



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

A MEMBER OF THE NATIONAL KIDNEY FEDERATION

Fabulous Food Raises Funds for AKPA



The Gharu family presenting the cheque to Ralph Slattery, Chair of AKPA and Fundraiser Janet Man

The proprietors of Lally's News on Mill Road in Cambridge once again used their shop front to host a fundraising effort for AKPA during the annual *Mill Road Winter Fair*.

Their food stall attracted a constant stream of customers to the delicious selection of bread pakoras, samosas, chicken curry, paneer curry and chickpea curry. The chickpea curry in particular has become a favourite with locals who come back for it every year.

The family, Raj, Amrik, William and Saira Gharu, all pull together. With Amrik and Saira doing the cooking while William runs the shop and Raj

sells the food from the front stall. They also hold a raffle with various donated prizes.

This food stall has been a regular event for many years, and a part of the family's long term support for AKPA. William Gharu received dialysis for many years and recently had a kidney transplant.

However, this may be the last year as they are planning to move – if so, it's nice that they raised the highest amount ever, a whopping £1,425.

Our thanks to all the Gharu family for their wonderful fundraising efforts.

www.akpa.org.uk

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Dates for 2020

Mon. September 21st – 6.00pm
AKPA AGM
Cambridge Dialysis Centre

Sat. December 9th – 3.00pm
AKPA Carol Service
Great St Mary's, Cambridge

For the latest news and information about Coronavirus for kidney patients visit KidneyCare UK website

www.kidneycareuk.org/news-and-campaigns/coronavirus-advice

**Help Needed,
See Page Three.**

Where the Money Goes

As well as our regular support for patients we have recently funded some important pieces of medical equipment not supplied by the NHS. Plus, funding for an important research trial and for patient comforts.

- Four Infrared, fistula treatment machines at a total cost of £15,200; providing one each for the Dialysis Centre and the three Satellite units.
- Four portable Ultrasound Scanners for fistula examinations

at a total cost of £23,000; also providing one for each of the four units.

- Transport costs for patients involved in the SONAR haemodialysis fistula research trial at a total cost of £3,297.
- Two Dialysis simulators for training staff and patients at a cost of £1,270.
- Thirteen cushions for dialysis unit beds and chairs at a cost of £364.



- A Bladder Scanner (above) for use in the Dialysis units at a cost of £7,000.

New Scanners for Dialysis Units



From left to right: Anj Caneda, Reg Lagaac, Soumya Vasantha Sasi, Rosana Kriger, Cristina Menendez Garcia, Helen Thompson and Junard Villanos

Presentations at our last two AGMs have emphasised the importance of healthy arteriovenous fistulas for Haemodialysis

patients. Regular monitoring is necessary to ensure newly formed fistulas develop successfully and remain healthy.

AKPA have recently funded four state of the art, ultrasound scanners so that equipment is available in each unit to regularly check fistulas for all dialysis patients.

Along with the infrared fistula treatment equipment purchased last year, plus funding for the SONAR Trial, AKPA has made a great effort to support treatment for what is a vital lifeline for haemodialysis patients.

SONAR Trial – Phase One Completed

The first stage of this multi-centre medical trial to evaluate the role of ultrasound in creating healthy fistulas has now been completed. The aims of the trial were first outlined at our 2018 AGM and AKPA agreed to fund the travel expenses of patients who were involved.

Studies like this have the potential to improve patient care for a large number of patients.

The first part of the SONAR project was to see if problems can be identified within the first ten weeks after surgery using ultrasound scans at various time intervals. Data from the scans plus other information about the fistula were collected for analysis.

By November 2019, 348 patients had agreed to take part, meeting the study targets. The data from the trial is currently being analysed and the results will be released in the next few months when planning will start for phase two.

AKPA Committee member Andrew Norton has worked with the SONAR team since the idea was first developed, sharing his experiences as a patient to shape the way the study was run.

Trial manager, Anna Siders gave great thanks to AKPA for supporting the project by funding patients' travelling costs.

We Welcome New Members and Supporters

This includes family, friends and carers as well as kidney patients. AKPA is for any patient who has been treated at Addenbrooke's or any of the satellite dialysis units. It is also for anyone who has had, or is waiting to have, a kidney transplant at Addenbrooke's.

