

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

A MEMBER OF THE NATIONAL KIDNEY FEDERATION

Professor Sir Roy Calne (1930 – 2024)

Pioneering Transplant Surgeon and
Founding President of AKPA



We were very sad to hear of the death of Professor Sir Roy Calne on the 6th January 2024 at the age of 93.

Many kidney patients have reason to be very grateful for his early work on transplantation and his development of immunosuppressant drugs such as Azathioprine and Cyclosporine crucial for preventing organ rejection.

His remarkable career included appointments at Oxford University, Boston USA and Singapore. He was Emeritus Professor of Surgery at Cambridge University and Consultant at Addenbrooke's Hospital from 1965 to 1998. During that time his transplant programme flourished, conducting annually, over 100 liver and 80 kidney

transplants by the 1990s. Countless people owe their lives to his work.

Sir Roy Calne was also President of AKPA, which was founded at his suggestion. Sir Roy was an active supporter, attending AGMs and with his wife Lady Patsy, our annual Carol Services.

Our deepest condolences to Lady Patsy and their family.

A celebration of the life of Professor Sir Roy Calne will be held at Trinity Hall College, Cambridge on 11th July. The event will be live streamed, giving all AKPA members the opportunity to join the memorial meeting.

The live stream link will go to all on the AKPA email list.

For details email: info@akpa.org.uk

www.akpa.org.uk

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Dates for 2024

Thurs. July 11th – 11.00am onwards
A Celebration of the Life of Prof. Sir Roy Calne
(Also streamed)
Trinity Hall College, Cambridge

Tues. October 15th – 6.30pm
AGM (Also via ZOOM)
Quaker Meeting House,
91–93 Hartington Grove,
Cambridge CB1 7UB

Sat. December 7th – 3.00pm
AKPA Carol Service
Great St Mary's Church, Cambridge

New President for AKPA

We are very pleased to announce that Professor John Bradley has agreed to become President of AKPA following the death of Professor Sir Roy Calne.

Professor Bradley has been AKPA Vice President for many years, supporting our work and attending AGMs. With his background in dialysis and transplantation he has a wide knowledge of Renal Medicine and the needs and experiences of kidney patients.

After completing his undergraduate medical training in Nottingham he trained in renal medicine in Cambridge during the 1980s, working

at Addenbrooke's Dialysis Centre when it was at Douglas House, Trumpington Road before undertaking research fellowships at Harvard, Yale and Cambridge Universities.

His current roles include Consultant Renal Physician and Director of Research at Cambridge University Hospitals, honorary Professor of Experimental Medicine at University of Cambridge, Director of Research for Cambridge University Health Partners and Regional Specialty Advisor in Renal Medicine, Royal College of Physicians.



Professor John Bradley, CBE MA DM FRCP

AKPA Carol Service – Great St Mary's Cambridge

9th December 2023



Great St Mary's, the University Church of Cambridge, was once again packed for the AKPA Carol Service. This always popular, annual event, heralds the start of Christmas celebrations for many patients, staff and their families, and is a way of saying thank you to all who support this small local charity.

The service started with choir and congregation joining to sing the opening carol, *Veni Veni Emmanuel*, followed by a welcome prayer from the Reverend Janet Bunker, Vicar of the Parish of the Ascension.

The St Augustine's Singers led the carols and displayed their musical virtuosity in solo pieces – William Byrd's *Beata Viscera*, the gently rocking lullaby, *Qui*

Creavit Caelum and Morten Lauridsen's *Veni, Sancte Spiritus*.

The traditional bible readings were given by the Mayor of Cambridge, Councillor Jenny Gawthorpe-Wood, Sally Taber former Chair of British Kidney Patient's Association, Martin Harnor AKPA Committee Member, Dr Andrew Fry Renal Consultant Addenbrooke's and Benedict Peers, relative of a transplant patient.

But perhaps the highlight of the service was the performance by a group of enthusiastic and vibrant children from Hatton Park County Primary School. They performed three popular Christmas songs including, "Rocking around the

Christmas Tree", accompanied on guitar by their music teacher, Matt Thompson. All to rousing applause!

