

# Addenbrooke's Kidney Patients Association

# NEWSFLASH

Issue 1 2025

No. 76

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

## AKPA Have Funded a New Drinks Trolley for Cambridge Dialysis Centre



Healthcare Support Workers Lee Pudifoot and Blessing Afangudo with the new Drinks Trolley.

See page 2 –  
Where the Money Goes

### Scanner Needed

An Ultrasound Scanner is urgently needed for Hinchingsbrooke Dialysis unit.

The other units now have them, all funded by charitable donations – AKPA have offered to help.

[www.akpa.org.uk](http://www.akpa.org.uk)

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## AKPA 50th Anniversary 2025

*We need your support more than ever*

**We provide help for kidney patients and their families treated at Addenbrooke's hospital and its satellite dialysis units.**

AKPA is run by volunteers; our running costs are very small.

All of our income comes from fundraising and donations.

We would be very grateful for any help and support you can give.

**We need committee members and volunteers:**

To run raffles, sell Christmas cards and distribute collecting tins and to organise publicity and communications.

*If you think you could help please contact us.*

**Paul Smyth, Email: [paul51.smyth@gmail.com](mailto:paul51.smyth@gmail.com) or**

**Brian Wood, Email: [brianwood389@gmail.com](mailto:brianwood389@gmail.com)**

*We rely on people who are prepared to give their time and those who are prepared to donate, fundraise or remember us in their wills.*

A MEMBER OF THE NATIONAL KIDNEY FEDERATION (NKF)

# AKPA Carol Service – Great St Mary’s, Cambridge

Saturday 7th December 2024

Despite very high winds, Great St Mary’s was again packed for the AKPA Carol Service. This annual event, now part of a long tradition, is a way of saying thank you to all who support our small local charity and heralds the start of Christmas for many patients, staff and their families.

The service started with choir and congregation joining to sing the opening carol, *O Come, O Come Emmanuel*, followed by a prayer from the Reverend Ally Barrett, Associate Vicar, Great St Mary’s.

The St Augustine’s Singers directed by Paul Jackson led the carols and displayed their musical virtuosity in solo pieces – beginning with *O Radiant Dawn* by James Macmillan, then *Resonet in Laudibus* and finishing with *Wassail Song* by Ralph Vaughan Williams.

The traditional bible readings were given by Sally Taber (previous Chair of British Kidney Patients Association), Dr Elaine Jolly, Renal Consultant Addenbrooke’s, Trish Peroni, Friend of AKPA, Nicholas Kennedy, son of a Renal Consultant and Dr John Firth, Renal Consultant Addenbrooke’s.

We were then treated to a monologue from Nick Warburton’s *Christmas Diaries* read by James Dowson. And perhaps the highlight of the service, a performance by enthusiastic youngsters from Ely College with a choral rendition of *The Lamb* by John Tavener, followed by their “Real Group”, directed by Kate Arnold singing *The World at Christmas*, all to rousing applause!

*“Perhaps the highlight of the service was the performance by youngsters from Ely College.”*



*The St Augustine’s Singers, Great St Mary’s*

Organist, Mo Wah Chan, gave brilliant performances throughout, ending the service with the glorious voluntary *In Dulci Jubilo*.

Our thanks to all who contributed and made this event so successful. And special thanks to Suzi Turton for her hard work organising and arranging all the elements that made this service run so smoothly and successfully, and particularly for organising the children’s performance.

## Where the Money Goes

### New Tea Trolley for CDC

Drinks whilst dialysing are a much appreciated treat for patients and sorely missed during Covid restrictions.

However, when restrictions were lifted, staff at Cambridge Dialysis Unit were unable to resume drinks rounds due to a faulty drinks trolley. They were also unable to get NHS funding to replace it, and appealed to AKPA for help.

We agreed to fund the NHS approved drinks trolley at a cost of £3,468, using money donated specifically to support CDC. The new trolley has now arrived and patients can once more enjoy a drink whilst dialysing.

### Christmas Cheer for Dialysis Patients

In order to bring Christmas cheer to those patients who have to dialyse over the Christmas period AKPA



*Adella preparing to deliver Christmas gifts*

provided presents and snacks for every patient at a cost of £851. For Christmas 2024 we delivered specially designed notebooks and bookmarks plus a selection of snacks, including shortbread biscuits, crisps and fruit pastels.

Our thanks to Adella Charlton for completing the huge task of organising and delivering these to all four units – Cambridge, West Suffolk, Kings Lynn and Hinchingsbrooke.

### Welfare Support

There is continuing demand for our welfare support to sick and needy patients due to the current economic conditions and we have paid almost £3,000 in welfare grants over the last six months.

