers for the bible readings.

As we formally conclude our 49th year and move into our 50th year, I need to share a genuine concern regarding the future of AKPA. My fear is, that without an injection of several fresh, healthy faces to our committee we will struggle to survive. Currently, we do not have the collective effort to plan and celebrate 50 Years of sustained help to so many. Malcolm is our only patient representative, the other three sites are unrepresented. I do not believe that it is an exaggeration to say that we are desperate for new committee members.

Despite my concerns, I can only close by offering my sincere thanks to the committee and all members and supporters for everything that has been achieved in the past year."

Paul Smyth

AKPA Annual General Meeting 15 October 2024

Treasurer's Financial Report

Year ending 31st March 2023

Income:

Our total income for the year was £27,437.

Income from **fundraising** remained high with fundraising events by patients and their families raising £8,343. Thank you to all involved.

Our **200 Club**, **Christmas Card** sales and **Collecting Tins** raised a total of £2,277.

However, following the retirement of Carol Slattery and Janet Mann we urgently need people to take on organising **Raffles**, **Collecting Tins** and **Christmas Card** sales.

Despite regular Standing Order donations dropping, total General Donations were higher this year at £3,836. Thank you to all those who continue to donate.

Income from **In Memory** donations totalled £3,858. And **Interest** earned by our reserves in high interest accounts totalled £6,663.

Expenditure:

Our total expenditure was £68,585.

Although expenditure is again in excess of income, it was planned to use money from reserves to fund important projects as detailed under

Special Projects. (Projects outside of our regular remit.) However, without significant increase in income during the next few years we will be unable to continue funding those projects.

Welfare Awards: £18,227. There is continuing demand for our welfare support to sick and needy patients due to current economic conditions.

Christmas Gifts: for patients receiving treatment over the Christmas period in the Dialysis Centre, and Satellite Units £635.

We continued to help with travel and accommodation costs of patients participating in the **Transplant Games:** £1,625 and **NKF Conference:** £346.

Special Projects: (projects outside of our regular remit) total £37,256. We have continued to use money from our reserves to fund important projects.

They include:

Mobile Phones: £2,335 for use by the Dialysis Counsellors, specialist nurses and vulnerable patients.

COLBALT Research Project: £16,860 research to measure the effects of haemodialysis fistulas on patient's heart performance.

Fleeces: £275 – 50 fleeces for use by patients on dialysis who need to keep warm.

Trolleys: £1197 – four medical dressing trolleys for the Hinchingsbrooke Satellite Dialysis Unit.

Pressure Relief Mattresses/Cushions: £10,228 – for patients dialysing at Cambridge Dialysis Centre.

Peer Support: £820 – Training Course for patients who wish to support/advise new dialysis patients.

Ultrasound Scanner: £5,210 – for the West Suffolk Dialysis Unit to improve the accuracy of dialysis needling.

Cost of Generating Funds: £7,755 this includes printing and distributing our newsletter, running the 200 Club and selling Christmas cards.

Governance Costs:

Despite ever-increasing costs, our administration costs remain low. At £2,225 this represents a small proportion of our total annual spending.

Future Developments:

Continued funding of smart phones up to a cost of £2,335. These have proved invaluable for communication with vulnerable patients.

Ultrasound scanners at a cost of £11,341 for CDC and Kings Lynn Dialysis Centres.

Continuing support for dialysis patients, including welfare payments, plus funding for patient comforts and equipment not supplied by the NHS to Addenbrooke's Renal Units.

Andrew Collins

AGM Talks

National Kidney Federation

<https://www.kidney.org.uk>

Chris Talbot – How the National Kidney Federation (NKF) can help patients.

Chris gave a Keynote presentation illustrating the many ways the **NKF** provides valuable information to help kidney patients.

There are currently 50 Kidney Patients Associations (KPAs), mostly based at large hospitals, who are members of the **NKF**.

The **NKF** publish *Kidney Life* magazine, monthly by email and quarterly printed and posted, free to all who join KPAs and **NKF**.

They provide a peer support service to patients who would like to talk to someone regarding the options of dialysis at home or other home dialysis support.

They provide Webinars on various subjects of importance to patients – available through the **NKF** website.

The **NKF** are the secretariat for the **All Party Parliamentary Kidney Group**. The role of this group is to improve

understanding in Parliament of kidney disease and transplant medicine and to promote improvements.

