Addenbrooke's Kidney Patients Association

NEWSFLASH

Issue 1 2013 No. 5

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

A MEMBER OF THE NATIONAL KIDNEY FEDERATION

Jenny's Extra Mile



Jenny Jennings presenting cheque to Nicky Moncrieff

Staff Nurse Jenny Jennings never ceases to amaze, not only the patients but also her fellow staff at Addenbrooke's Dialysis Centre. She recently completed the Bourn 10km run in 1hr 20mins 29secs raising £388 for AKPA. Jenny has now completed nine half marathons raising over £2,000 for AKPA.

In her own words, Jenny, who is in her 60's says "I was thrilled to complete

the 10km run slightly faster than last year (30 seconds is not to be sneezed at, at my age). I was spurred on knowing I was being sponsored so generously by the Addenbrooke's Dialysis Patients and their families."

Our thanks to Jenny for another amazing run.

Addenbrooke's award for Jenny, page 4.

www.akpa.org.uk

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ALSWICK HALL

BUNTINGFORD • HERTFORDSHIRE SG9 0AA

SUNDAY 21st APRIL 2013 12.00 – 4.00 p.m.

SPRING GARDEN OPENING

HOG ROAST • BAR • TEA/COFFEE
PLANT STALL • ENTRY £4 CHILDREN FREE

ALL PROCEEDS IN AID OF THE

ADDENBROOKE'S KIDNEY PATIENTS ASSOCIATION

AKPA is urgently seeking new committee members – can you help us to continue our work of supporting Addenbrooke's kidney patients?

Please contact Tony Weaver Tel: 01799 525875.

More information on page 2.

The Future of AKPA? — New Committee Members Needed



Committee member Ralph Slattery tells why he is pleased he became involved

Ralph Slattery

You may have seen announced in the last *Newsflash* that I recently joined the

AKPA committee. I did this partly as a way of 'giving something back' in recognition of the 25 years of my kidney transplant.

AKPA has provided great help to Addenbrooke's kidney patients for 38 years. Our work includes; supporting research in kidney treatments; giving support to Addenbrooke's patients, – by improving the dialysis unit, or helping patients in need, – and fundraising to support this work.

The committee meets every two months for two hours in the evening at

Addenbrooke's. We are a happy band and I have enjoyed taking part. I have been amazed at the work 'we' support and I am now even more pleased that I became involved.

There are currently eight Trustee and three co-opted staff committee members and we all contribute our different skills and experiences, but there are one or two areas where we could use some help.

One of these is publicity, and another is coordinating fundraising. If you have experience in these areas and would like to help support kidney patients then please get in touch with anyone on the committee for an informal chat.

I would also highlight that the committee may need more 'New Blood' soon as there are rumblings that two of 'us' maybe taking a step back in the Summer.

Ralph Slattery

Can you spare some time to ensure the future of a Charity that has supported Addenbrooke's Kidney patients since 1975?

As well as committee members we also need volunteers to help with fundraising.

For all AKPA contact information see back page

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Where the Money Goes

Home Haemo Machines

Four more patients have been able to start home dialysis as a result of AKPA funding dialysis machines.

NHS budget cuts had restricted the planned expansion of Home Haemodialysis by Addenbrooke's Home Therapies group. But after receiving a generous legacy, AKPA were able to help by funding four reconditioned machines. This enabled the group's home dialysis programme to get back on track.

Fistula Alert Bracelets

The staff in the dialysis unit would like to thank Addenbrooke's Kidney Patients Association (AKPA) for giving generous funding to purchase fistula alert bracelets for dialysis patients and those pre-dialysis patients with fistulas not yet in use.

For haemodialysis patients the ideal access to the bloodstream is via an Arterio Venous Fistula and it is a priority to preserve and protect this lifeline. To help achieve this patients are advised to wear a Fistula Alert Bracelet and carry a Fistula Alert Card.

The Fistula Alert Bracelets and Fistula Alert Cards are distributed to appropriate



patients at Addenbrooke's and the satellite units (Hinchingbrooke, West Suffolk and Kings Lynn). If you have not received them and would like either, they can be obtained from Low Clearance

(RenalLowClearanceTeam@ addenbrookes.nhs.uk) and Regin Lagaac (regin.lagaac@addenbrookes.nhs.uk) at Addenbrooke's renal unit on request.

Contact number: 01223 349290.

Fundraising • Fundraising • Fundraising

Bric a Brac Stalls

Two bric a brac stalls organised by Sue Oates in Addenbrooke's outpatients hall successfully raised funds for AKPA. The sale in December, with help from Monica Taylor, raised £362. And the sale in March, with help from Alison Loose, raised £315.

Our thanks to Sue, Monica and Alison, and to Sue's husband Graham for delivering the stock. Also, thanks to all the friends and supporters who donated items for the stalls.