The coming changes to Government welfare benefits (see p6) could mean even more demand for our support.

### Mobile Phones for Counsellors and Specialist Nurses

We have continued funding these phones that have proved invaluable for staff to contact vulnerable patients at £1,200 in the last six months.

# The Addenbrooke's Family

Hi, I'm Julian. I have been married to the love of my life, Elaine, for 30 years. Elaine is also my live donor for a kidney transplant.

My family has a history of polycystic kidney disease, and I was diagnosed with the condition in my late twenties.

Elaine and I had talked about the possibility of live donation over the years, but the conversations became more focused in my late forties when my kidney function deteriorated. Elaine firmed up her donation offer, and we started on the live donor journey together. Elaine was very impressed by the range of tests undertaken on her to test her suitability to be a donor. Most of the tests were done over a couple of days for convenience. The consultants went through the operation and recovery procedures in detail and answered any questions and concerns we had.

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*“Elaine was very impressed by the range of tests undertaken on her to test her suitability.”*

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I recall the most worried person during the build-up was our

daughter, understandably, as both her parents would be undergoing simultaneous operations.

Once Elaine's suitability was confirmed in September 2016, we were offered a slot quite quickly – in January 2017. We had a family commitment in January so plumped for the next available slot. We went into Addenbrooke's in May 2017 for the transfer. Incidentally, my mother, who had been on the transplant list for several years with the same condition, beat me by about 10 weeks, having her transplant in the Queen Elizabeth II hospital in Birmingham in February.

After the operations we spoke to each other briefly in the recovery room, before going up to the transplant ward. Once we were able to get up on our feet (after about 36 hours) we could visit each other in our separate bays.

Elaine came home first after five days' care. I was home after eight days.

I had some follow-up surgery a couple of months later for a complication – another eight-day stay. After that, my recovery started in earnest. Elaine was fine.



Julian and Elaine

The only time I am physically aware of Elaine's kidney inside me is when grandchildren are around, jumping all over me. Elaine forgets most of the time that she only has one kidney.

Aftercare for both of us has been great. I have a quarterly checkup, and Elaine has an annual check which will continue for the rest of her life.

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*“Aftercare for both of us has been Great.”*

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Addenbrooke's is an amazing hospital, and the kidney consultants are professional and caring. You do feel like you are part of a big Addenbrooke's family.

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## Welfare Benefit Changes

**You have probably seen that the government has announced reforms to the welfare benefits system. These changes may impact some kidney patients who are unable to work.**

**The Trust's Renal Social worker, Aimee Robinson, has written the following to clarify some proposed changes.**

“The proposed reforms are fairly vast and complicated, but what is clear is that these changes are happening and eligibility criteria to claim for PIP will be much higher, with proposals of scoring 4 points or more in one task of

daily living to be able to claim the daily living component of PIP.

Currently you have to score a minimum of 12 points across all domains to qualify for the daily living component.

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*“These changes will not happen immediately and will certainly take further consultation processes to be developed and ultimately time to take effect.”*

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The Work Capability Assessment (WCA) will be scrapped and the assessment for PIP will become a single point of access for all disability benefits in England and Wales.

However, I believe that this announcement and following press coverage will increase many patient's anxiety and financial concerns. I also believe that many patients will be less likely to apply for benefits and engage with benefit support services. This in turn may increase the applications for grants both via the AKPA and KCUK”.

**Aimee Robinson**  
*Renal Counselling and Social Care Team*

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### NKF Helpline

Please note: new number is  
**FREEPHONE**

**Tel. 0800 169 09 36**

E-mail: [helpline@kidney.org.uk](mailto:helpline@kidney.org.uk)

Website: [www.kidney.org.uk](http://www.kidney.org.uk)

# NKF Kidney Patients Association Day – Birmingham – 5th April 2025

**Julie Walker attended this event as AKPA representative:**

“Following the welcome from NKF Chair David Coyle, we moved on to the formal AGM. The Trustee’s report and financial statements for 2024 were approved and the committee elected.

After coffee we reconvened for a Council meeting. This was most informative, with the new NKF strategy being discussed. It highlights the challenges of adapting not only to a new UK government, but also to a changing global economy. It is extremely tough to raise funds as people’s finances are squeezed very hard.

The NKF intend to capitalise on their uniqueness as the only national Kidney Charity run by patients for patients. They operate very effectively but with just 10% of the staff of other kidney charities.

Part of the strategy is to target GP surgeries, providing them with leaflets signposting patients to the NKF website, local KPA’s and other

resources. Many newly diagnosed patients are overwhelmed and most GP’s have limited information.