Organist Mo Wah Chan gave a brilliant performance and, after the final carol, *O Come All Ye Faithful*, ending the service with the glorious solo Sigfrid Karg-Elert's *Marche Triomphale Op. 65 No 59*.

Our thanks to all who contributed and made this event so successful. And very special thanks to Suzi Turton for her months of 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.



Sally and the children of Hatton Park Primary School

Film Made at CDC by Kidney Research UK

Patients and staff from Addenbrooke's have helped a national research charity raise awareness of kidney disease with a powerful new video.

Renal Nurse Junard Villanos and Psychotherapist and Specialist Renal Counsellor Gillian Chumbley of Cambridge University Hospitals talked about the impact of kidney disease and the importance of research in a video filmed by Kidney Research UK at the Cambridge Dialysis Centre.

The film coincides with new figures showing 40 patients donated their organs after death at Addenbrooke's last year. Their generosity, combined with that of donors at other hospitals, has helped to save or improve the lives of 4,532 people across the UK waiting for a variety of organ transplantations.

Addenbrooke's is internationally renowned for its transplant programme

and ranks third out of the top 20 donor hospitals in the UK, according to figures from NHS Blood and Transplant.

Kidney Research UK has recently announced a new set of grants specifically aimed at transforming transplantation to ensure they last longer and are available to many more patients.

Named after Cambridge University professor Mike Nicholson, the awards will be available to experienced researchers as well as nurturing young talent.

CUH consultant in paediatric intensive care and clinical lead for organ donation, Dr Riaz Kayani, said: "We are proud to have been able to help so many patients this year, but the real heroes are the donors and their families for allowing these procedures to happen."

To view the full film or three short clips use link on the right:



Psychotherapist and Specialist Renal Counsellor, Gillian Chumbley and Renal Nurse, Junard Villanos of Cambridge University Hospitals talked about the impact of kidney disease and the importance of research in the video filmed by Kidney Research UK at the Cambridge Dialysis Centre.

<https://www.cambridgenetwork.co.uk/news/new-film-highlights-importance-kidney-research>



British Transplant Games 2024

The British Transplant Games are being held in Nottingham from 1st August until the 4th.

Registration is open until the 26th May and currently we have several new members as well as existing members. It is always good to have new people joining our Addenbrooke's team.

The venues are around the Nottingham area, the Opening Ceremony is to take place in Nottingham Castle, the Golf is

to be played at Wollaton Park Golf Club and the Athletics on Sunday the 4th is at the Hadden Sports Village Track and Stadium.

Anyone wanting further information or to register go to Transplant Sport.

Once again thank you to AKPA for their continued support.

www.britishtransplantgames.co.uk

Val Cooper



1st-4th August 2024



Christmas Gifts to Patients

For very many years AKPA has provided food and presents to patients who dialysed over the Christmas period. Covid has meant restrictions on what we can provide, but we hope our seasonal gifts will still bring some cheer.

With a suggestion from nursing staff last Christmas that fingerless gloves might be a useful present, we set about the task of sourcing, wrapping and

delivering close to 400 pairs across the region, to CDC, Hinchingsbrook, West Suffolk and King's Lynn dialysis units.

These gloves should provide some relief for "dialysis cold hands" and we hope they give comfort to all who received them.

Our thanks to the youth group at St Mary's Church in Ely who very kindly gave up their time to wrap the vast



St Mary's Youth Group

majority of the gloves in two of their club sessions before Christmas. Thanks also to Adella Charlton for all her work organising and delivering.

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

We Will Be 50 Next Year!

AKPA 50th Anniversary 2025

Addenbrooke's Kidney Patients Association was started in 1975 by a small group of patients with support from medical and nursing staff including Professor Sir Roy Calne, and Dr David Evans.

AKPA is run by volunteers, and we rely on fundraising and donations from our supporters to continue our work. We do not receive funding from any other sources, and we would be very grateful for any help and support you can give.