To become a supporter (mailing list only) or full member of AKPA, please go to our website: www.akpa.org.uk/join.htm and download the form. Printed versions are also available at Dialysis Units.

Alternatively can you complete this form and send to the address below.

Name _____

Address _____

email _____

AKPA Membership,
10 Craven Close,
Cambridge CB2 9NW

AKPA Carol Service – Great St Mary’s, Cambridge

Despite traffic chaos and an icy wind, Great St Mary’s was crowded for the annual AKPA Carol Service.

Ralph Slattery, Chairman of AKPA, welcomed everyone, and the service started with choir and congregation joining to sing the opening carol, *Veni, Veni, Emmanuel*. This was followed by a welcome prayer from Dr Rowan Williams, former Archbishop of Canterbury, who had again kindly agreed to officiate.

“organist David Poulter also treated us to some fine solo pieces.”

The St Augustine’s Singers directed by Philip Mead, led the carols and displayed their musical virtuosity in the solo pieces – William Byrd’s *Beata Viscera* and Philip’s own gently rocking lullaby – *Qui Creavit Caelum*. They were accompanied by organist David Poulter, who also treated us to some fine solo pieces.

The traditional bible readings were given by the Deputy Mayor of Cambridge, Councillor Russ McPherson, Renal Transplant Co-ordinator Michelle Harris,

AKPA Committee Member Janet Man, Retired AKPA Chairman Peter Constable and Great St Mary’s Lay Minister Shirley Holder.

Dr Williams, who is always an outstanding speaker, delivered a thought-provoking address, praising the dedication of NHS staff and the brilliance of recent medical advances. This was followed by the Lighting of Candles: always an emotional ceremony.

“Many stayed to enjoy a drink and chat with friends old and new.”

Congregation and Choir joined in the joyous final carol, *O Come All Ye Faithful*, which was followed by the blessing from Dr Williams.

Wine and seasonal nibbles were served at the back of the church and many stayed to enjoy a drink and chat with friends old and new.

AKPA Carol Services become more popular with every year, and our thanks to all who contributed and made this event so successful. To Dr Rowan Williams, Philip Mead and the St Augustine’s Singers and organist David



Dr Rowan Williams and Sally Tabor, ex-Chair of Kidney Care UK

Poulter who all gave their services freely. Thanks to Trevor Barwood’s Aston Catering for donating the food, and Nicky Moncrieff, Angela Green, Carol Slattery and Monica Taylor for serving the drinks.”

Very special thanks must go to Sarah Oughton for her months of hard work organising and arranging all the many elements that enabled this service to run so smoothly and successfully.

Help Needed

We are looking for new Committee Members to help run the charity, in particular, people with computer, financial or publicity skills.

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.

Minutes Secretary Needed

We also need someone with secretarial skills to type and distribute minutes of our committee meetings. Meeting times and venue as below.

We are looking for an experienced person who would work on a freelance basis and charge an hourly rate.

**Meetings take place every two months at
Cambridge Dialysis Centre, off Newmarket Road, Cambridge
and usually last around two hours.**

For more information about both the above please contact:

**Ralph Slattery
Telephone: 01223 564752 • Email: r.slattery@ntlworld.com**

M&S Retirees Club Donation

In June last year AKPA Chairman, Ralph Slattery attended the M&S Retirees Club to be presented with a cheque for £500. The money had been collected in memory of their colleague Glenys Knights, a very active member of the group who had recently died. Glenys was a haemodialysis patient for a short while, and the group were keen to help with the care of dialysis patients.



They asked for the money to be put towards the purchase of the Far-Infrared Therapy unit that AKPA was buying for CDC. And of course, there was the opportunity for a good chat over tea and (M&S) cakes!

Our thanks to all the members of the M&S (1740) Club for their generous donation.

AKPA Christmas Cards

Sales of AKPA Christmas cards were again very successful, raising a total of £2,513. Our thanks to Carol Slattery for all her hard work organising and distributing cards. And thank you to everyone who bought our cards.

Pearce's Farm Shop in Buntingford again did well, selling £732. Our thanks to all at Pearce's Farm shop for another brilliant contribution.

AKPA cards sold well in Clinic 12, Dialysis Centre and satellite units. Card sales in Clinic 12 again did well at £497. Thanks to all who bought and sold cards in those venues.