Sue is planning more stalls and would welcome donations of good quality bric a brac to sell. Items can be left in the Dialysis Centre.



Winter Fair Fundraiser

Mr and Mrs Raj Gharu once again raised funds for AKPA at their Cambridge Newsagents during the annual Mill Road Winter Fair. The fair was a big success, attracting crowds of people. The Gharus sold delicious indian snacks from a stall in front of their shop and generously donated all the proceeds to AKPA, raising a brilliant £570.

Our thanks to Mr and Mrs Gharu for all their hard work and for the stream of very well filled collecting tins they regularly send to us.



Barbara's Collecting Tins More support from Fulbourn Co-op

Fulbourn Co-op raised a total of £449 for AKPA in collecting tins placed there by Barbara Vining.

Manager Bryce Wilson was happy to have AKPA as the store's featured charity also donating a prize for the AKPA Christmas Raffle.

Our thanks to Bryce for his support and to Barbara for all her fundraising.

Rushden Lunch Club Donation

The Rushden, Highfield Baptist Lunch Club, which caters for elderly and livealone people, donated £150 to AKPA. They raised the money with various small fundraising events throughout the year and selected AKPA because one of their members very much appreciated the work done by AKPA.

Our thanks to all the members for their help.

AKPA Christmas Cards

A big thank you to everyone who bought and sold AKPA Christmas cards. Sales of the cards, which included new designs for 2012, did very well and raised over £2,500.

Cards were on sale in various hospital outlets including Clinic 12, the Dialysis Centre and satellite units. Margaret Johnson once again sold our cards at her joint charities card stall in the Hospital Concourse and Nicky Moncrieff organised the postal sales. Our thanks to Nicky, Margaret and all who helped with the Hospital card sales.

Our cards were also sold in the Cambridge Cards for Good Causes shop and Pearce's Farm shop in Buntingford. Our thanks to Monica Taylor for her hard work in the Cambridge card shop and to all at Pearce's farm shop for their excellent contribution.

We will need volunteers to help with Christmas card sales next Christmas. If you would like to help please phone 01223 353575.

Internet Fundraisers

Thanks to all the people who have raised money through the **JustGiving** and **Charities Trust** web sites. Sorry that we don't have details of all internet fundraisers. If you let us know by writing or emailing we would be very pleased to publicise your fundraising efforts.

Thank you all.

Help Addenbrooke's Kidney
Patients when you
shop on-line
visit: www.akpa.org.uk/
easyfundraising
for more information.

Haig Court Bring & Buy

Residents at Haig Court Chesterton once again supported AKPA with their annual Bring and Buy sale held in November last year.

The sale raised a magnificent £250 for AKPA. Our thanks to the residents for their generosity and to House Manager Adrian Livermore for organising the sale and again supporting AKPA.

Exercise on Dialysis – Exciting New Developments

In recent weeks two exciting new developments have been initiated, which could benefit dialysis patients at Addenbrooke's and its Satellite Units.

First, Mr Sushant Jeurkar (Medical Team Lead Physiotherapist) contacted AKPA to find out about our interest in exercise on dialysis and this led to meetings between AKPA and Physiotherapy Department staff.

Sushant is currently planning to improve the inpatient physiotherapy services for Renal / Dialysis patients and Carly Readings, one of the Physiotherapy staff is currently doing a six-month rotation as Renal Physiotherapist looking after renal patients on the Medical wards.

"Exercise on dialysis will bring clear health benefits"

Sushant intends to introduce exercise into patient treatment regimens and will

be applying to AKPA for funding early this spring. He is confident that introducing exercise on dialysis will bring clear health benefits for patients. And hopes that the outcomes of this research will persuade the Trust of the financial benefits too, as more patients have improved health outcomes and fewer associated complications.

Independently from this, just before Christmas, AKPA was contacted by John Saxton, Professor of Clinical Exercise Physiology at the University of East Anglia, Norwich. A team from Norwich is planning a major piece of research on exercise for dialysis patients called the PRIDE trial. Dr Alex Heaton who is leading on this research used to work at Addenbrooke's. Many older AKPA members will remember Dr Heaton from his days at Douglas House. The Norwich team is through to the final stage of an application for funding from the National Institute of Health Research (NIHR).

Professor Saxton picked up on AKPA's interest through the newspaper articles



on Barrie Mill's John O'Groats to Land's End ride. The Pride Trial is recruiting dialysis centres interested in taking part, and Professor Saxton has visited Addenbrooke's to meet some of the Physiotherapy and Renal Services staff. Dr Pritchard has stated that Addenbrooke's would be keen to take part if the NIHR grant is awarded. Everyone is now eagerly awaiting the end of March to learn if the application has been successful.