In the year 2000 we celebrated our 25th Anniversary.

There was a party at Wolfson College which was attended by the Cambridge MP and sponsored by a whole range of Medical Companies

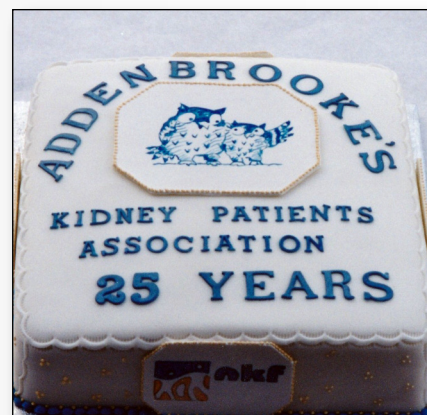
and Health Care providers. It was also featured on local radio, Anglia Television and in the *Cambridge Evening News*.

Guest speakers at that event praised the work of AKPA, and Sally Taber gave a brief history, ending by saying that:

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

Help Needed

Now, almost 25 years later, Sally's words remain true. Despite the amazing advances of medical research, there are immense strains on



Cake baked for AKPA's 25th Anniversary

both the NHS and welfare services and the work of AKPA is even more important. We still rely on people who are prepared to give their time. Also, those who are prepared to donate, fundraise or remember us in their wills.

Can you help us into our 50th year and beyond?

We are currently looking for volunteers to help us run the charity, in particular, people with experience in communications, fundraising, or finance.

AKPA is a registered charity, run by an Executive Committee. We raise money to provide support for Addenbrooke's Renal Services with such things as welfare assistance for patients, funding for research projects and equipment not funded by the

NHS. Most committee members are also trustees and all are volunteers.

Meetings take place every two months, currently at:

**The Quaker Meeting House,
91-93 Hartington Grove,
Cambridge CB1 7UB**

and usually last around two hours. There is also an option to join the meetings by Zoom.

*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

Funding Medical Equipment

New Ultrasound Scanners for Dialysis Units

From the earliest days of haemodialysis, shortages of medical equipment have been a constant problem. When AKPA was founded in 1975 there were fundraising campaigns to buy equipment not supplied by the NHS; in 1995 AKPA raised £100,000 to buy dialysis machines.

*“In recent years
Ultrasound Scanners
have become vital for
diagnosis and treatment
of dialysis patients.”*

AKPA first funded an ultrasound scanner in 2006, since then there have been huge improvements in the technology but once again there is lack of funding from the NHS.

Fortunately, charitable donations have again filled the funding gaps.

New Scanner for Cambridge Dialysis Centre

AKPA have provided a new ultrasound scanner for Cambridge Dialysis Centre at a cost of £5,460.

Regin Lagaac CNS Vascular Access describes why this state of the art equipment is so important.

He says: “Haemodialysis (HD) treatment is not possible without a functioning access. For this, the arteriovenous fistula (AVF) has fewer complications than other methods.

In my clinical experience, some patients may refuse to have permanent AVF created due to fear associated with pain during cannulation, when this occurs it is usually related to needle misplacement.



Regin Lagaac

Most guidelines recommend Doppler Ultrasound to guide cannulating. However, its use is not limited to surveillance, as it can also be used for

needling, which allows needling results to improve and the number of complications to be reduced.

Acquiring this new state of the art machine has enabled our haemodialysis service to initiate ultrasound guided AVF cannulation. Doing so has meant the team now provides an enhanced, high-quality service to our patients by reducing pain and distress from multiple cannulation attempts.

We are fortunate that Addenbrooke’s Kidney Patient’s Association (AKPA) has supported our work by funding this portable ultrasound machine. It will prove very useful in the daily work of our dialysis nurses.”

Regin Lagaac

New Scanner for West Suffolk Dialysis Unit

Mildenhall Masons to the Rescue

When Trevor Manville, the current Mildenhall Masonic Lodge Master, heard that the WSH Bury St Edmunds dialysis unit needed a new ultrasound scanner he very kindly chose us as his nominated charity. Trevor galvanised his 60 or so Lodge Members and their families to raise funds for the new equipment. After a successful year they had raised £3,686 which met the cost of the scanner in full.