Cambridge Cards for Good Causes shop also sold our cards. Our thanks to Janet Man for all her hard work as AKPA volunteer in their Cambridge Card shop.

Carol is now planning the order for this year's cards.

Rugby Fundraising



Helen Burns, Riky Green, Mark Anderson and Nicky Moncrieff

Haverhill Rugby Club held a Fundraising Day in February with a lunch followed by a raffle and "fines" for all sorts of hilarity.

Nurses Nicky Moncrieff and Helen Burns attended the lunch and gave a talk about CKD.

The Club's fundraising efforts resulted in £321 being donated to AKPA and £400 to Kidney Research UK.

Our thanks to all the club members for their generous donations.

Help Needed

We sell AKPA Christmas cards in the Cards for Good Causes shop in Cambridge and to do this we are required to have a volunteer to help for a few hours once a week from October to Christmas. If you are interested please contact Carol Slattery on 01223 564752 for more details.

The Norfolk Broads Walk Challenge

Saturday 13th June 2020

Natalie Wood will be taking part and walking 50km (35.1 miles) to raise money for Addenbrooke's Kidney Patients Association.

Her husband is currently on dialysis and is patiently waiting for a kidney transplant.

So as a thank you for all the care and help he has received, she is trying to raise as much money as possible to say thank you and to get her, through this challenge.

To sponsor her please visit Natalie Wood's JustGiving page

Haig Court Bring and Buy

Residents at Haig Court Chesterton once again supported AKPA with their annual Bring and Buy sale in November. The sale raised a magnificent £131 for AKPA. Our thanks to the residents for their generosity and to the House Manager, Bob MacGuinness for organising the sale and supporting AKPA.

Getting Fun Out of Fundraising!



Eileen Hyde and her colleagues at Royston Bowls Club know how get fun out of fundraising. Thanks to great teamwork and enthusiasm, Eileen Hyde (past club president) and her friends have raised the amazing sum of £2,420 for AKPA.

Eileen, 82 decided to mark the last year of her Bowls Club presidency by fundraising in memory of her late husband who suffered from polycystic kidney disease and needed regular dialysis. She said; “the Dialysis Centre Staff were excellent, we couldn’t fault them”.

Eileen inspired her Bowls Club friends to organise events including afternoon teas, a Body Shop sale and a Bowls tournament featuring a spider! The sum raised is great testament to Eileen’s inspiration and the respect and affection held for her and her husband by members of the Bowls Club. These activities must also have been great fun and a good time had by all!

Nicky Moncrieff, Senior Renal Nurse Specialist, said; “AKPA intends to use this generous donation to fund bits of medical equipment we often need but can’t get from Addenbrooke’s for example, blood pressure kits.”

AKPA gives thanks to Eileen and Royston Bowls Club for all their efforts in raising such a large sum. It is only with donations like these that AKPA is able to continue supporting local kidney patients.

200 Club – Winners

NOVEMBER 2019

First prize £100 • Ann Peet
Second prize £60 • Nicky Moncrieff
Third prize £40 • Mrs M Reid

JANUARY 2020

First prize £100 • Mr G R Smith
Second prize £60 • Laura Banks
Third prize £40 • Mrs D Scarff

The new year of 200 Club Draws will start in May.

For a chance to win three large cash prizes every two months please see enclosed 200 Club Membership form.



For more information email: fundraising@akpa.org.uk



Handmade Quilts for Satellites

Keeping warm in style – The Barton Mills Quilting group recently donated more of their beautiful handmade quilts for patients dialysing in the satellite units. The group began donating the quilts when they heard that patients often needed extra warmth when dialysing.

Our thanks to the quilters for their hard work and generosity.



Internet Fundraisers

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

Thank you all.

**Help Us Raise More
– Fundraise on
JustGiving**

you are raising money. Please visit www.justgiving.com/akpa

You can set up your own JustGiving fundraising page to say what you are doing and why



The National Kidney Federation Annual Patient Event October 2019 – Radisson Blu Hotel, East Midlands Airport

Opening Address – David Marshall

The retiring NKF Chairman, David Marshall, gave a short welcoming address highlighting the fact that it has been 40 years since the NKF was founded from the fourteen KPA's. Also, that their Helpline has operated for twenty years, taking over 55,000 calls!