They hold an annual **Patient Event** and **KPA Day**.

They work with important national and international organisations such as **Baxter**, **Fresenius**, **NHS** and **Kidney Research UK**.

Chris's talk illustrated the importance of the national organisation for kidney patients.

AKPA urgently need someone to act as their representative at NKF meetings. If you are interested please let us know.

The 46th British Transplant Games 2024

This year's games were held in Nottingham and Addenbrooke's had a total of fifteen Kidney Athletes competing.

The Opening Ceremony began with a parade up to Nottingham Castle and the ceremony was held within the castle grounds. It is extremely moving when the children parade in, but even more so when the Donors and the Donor families enter the arena they receive such a rousing welcome applause, we are all so grateful to them.

We were extremely lucky the rain held off until the ceremony was over. As usual the event was exceptionally well organised hosting so many sporting and social events for all abilities, children and adults alike and not forgetting the live donors.

Our athletes competed in a variety of events beginning with Archery where Sam Newton retained his title winning his first Gold medal. This was followed by a silver in Ten Pin Bowling and a gold in the Shot Putt.

Friday was golfing day and although Addenbrooke's didn't win any medals it was a great weather for golfers. In Table Tennis Waseem Qureshi won the gold medal after a tough battle in a thrilling final against his opponent from last year. And John Curtis and Doug Choat, taking part in the football helped to win a silver medal for a mixed team.

The swimming was held at the Harvey Haddon Centre. Addenbrooke's presented its largest team yet with seven swimmers competing in a variety of swimming events. The atmosphere on poolside was amazing, it was exciting, supportive and friendly not only amongst our team but from across all competitors from over 25 different hospital teams.

All of our swimmers seasoned and new pulled out all of the stops. The team racked up an amazing number of medals, and for the third year in a row the Addenbrooke's relay team won gold. Newcomer Richard Jones and seasoned swimmer Anne Peet won nine gold medals between them with Ann swimming the gruelling 50m butterfly. All of the medals contributed to Addenbrooke's winning the Best Adult Swimming Team which was awarded at the closing ceremony.

The Badminton on the Saturday saw Tim Adamson win silver with his partner in the men's doubles and Val Cooper won gold in the ladies doubles. Athletics on the final day saw our team winning more medals with Richard Jarvis retaining his title by winning gold in the 5k run. Sally Dalton won a gold in both the Ball Throw and Long Jump and a silver in the Javelin. Kirsty Clarke won a gold in the Shot Putt.

The games were very successful this year and we are looking forward to



Swimmers, Richard Jones and Anne Peet

2025 when the games will be held in Oxford on 31st July to 3rd August. For anyone wanting to join us, registration opens in March on the Transplant Sport website.

We are an amazing team and very friendly with so much comradery, newcomers are very welcome. Keep fit and healthy and hope to see you in Oxford next year.

The World Transplant Games 2025 are being held in Dresden Germany August 17th until 24th usually competitors are selected on their performance from the British Games.

Val Cooper & Anne Peet

AKPA support the Addenbrooke's team with grants towards travel and accommodation.

www.britishtransplantgames.co.uk

Cambridge Half Marathon – 9th March 2025

Run for AKPA and NKF – sponsorship money will be split between our two charities.

This fast and flat course starts and finishes on Victoria Avenue, with Midsummer Common as the event site. Previous courses have guided athletes from Midsummer Common through the city centre and have included exclusive access to four University of Cambridge colleges, providing breathtaking views and a

glimpse of iconic landmarks not typically visible.

Whether you are a novice runner or a competitive athlete aiming for a personal best, this event is an ideal selection.

Registration fee: £25

Sponsorship: £299

For more details visit:
<https://www.kidney.org.uk/Event/cambridge-half-marathon-2025>

Internet Fundraisers

Our thanks to all the people who have raised funds and donated money through *JustGiving*, *Charities Trust* and other on-line giving websites.

Also, those who have donated through our web-site:

www.akpa.org.uk

It is sometimes difficult to obtain details of all who donate in this way, but if you inform us by email we will be pleased to publicise your fundraising efforts.

Thank you all.



Online Fitness Support

Kidney Beam is an online service helping kidney patients take care of their physical and mental health. It offers you a way to improve your physical activity in your own home.