The NKF Webinars are proving popular, held on Wednesday’s at 5pm on various topics – advertised on the NKF website. There has been a massive increase in the number of calls to the NKF helpline, mostly about PIP changes, but requests for peer support are on the increase.

The Committee asked all the delegates what WE wanted them to campaign for on our behalf. The overriding concern was about the changes to PIP and the benefits system, creating huge uncertainty for patients. No details have yet been finalised by government.

Also, the dissolution of NHS England is a cause for concern in that a central point of contact will be removed. However, the NKF will be meeting with the new All Party Parliamentary Committee to discuss both these issues.

An open forum followed, giving delegates an opportunity to ask

questions. *Could the NKF strategy include a focus on Education and Awareness of Kidney disease?*

Following lunch we worked in small groups. We talked about how we manage our websites and social media, how we can utilise the NKF as a joint fundraising resource, how they can assist us in promoting our KPA’s and raising our profiles. We shared ideas on best practice, fundraising and discussed the challenges we all face as fundraisers and supporters. It was very interesting to see that although we were all from different geographic areas with vastly differing membership numbers, all the KPA’s faced similar challenges.

It was a great opportunity to meet other KPA members, I left feeling very positive about the help the NKF can offer all of us in the kidney community.”

**Julie Walker**

*The National Kidney Federation (NKF) is the umbrella organisation for the 51 local KPAs – [www.kidney.org.uk](http://www.kidney.org.uk).*

## Local Advocacy and Support Officer

**In addition to the Social Welfare and Counselling Team at CDC, an Advocacy & Support Officer from Kidney Care UK (KCUK) is now available.**

She will be able to provide help with housing queries, benefits, grants, financial assistance for holidays, and general support.

*For example:*

- Provide a listening ear if you need to speak to someone outside your family.
- Help navigate the welfare benefits system and find out what benefits and cost of living support you might be entitled to.
- Offer expert advice about a Personal Independent Payment (PIP) or

Adult Disability Payment (ADP) application.

- Suggest ways you could save money through smarter energy usage and make sure you are on the best tariff with your utility suppliers.
- Give you information about applying for one of KCUK patient grants or holiday grants.

*Patients can self-refer or staff can refer to:*

**Deborah Patten**

**T: 07955402096**

**E: [deborah.patten@kidneycareuk.org](mailto:deborah.patten@kidneycareuk.org)**  
(Support over the phone)

It’s hoped to provide monthly clinics at CDC.

## Kidney Care UK (KCUK)

**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

Sales of AKPA Christmas cards in the run up to Christmas raised a total of £441.

We were very pleased that several people again purchased by mail order and also included donations. Thank you all.



*Thank you to everyone who brought our cards.*

## Pearce's Farm Shop



Pearce's Farm Shop in Buntingford sold an amazing total of £366.

Every year they sell a large number of AKPA Christmas Cards from their well stocked shop and popular restaurant. They also continue to send us a good supply of well filled collecting tins.

Our thanks to Dinah, David and their staff for once again supporting AKPA.

<https://pearcesfarmshop.com/>

## West Suffolk Raffle

A Christmas Raffle held at the West Suffolk Satellite Unit raised £148 for AKPA.

Our thanks to Sid, Marilyn and all staff and patients for organising this raffle and for buying tickets to support AKPA.

If staff and patients at any of the satellite units are thinking of organising raffles or any other fundraising for AKPA please let us know we would be happy to help and advise.

**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.*

## Internet Fundraisers

Our thanks to all the people who have raised money through the *JustGiving*, *Charities Trust* and other web sites. It is often difficult to obtain details of all who donate in this way, but If you let us know by email we will be very pleased to publicise your fundraising efforts.

*Email: [fundraising@akpa.org.uk](mailto:fundraising@akpa.org.uk)*

**Don't forget to visit  
the AKPA Website:  
[www.akpa.org.uk](http://www.akpa.org.uk)  
For latest information  
and news.**

## 200 Club – Winners

NOVEMBER 2024	JANUARY 2025	MARCH 2025
1st prize £84 • D Choat	1st prize £84 • J Moy	1st prize £84 • A Johnson
2nd prize £51 • J Dennis	2nd prize £51 • S Pitts	2nd prize £51 • D Flint
3rd prize £34 • M H Reid	3rd prize £34 • Wakling	3rd prize £34 • L Riley-Smith

## The new AKPA 200 Club year will start in May

To Join or renew please use enclosed membership forms, also available on the AKPA website [www.akpa.org.uk](http://www.akpa.org.uk).  
Renewal will be automatic for those paying by Standing Order.