He continued by mentioning the changes to the Organ Donation laws and adding that the NKF would be pushing the Government on various issues in the coming year.

The NKF Celebrity Cookbook – Lawrence Keogh

The well known TV Chef presented his new cookery book for kidney patients. It is well illustrated and contains recipes for easy, tasty and nutritious meals. Each recipe has been tested three times for approval prior to inclusion.

Transplantation and Fistula Access – Rowland Storey

Rowland reviewed the history of dialysis and transplantation. Saying that during the 1950s there were only two or three dialysis units in the UK and the first transplant took place at this time between identical twins.

He went on to review the current methods of surgery used to provide vascular access for dialysis, mentioning the on-going research to refine fistula surgery outcomes.

He said the average wait for a transplant now is 1000 days and mentioned that the fastest was the Cambridge Centre.

Again, the changes in organ donation law were highlighted and the potential extra kidneys available were estimated at 700 annually in five years time. We were told that 1000 transplants had been achieved by the 'sharing' scheme and that there was potential for robotic surgery for transplantation becoming available in the future.

Fistula Bleeds – Terry Sopp

Terry, who dialysed for 24 years prior to transplantation, was the first person in the world to receive EPO and also the first and so far the only, dialysis patient to cycle from Lands End to John O'Groats!

He told the story of his sister who died following a fistula bleed. Last year there were 11 deaths reported from fistula bleeds and he wanted to promote awareness of this situation with both patients and medical staff.

He showed the small pack which the Reading unit have developed; a small sealed plastic bag containing gloves, a milk bottle plastic cap and a reel of tape. If bleed occurs, the bottle top is clamped over the area and taped firmly round. This stems the bleed which will eventually clot, giving time to seek help. After any bleed the person must be seen by the renal team to ensure correct actions are taken to prevent a recurrence.

My Journey with Home Haemo – Enoch Saffo

Enoch gave us his perspective on how home haemo had enabled him to travel with his Nx Stage to his home country of Ghana. And what it had meant to him in getting his life re-organised after a long period of not dialysing prior to complete renal failure. He has put together a YouTube video and has had 32,000 hits.

The Kidney Patient's Involvement Network (KPIN) – David Coyle & Andy Henwood

This presentation gave the background to the KPIN. This network can provide links to facilitate patient and professional involvement in the care and treatment of renal failure patients at levels up to shared decisions in equipment used, procedures and the way units are run.

David is also the lead for NHIR Devices for Dignity and is an enthusiastic supporter for patient involvement and representation. The network can advise on best practice, how to be involved and is non-political. Find them at www.kpin.org.uk

Empowering Patients by Shared Decision Making – Jean Featherstone, Angela Wood & Michelle Barber

This presentation followed on from the previous one in giving the practical experience of three people from the Hull Dialysis Centre, two staff and one

patient (Michelle). The unit has made self-care a target for as many of their patients as are able to contribute by having patient advocates like Michelle.

"I believe we are some way along that path at CDC but could really benefit from a task force of our own."

They are very successful and have over 70% of their dialysis patients on some degree of self-care, even if its just laying out the equipment for the nurse, taking their own BP or completely looking after the whole operation. This has led to more home haemo as well as smoother and more integrated performance in the unit. 'Dialyse to live – not live to dialyse' is their mantra and they have encouraged a shared-care mentality in their unit.

Renal Nutrition Group – Bruno Mafri & Tina Dilloway

This group of dieticians, specialising in Renal Nutrition, first came together in 1972. Although the group has grown since then their aims remain the same – to improve patients' experience and quality of life. The session focussed on the national projects which RNG are currently promoting specially to reinforce understanding of the balance of diet for safety.

Peer Support Groups – Kirit Modi & Hope Clayton

Kirit is a kidney transplant recipient and is a past chairman of the NKF. He is a founding member of the National BAME Transplant Alliance and currently chair of the Lister KPA. Hope Clayton is a Health Psychologist in the East Hertfordshire Renal Team.

They outlined how the North and East Hertfordshire Trust and the Lister KPA established a Peer Support Group and are very keen to help other KPA's in developing their own schemes to the benefit of local kidney patients.

This information could be shared with any KPA who thought such a scheme would benefit their area.