These two pieces of research are exciting opportunities to kick-start exercise for dialysis patients with the promise of vital staffing resources needed to get it off the ground!

Alan Craig

"Bionic Super Kidney" Aims for Gold Again



Ottilie Ouince

Ottilie Quince has again been selected to represent Great Britain in cycling at this year's World Transplant Games in Durban, South Africa. Ottilie keeps extremely fit as a Sports Tutor at Barnfield College, Luton and she jokes about "my bionic super kidney's progress on the bike". Ottilie is determined to retain her world champion titles in both the 5km time trial and 20km road race this summer.

The official World Transplant Games website is http://www.wtg2013.com When the Games are on, this website should have links to live streaming so that Ottilie's supporters in the UK can watch the events. Durban is only about two hours ahead of the UK so this should be straightforward. Ottilie's events to watch out for are:

Tuesday 30th July, Cycling – Time Trials AM only

Wednesday 31st July, Cycling – 20km Road Race AM only

There is also a website called Bambuser that filmed all of the events live last time and streamed them on the Internet for people around the World to watch. See http://bambuser.com/

Watch out for more information as the summer approaches.

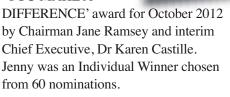
Alan Craig



Addenbrooke's Award for

Jenny

Staff Nurse Jenny Jennings was presented with Addenbrooke's 'YOU MAKE A



Fellow Staff Nurse Silvia Kyon Yon nominated Jenny for the Award, saying, "Jenny is an exceptional role model. She is excellent and never minds staying extra hours to make sure everything goes smoothly."

The patients and everyone at Addenbrooke's Renal Department offer their sincere congratulations to Jenny. She is respected by all those who have had the good fortune to come into contact with her during her many years in the Dialysis Centre.

Renal Patient View: Update



The Renal Patient View (RPV) database at Addenbrooke's is now even closer to launch.

Dr Afzal Chaudhry, Consultant Nephrologist and IT Dr Afzal Chaudhry Lead at Addenbrooke's, reports that it will be

trialled after Easter and hopefully live by June. A small group of patient volunteers will be testing the system, prior to invitations going out to all renal patients.

Two articles related to RPV appeared in the recent winter issue of NKF Kidney Life magazine and may be of interest to

On p20, the Medical Matters section begins with a summary of a recent analysis of Renal Patient View (BMC Medical Informatics and Decision Making 2012;12:87). Two key points are:

"An analysis of Renal Patient View usage concludes that the system is popular, empowering patients and increasing their understanding of their kidney problems and treatment."

"Neither patient nor staff responses indicate the RPV has made patients more anxious or increased workload for renal units beyond the time taken to enrol each patient."

"You can share up to the minute details with other doctors and nurses when the unexpected occurs."

On p16, on the Donal's Question Time page, Dr Donal O'Donoghue concludes his reply to a patient letter with some interesting comments on the value of signing up to RPV: "Every person with advanced kidney disease, on dialysis or with a kidney transplant has the right to see their own record and they can do this today by joining Renal Patient View. You can then share the up to the minute details with other doctors and nurses when the unexpected occurs. If you are not signed up you should be. I know some units are not as good as others are at promoting a patient centred approach and therefore from next April, in England, kidney teams will get a financial incentive to encourage uptake of Renal Patient View, in an effort to improve the situation where coverage is low. I would argue that it is not only your right under the constitution of the NHS, but that it is also your responsibility, not least to your donor and their family, to protect your 'gift of life' by signing up to Renal Patient View."

Alan Craig

Renal Diet Information

If you have any questions regarding your diet please contact the relevant dietician. Here's a who's who of the dieticians in our area:

Addenbrooke's – Cambridge

Elaine Corden – covers CAPD. Clare Parslow – covers ward C5, haemodialysis, Hinchingbrooke dialysis, low clearance clinic. *Alice Lunt* – wards G5/F5, renal transplant, home haemodialysis. We can be contacted on 01223 216655.

• Queen Elizabeth Hospital – **Kings Lynn**

Hannah Gilbert Contact on 01553 613861.

■ West Suffolk Hospital – **Bury St Edmunds**

Sara Ennew Contact on 01284 712920.

Helping Patients Decide

A project to improve patient knowledge about renal replacement therapies was given a boost when Addenbrooke's Low Clearance team recently secured an NHS Kidney Care grant. The project aims to encourage patient use of the newly launched "Established Kidney Failure patient decision aids" (PDA) and we are grateful for their support.

These interactive internet tools enable patients to explore the pros and cons of different treatments (unit and home haemodialysis, different types of peritoneal dialysis and conservative management). Lifestyle preferences can be entered and opinions formed about available options. A summary can then be emailed to the patient, enabling them to discuss options in a more informed way with clinical staff.