## 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](http://www.justgiving.com/akpa)



For more information visit website [www.akpa.org.uk](http://www.akpa.org.uk)  
or email [fundraising@akpa.org.uk](mailto:fundraising@akpa.org.uk)



# Fifty Years

## A few notable achievements...

**1975 – Addenbrooke’s Kidney Patients Association (AKPA) was started by a small group of kidney patients with support from medical and nursing staff, to improve the welfare of patients.**

**1977 – Dialysis holidays started:** AKPA funded two caravans in Felixstowe with dialysis facilities to provide holidays for patients and their families, later we funded individual holidays. Kidney Care UK are now the main provider of Dialysis Holidays.

**1978 – NKF started:** AKPA Chairman Brian Pearmain proposed the formation of a national patients’ association, and with representatives from the other Kidney Patient Associations formed what is now the National Kidney Federation (NKF).

**1978 – Transplant Games started:** AKPA has always supported the Addenbrooke’s team competing in the Games.

**1980s – Dialysis equipment:** from almost it’s beginning AKPA has raised money to buy equipment not supplied by the NHS. In 1995 we raised £100,000 to buy dialysis machines for the new dialysis unit at Addenbrooke’s. Today we are still raising money to buy much needed equipment such as ultrasound scanners.

**1982 – Renal Social Worker:** to ensure patients received their state benefits AKPA began funding a Renal Social Worker. Realising its value the post was eventually funded by Cambs Social services.

**Welfare payments:** from the earliest days we have helped patients with problems on advice from the Social Worker.

**1992 – Renal Counsellor:** staff felt that extra emotional care was need for patients and AKPA provided funding for a counsellor, which was eventually taken up by the hospital.

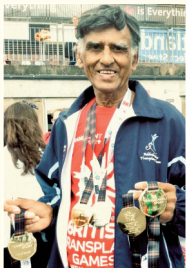
**Dialysis Centre comforts:** from the early days AKPA has funded mattresses, cushions, chairs and televisions to ease the time spent on dialysis.

**Research:** Addenbrooke’s has always been a centre for medical research and AKPA has always supported the research carried out here.

From our beginnings of providing dialysis machines and holidays for patients, fifty years on we are still providing much needed support. Despite the advances of medical research in that time, there are still immense strains on both the NHS and welfare services. The work of AKPA is still as important.

## Sadly we have to report the recent deaths of previous committee members and supporters.

### Malcolm Souza-Lewis



Malcolm Souza-Lewis

**Malcolm** was a long time supporter of AKPA, a member of Addenbrooke’s Transplant Games team and served on the committee as NKF Rep.

Malcolm could be relied on to bring home medals from every Transplant Games he attended. And was keen to promote exercise for his fellow patients to help them regain health and keep fit.

He also represented AKPA at NKF conferences, and after returning to dialysis became AKPA Patient Rep. for the Kings Lynn Unit. He was devoted to improving the lives of his fellow patients and will be sorely missed.

### Janet Evans – AKPA Vice President

**Janet** was always a strong supporter of AKPA, taking on the role of *Vice President* shortly after the death of her husband Dr David Evans in 1997.

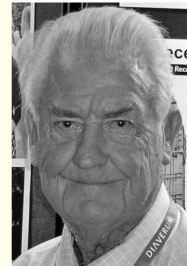
Dr David Evans was a pioneer of dialysis in the UK and both he and Janet were very involved in the creation of AKPA. Janet always attended and contributed to our AGMs. She will be sadly missed.

### Roger Ward

**Roger** was also a long time supporter of AKPA. He served on the committee in the early 2000s as publicity and information officer, publicising the work of AKPA and distributing information leaflets and books to help patients deal with dialysis, diet and drugs.

He continued supporting AKPA as well as a myriad other social and environmental causes. He will be greatly missed.

### Colin Gant



Colin Gant

**Colin** was an early member of the AKPA committee. He served as Vice Chairman and publicity officer during the 1990s.

Colin and his family operated the AKPA publicity van for several years. They drove the van to local fetes and events to publicise dialysis, transplantation and the work of AKPA. Also to raise much needed funds.

Colin was also involved in the early days of the Transplant Games and with organising dialysis holidays for patients and their families. Colin’s work was vital in beginning these important functions. He will be missed.

# New Medical Development Gives Hope to Diabetic Patients

## Preventing Amputations



Alan Webster

Diabetes is one of the main causes of kidney failure with many diabetics ending up on dialysis or having to undergo a kidney transplant.

Kidney failure is not the only problem that diabetics face.