Andrew Norton – October 2019

Dialysis Staff Receive Addenbrooke's Award

The staff of Cambridge Dialysis Centre were awarded the prestigious "You Made a Difference Award" in December last year.

During September 2019 the Dialysis Centre was asked, for the second time, to accommodate patients requiring dialysis from the West Suffolk (Bury St Edmunds) Dialysis Centre after their site suffered a second water plant failure.

Patients were transported to Cambridge Dialysis Centre (CDC) by taxi and cared for by teams of nurses from both CDC and the West Suffolk dialysis unit. Additional support was also provided by specialist nurses from low clearance, home therapies and admin staff who all pulled together in a magnificent team effort.

Charmaine Lee, senior sister at the Cambridge Dialysis Centre said: "I am privileged to work with a dynamic, flexible and supportive team. Dialysis is such a specialist skill that we only have the team we work with to meet the needs of our service. Also, we work in an off-site unit and as such often only have each other to rely on to trouble shoot and problem solve. I am thrilled that they have been recognised for this award."

C5 Makeover

Addenbrooke's ward C5, the renal inpatient ward, has recently undergone a massive refurbishment. This nature-inspired transformation was funded by a £400,000 legacy gifted to the ward by the late Marcia Cunningham whose friend had worked there.

Each of the ward's 24 beds now has the option of offering dialysis – reducing the need to move patients to another area for treatment. The refurbishment project also includes comfortable furniture, artwork, a new nurses' station and a waiting room.

Laura Wilton-Cox, senior sister on C5, said: "It looks amazing and will make a real difference to all the patients who use the ward. We are grateful to Marcia for the donation."

AKPA XMAS RAFFLE 2019

Drawn at 2pm on Wednesday 18th December
at Cambridge Dialysis Centre

List of Prize Winners

1	£300 Cheque	04655	Booke, Royston
2	£150 Cheque	07438	Bosher, Oxford
3	£100 Cheque	06901	Cooper, Tiptree
4	£40 Sainsbury Voucher	09670	Gallagher, Kings Lynn
5	£40 Tesco Voucher	00807	Render, Huntingdon
6	£20 Boots Voucher	04936	Bates, Saffron Walden
7	£10 M&S Voucher	07046	Moncrieff, CDC
8	£10 M&S Voucher	06136	Taber, Langstone
9	£10 M&S Voucher	09959	Rogers, Stamford
10	£10 M&S Voucher	05378	Anderson, Hardwick
11	£10 M&S Voucher	08093	Harris, Spalding
12	£10 M&S Voucher	02532	Freestone, Cambridge
13	£10 M&S Voucher	03806	Day, Sandy
14	£10 M&S Voucher	04476	Craig, Stotfold
15	£10 M&S Voucher	09479	Ellis, Bishop Stortford
16	£10 M&S Voucher	07436	Beard, Bicester

Our thanks to Carol and Ralph Slattery for organising another very successful raffle that raised £1,490 for AKPA. Thanks also to all who generously donated prizes and to all those who bought and sold tickets.

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

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

Christmas Lunch



In November last year a Christmas Lunch was arranged for Kings Lynn dialysis patients at the local Masonic Hall. Approximately 70 patients attended and enjoyed a traditional Christmas lunch.

The meal was part of the celebrations for twenty years since the unit's opening.

During the meal a magician went round tables doing tricks. And at the end of the meal entertainment was provided by a local artist who played the banjo and sang, ending with a singalong of George Formby songs.

AKPA funded transport for patients who otherwise would not have been able to get to the venue.

Our website address is:

www.akpa.org.uk

- For information about AKPA.

You can e-mail us at:

info@akpa.org.uk

- For general enquiries to AKPA.

fundraising@akpa.org.uk

- For help with fundraising.

webmaster@akpa.org.uk

- To advertise events on the website.

Postal Address:

AKPA, 48 Montague Road,
Cambridge CB4 1BX

Newsflash Contributions

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.

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 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

AKPA Patient Representatives

Local contacts for information about AKPA, also AKPA Christmas cards and raffle:

Addenbrooke's Dialysis Centre – Suzi Turton

Hinchingsbrooke – Shahzeda Kauser

Email: shahzedakauser1@gmail.com

Kings Lynn – Colin Gant

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

West Suffolk Hospital, Bury St Edmunds – John Smitherman

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

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