The overall cost, however, including training, extended guarantees and ancillary kit came to just over £5,200; so



Trevor Manville presenting new scanner to Unit Manager, Irene Pantoja. On right Trevor's wife, Angé who helped with the fund raising

heartfelt thanks also to AKPA who have generously contributed the difference.

Anyone on haemodialysis knows just how essential an ultrasound scanner is, not only in cannulation but also in

detecting other fistula related issues. The new scanner is something of a departure from the rather cumbersome and ailing kit we have at present. The new scanner is highly portable, far more practical and the the connection between transducer (probe) and screen is wireless. Moreover the images are clearer and can be in colour to differentiate the needle from surrounding tissue. With the right software the probe can even be used in conjunction with a smartphone.

For those wanting to see full scanner details:

<https://xtra-med.com/our-products/ultrasound>

Alan Webster

The importance of these machines can't be over stated. The Dialysis Unit at the Queen Elizabeth Hospital, Kings Lynn have also approached AKPA to fund a machine for their patients.

Peer Support Training

Thanks to all who joined the AKPA Peer Support training course at West Suffolk in February. The four hour session, which was given by Eleri Wood, Renal Nurse Consultant who has developed Peer Support training at King's College Hospital, London, was a great success.

Eleri is a wonderful communicator who spoke of Peer Support as a way of helping patients feel more confident and empowered. Her training was gently paced, making it easy to follow, to join discussions; ask questions and share experiences.

“I remembered thinking I can't cope with all this on my own.”

Trainees' experiences were very different; one was transplanted quite quickly after low clearance, another had received a couple of kidneys and suffered other illnesses, another had spent several years on dialysis, could set up her own home machine and dialysed with support from her husband.

Ages also differed, from 20s to 70s. The one thing we shared was living with kidney failure and the hope to help others who were going through or about to go through the same thing.

Eleri made the training interesting by giving us useful, alternative tasks. We all agreed our active listening skills weren't what we thought they were – good to have this pointed out, and to

“Having somebody else to talk to who's experienced it and understands what you might be feeling – could be a great relief.”

become aware of small details we can miss when not fully actively listening!

Most reassuring was the discussion about when you've had a bad experience; for example with Peritoneal Dialysis, but, however, you know many people find it a good therapy, and how you present that information in a fair way to a patient. Volunteers shared their opinions of what could be said in different circumstances.

A fabulous lunch was provided, but we were so involved we wanted to carry on. Next time we might need a slightly longer lunch considering the energised discussions flowing between volunteers.

By the end of the session we understood much more about the role of a Peer Supporter. Eleri was quite clear in reassuring us: you are not expected to be a counsellor or give medical advice. You simply practice listening skills, talk about dealing with emotional issues, and dealing with negative experiences that you may also have experienced.

As we left we felt that, as patients, we could support people, address their anxieties and hopefully give them the encouragement to continue with their kidney journey, whatever problems they



*Eleri Wood, Kidney Nurse Consultant,
Kings College Hospital*

might come up against. We also understood we were not alone, if we felt another voice of support was needed then sign-posting to different agencies within the clinics: the dietitians, counsellors and so on would be useful. And we had our Peer Support team to talk to should we need advice or simply an ear to listen.

Anyone who is thinking of training to become a peer supporter please put your name down early for the next training session, you might just be the support another patient needs right now.

Suzi Turton

To express interest in Peer Support training please contact:

For West Suffolk:
annika.wallis@wsh.nhs.uk

For Cambridge, Hinchingsbrook and King's Lynn:
suziturton@hotmail.com,
gillian.chumbley2@nhs.net

Where The Money Goes

AKPA purchased a new ultrasound scanner for CDC at a cost of £5,460 and with the help of a generous donation of £3,686 from the Mildenhall Freemason's Lodge we contributed £1,514 for ancillaries and training for a much needed ultrasound scanner for the West Suffolk Dialysis unit.