The online platform is hosted by specialist kidney professionals – from renal physiotherapists to renal counsellors – from a number of different NHS trusts and backgrounds, as well as people living with kidney

disease. **Kidney Beam** is aimed at anyone over 16, with any ability, any kidney condition, and at any stage of kidney disease.

All classes have a fitness rating so you can choose the right one for you. At the beginning and end of the classes you can chat to each other and the instructors, and building new friendships might help you to stay motivated.

AKPA have been in conversation with the founders of **Kidney Beam** to see if we could offer it to our renal patients.

We recently received the great news that the East of England Renal Network have agreed to 12 month funding of **Kidney Beam** for the whole of their region which includes Addenbrooke's. Hopefully the **Kidney Beam** service will be available to all patients very soon.

To find out more please see: <https://beamfeelgood.com/home>

Kidney Research Showcase

On Tuesday 21st May Kidney Research UK held a showcase for members of the public to attend. With canapés, drinks and access to medics and researchers, it was an exciting way to display where the money goes that is so generously donated.

The event was held in London with the main focus on funding impactful and meaningful research to improve the lives of all those suffering from

kidney disease, including patients' carers, friends and family.

The research supports all areas of the patient's life (researchers in attendance included Dr Greenwood from Kidney Beam and Eleri discussing peer support) from projects focusing on rare nephrotic disease, to research into the benefits of exercise.

Laura Tilbrook

Kidney Care UK

For advice, support and much more:

<https://www.kidneycareuk.org/get-support/advice-support/>

Contact Telephone:
01420 541424

Office Hours:
Monday-Friday
9.00am-5.00pm

AKPA Christmas Cards

Our Cards Will Be On Sale At:

Pearce's Farm Shop, Hemels Mead, Buntingford, Herts SG9 9ND.

<https://pearcesfarmshop.com/about-us/contact/>

Telephone No. 01920 821246

Opening times:

Monday – Saturday 8.30am – 5.00pm
Sunday 9.00am – 4.00pm

Pearce's not only have a wonderfully stocked farm shop but also a brilliant cafe serving a wide range of meals, from hearty farmhouse breakfasts to freshly cooked lunches and afternoon teas. All looking out over inspiring views of meadows and countryside.

It's well worth a visit.

200 Club – Winners

MAY 2024

1st prize £84 • M. Moore
2nd prize £51 • C. Ray
3rd prize £34 • Slattery

JULY 2024

1st prize £84 • S. Pitts
2nd prize £51 • R. Johnson
3rd prize £34 • J. Dennis

SEPTEMBER 2024

1st prize £84 • Wakling
2nd prize £51 • M. Reid
3rd prize £34 • J. Schoop



For more information visit website www.akpa.org.uk
or email fundraising@akpa.org.uk



Don't forget to visit the AKPA Website: www.akpa.org.uk. For latest information and news.

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 Adams – covers ward C5, haemodialysis, Hinchingbrooke dialysis, low clearance clinic.

Zoe Garnish – wards G5/F5, renal transplant, home haemodialysis.

We can be contacted on 01223 216655.

■ Queen Elizabeth Hospital – Kings Lynn

Hannah Edwards –

Contact on 01553 613861.

■ West Suffolk Hospital – Bury St Edmunds

Laura Riley –

Contact on 01284 712920.

AKPA Patient Representatives

Local contacts for information about AKPA:

King's Lynn – Malcolm Souza-Lewis

Email: souzalewis@yahoo.co.uk

Transplant and Dialysis Patients – Suzi Turton

Email: suziturton@hotmail.com

We are still hoping to find representatives from Cambridge, West Suffolk and Hinchingbrooke Dialysis Units.

Please contact Suzi Turton if you are interested. Meetings are held via Zoom.



Malcolm Souza-Lewis



Suzi Turton

Our website address is:
www.akpa.org.uk

You can email us at:
info@akpa.org.uk
fundraising@akpa.org.uk
webmaster@akpa.org.uk

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AKPA Committee Members 2024

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November 2024



NKF Helpline

Please note: new number is FREEPHONE

Tel. 0800 169 09 36

E-mail: helpline@kidney.org.uk

Website: www.kidney.org.uk

Newsflash is a free newsletter, sent out by post and email to inform people about the work of Addenbrooke's Kidney Patients Association (AKPA) and provide useful information for patients and their families.

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. Please visit www.justgiving.com/akpa



JustGiving™

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.

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