*“Micro-needles are being developed that tackle both problems.”*

However, recent developments in the use of “micro-needles” could dramatically improve the quality of life for people with diabetes who suffer from some of the worst complications this condition brings on – and prevent expensive, life-altering amputations.

The challenge with diabetic wounds is that they’re affected by persistent inflammation, and they don’t heal because the critical proteins that aid in recovery – known as growth factors – are broken down by enzymes called proteases.

Micro needle arrays are being developed that tackle both problems through precise drug delivery into chronic wounds, as well as extracting harmful cells from those sites.

You can find more details at <https://newatlas.com/diabetes/microneedles-extract-cells-deliver-drugs-chronic-wounds/>

Alan Webster

# Transplant Games 2025

The 2025 British Transplant Games are to be held in Oxford 31st July until 3rd August.

Registration is still open until the middle of May. Anyone wishing to join the Addenbrooke’s team can register through Transplant Sport.

The events are to take place around the sporting venues in Oxford but the highlight of the games is that Blenheim Palace grounds are to be used for the opening ceremony, Archery and the Donor Run. It is such an amazing venue.



## World Transplant Games

The World Transplant Games are to be held in Dresden Germany in August, we have some of our team competing for Great Britain and Northern Ireland. This is one of the largest teams to compete in the games we will give an account later in the year.

Val Cooper

*“The Addenbrooke’s Team would like to thank AKPA for their continued support which is greatly appreciated.”*

Once again the Addenbrooke’s Team have new members joining us as well as our existing members.

[www.britishtransplantgames.co.uk](http://www.britishtransplantgames.co.uk)

## An Ode for ‘In Centre’ Dialysis Patients’

*Dialysis is not much fun  
but you are not the only one  
when transplants are in vain  
kidney failure becomes a pain*

*Four very long hours tick by  
whilst cleansing our blood we try  
Either by fistula or line in  
it’s arterial out and venous in*

*Via plastic tubes thick and thin  
our blood is taken for a spin  
As the blood courses round and round  
raucous alarms sometimes sound*

*Nurses scramble to make amends  
Patients relieved when calm descends  
And when the cramps start to bite  
those same nurses put things right*

*And when feeling faint as we sometimes do  
those same dear nurses see us through  
For all the things that do us unsettle  
their unstinting care deserves a medal*

*Though It takes a while to settle in  
and life will never be the same again  
The reality of dialysis is far less grim  
It’s only taking your blood for a spin!*

Alan Webster

# 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, Hinchingsbrooke 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.*

Our website address is:  
**[www.akpa.org.uk](http://www.akpa.org.uk)**

You can email us at:  
[info@akpa.org.uk](mailto:info@akpa.org.uk)  
[fundraising@akpa.org.uk](mailto:fundraising@akpa.org.uk)  
[webmaster@akpa.org.uk](mailto:webmaster@akpa.org.uk)

**Postal Address:**

AKPA, PO Box 608,  
Cambridge CB1 0GJ.

*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.

## AKPA Patient Representative

*Local contact for information about AKPA:*

**Transplant and Dialysis Patients – Suzi Turton**  
Email: [suziturton@hotmail.com](mailto:suziturton@hotmail.com)

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

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



Suzi Turton

## UK Kidney Charities – Who's Who



**The National Kidney Federation (NKF)**  
(<https://www.kidney.org.uk/>)

is the national kidney charity run by kidney patients. It is made up of individual Kidney Patients Associations (KPAs), currently fifty one of them – AKPA is a founder member.

The NKF was founded when KPAs realised they needed a national organisation to fight their cause. It has two main roles: campaigning for improvements to renal provision, treatment and patient support services. It also has a huge amount of information available on all aspects of kidney disease, plus a Helpline and Peer Support service.



**Kidney Care UK**  
(<https://www.kidneycareuk.org/>)

It is a leading kidney patient support charity, providing practical, financial and emotional support for kidney patients and their families, as well as campaigning to improve care services across the UK.

They also provide grants to kidney patients unable to fund holidays or short breaks. Plus practical support with telephone counselling and Advocacy Officers to help with issues around treatment, transport and benefit concerns.

## AKPA Committee Members 2025

**Andrew Collins**

*Deputy Treasurer*

**Gillian Chumbley**

**Laura Tilbrook**

*Vice Chair*

**Martin Harnor**

*Fundraising*

**Paul Smyth**

*Chairman*

**Karen Dahlsveen**

*Staff Representative*

**Julie Walker**

*NKF Representative*

**Suzi Turton**

*Vice-Chair, Patient*

*Representative & Fundraising*

**Brian Wood**

*Treasurer & Newsflash Editor*



May 2025

Designed and Typeset by Natalie White Typesetting & Artwork