We supported a Renal Peer Support training session at West Suffolk Hospital at a cost of £821.

We paid the final instalment of £16,860 towards the COBALT Fistula research trial, which will provide information about long term fistula problems.

We provided presents and Christmas cheer to patients needing to dialyse over the Christmas period at a cost of £635.

We continued funding phones for staff at a cost of £195 per month and providing welfare support to the increasing number of patients facing hardships in difficult times.

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 9am–5pm

Woolly Reindeers and Snowmen

AKPA was chosen by the staff of ED&F Man Ltd as their annual good cause.

The company, who supply animal feed in several British and Irish cities, have an annual Christmas Jumper Day where they encourage all their office and operational staff to wear Christmas Jumpers and donate to a good cause – often with personal connections to a member of staff.

This year they chose AKPA because a colleague's son was getting dialysis at

Addenbrooke's. Leon was unexpectedly diagnosed with a kidney condition earlier in 2023 and was attending dialysis three times a week.

They raised £648 which was matched by a donation of £700 from the company.

We heard recently that Leon has received a transplant from a relative.

Our thanks and best wishes to all at ED&F Man for a wonderful seasonal fundraising effort.



Staff members of ED&F Man Ltd wearing their Christmas jumpers on Christmas Jumper Day in aid of AKPA

AKPA Christmas Cards

Sales of AKPA Christmas cards in the run up to Christmas were again very successful, raising a total of £1,577.

This includes another amazing total of £776 from Pearce's Farm Shop in Buntingford. Every year they manage to sell a large number of AKPA Christmas cards. Our thanks to Dinah, David and all their staff for again supporting AKPA.

Thank you to everyone who brought our cards and sent donations.

Special thanks to Carol Slattery for all her hard work in organising, distributing and selling cards. After very many years of organising the purchase, distribution and selling of AKPA Christmas cards, Carol has decided to retire. Our thanks for all her hard work, for the money raised and the Christmas cheer to all those who received cards.

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.

Thank you all.

West Suffolk Christmas Raffle

Patients and staff at West Suffolk Dialysis Unit raised a brilliant £358 for AKPA with their annual Christmas Raffle.

Our thanks to Senior Nurse Irene Pantoja for organising and to all who bought tickets and contributed to raise such a large amount for AKPA.

Thank you all.

200 Club – Winners

NOVEMBER 2023	JANUARY 2024	MARCH 2024
1st prize £91 • V Griffin	1st prize £91 • J Childerly	1st prize £91 • J Beytell
2nd prize £55 • H Pearce	2nd prize £55 • A Thompson	2nd prize £55 • C Barrass
3rd prize £36 • F Kingsley	3rd prize £36 • J Beytell	3rd prize £36 • M Sell

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. Renewal will be automatic for those paying by standing order.



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



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

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

Postal Address:
AKPA, PO Box 608,
Cambridge CB1 0GJ.



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.

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 Hinchingsbrooke Dialysis Units.

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



Malcolm Souza-Lewis



Suzi Turton

AKPA Committee Members 2024

Andrew Collins
Deputy Treasurer
23 Constable Road,
Haverhill
Suffolk CB9 7FQ
Tel: 01440 702750

Martin Harnor
Fundraising

Karen Dahlsveen
Staff Representative
Cambridge Dialysis Centre
Unit E
Beadle Estate
Cambridge CB5 8PD

Gillian Chumbley
CUH Addenbrooke's
Renal Services
Dialysis Unit E
Beadle Estate
Cambridge CB5 8PD

Laura Tilbrook
Vice Chair

Paul Smyth
Chairman
6 Longchamps Drive,
Ely CB7 4QS
Tel: 07766 070 362

Suzi Turton
Vice-Chair, Patient Representative & Fundraising
4 Bentink Street
Cambridge CB2 1HG
Tel: 01223 721173

Brian Wood
Treasurer & Newsflash Editor
48 Montague Road
Cambridge CB4 1BX
Tel: 01223 353575

May 2024

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



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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