As of April 2013 the tools will be available via the NHS Choices website. A paper version is also available, and both versions are being introduced in the Low Clearance and Nephrology clinics. Feedback will be collected, and anyone with an opinion about the tools, or a wish to be involved at a national level with the implementation of shared decision making, please contact me as below.

Those who attend clinic 12 will shortly see a new 'kiosk' in the waiting area. This is for patients to access the PDAs and other sources of information whilst waiting for appointments. Again, there will be the option of emailing yourself information for later reading and discussion with family and friends.

A further PDA for Advanced Kidney Disease, with information about planning for end of life care was developed nationally with Addenbrooke's Renal Unit input. It should join the other PDAs soon but is currently available at:

http://www.nhsdirect.nhs.uk/ decisionaids/PDAs/PDA_Advanced_ Kidney_Disease

Please contact Nicky should you want paper copies, help accessing the PDAs or with any queries.

Nicky Moncrieff, Renal Nurse Specialist. Tel 01223 217827

Dr Nick Pritchard, Consultant Nephrologist

Jonathan Allen

Shortly after Christmas we received the sad news that Jonathan Allen, a long time supporter of AKPA had sadly died.

Jon was an early kidney and pancreas transplant recipient: he also lost his eyesight and suffered a leg amputation, but if you met Jon you would probably be unaware of any of that. Jon just got on with life. Often achieving things people without his disabilities would think twice about tackling.

I first met Jon in 1998, shortly after I became *Newsflash* editor. Sister Heather Cook suggested we attended an "AKPA Benefit Gig" organised by Jon in his home village of Great Bardfield. The event featured The Honeycombs, a sixties hit making pop group who Jon had persuaded to come out of retirement, with all proceeds going to AKPA.

Jon and his wife Angela organised all the evening's entertainment, the bar, raffle and supporting groups. And they went on to organise more "Bardfield Gigs". Jon set his own "fundraising targets" and with meticulous planning, and gentle persuasion of his wide circle of friends, raised considerable amounts of money for AKPA.

Jon's other fundraising activities for AKPA included selling large amounts of raffle tickets. Reliably, year after year, Jon sold more raffle tickets than anyone else. He once told me how he and Angela became friendly with their fellow bus passengers on shopping trips and how, near to Christmas, they managed to sell AKPA raffle tickets to most people on the bus. Jon's raffle ticket sales also included a large network of "friends and family" across the

country who regularly bought tickets from him.

Jon and Angela met when Jon was having his transplant in Addenbrooke's. They married shortly after at Gretna Green and were always very close in all they did.

Jon's interests included involvement with his local community, his vegetable garden, – beautifully straight rows with not a weed in sight. And home improvements – the last time I met him he was building a new garage.

I sometimes felt that Jon, although sightless, had a clearer vision of life than many sighted people. He will be sadly missed.

Our deepest condolences to Angela and all Jon's family.

Ed.

AKPA 200 Club – Monthly Draw – Winners

OCTOBER 2012

First prize £47 • No 10, Margaret & John Thompson Second prize £23 • No 43, Carol Slattery Third prize £14 • No 160, Richard & Josey Fossey

NOVEMBER 2012

First prize £47° No 111, Mrs Rosemary Johnson Second prize £24 ° No 339, Mr & Mrs Wilson Third prize £14 ° No 99, Marion and Ed Ribnell

DECEMBER 2012

First prize £47 • No 169, Gillian Grist

Second prize £24 • No 171, Karen Andrews

Third prize £14 • No 181, Vito Walker

Grand prize £99 • No 251, Mr John Dilley

JANUARY 2013

First prize £41 • No 155, Mrs M Hawkes Second prize £20 • No 33, Stacey Pratt Third prize £12 • No 97, Martin Davies

FEBRUARY 2012

First prize £41 • No 105, Jane Colebrook Second prize £20 • No 78, Martin Davies Third prize £12 • No 166, Sue & Byron Harvey

New Members welcome contact David and Jayne Wyatt Tel: 01842 815941

Help for Kidney Patients and Carers

The National Kidney Federation (NKF) Helpline provides assistance to patients, carers, family, friends and medical professionals. Seek advice, obtain literature, get help, all from the one Helpline number (details below). It is open for calls from 9am to 5pm, Monday to Friday.

To obtain NKF Information Leaflets go to www.kidney.org.uk

Tel: (0845) 601 02 09 (charged at *Local Call Rate*, UK only)

E-mail: helpline@kidney.org.uk Address: Helpline National Kidney Federation The Point, Coach Road, Shireoaks Worksop, Notts S81 8BW

The Helpline also provides access to the NKF Advocacy Service.



AKPA XMAS RAFFLE 2012

1.00 pm – 13th December 2012 in the Dialysis Centre

List of Prize Winners

- 1. £300 J. Flude, Ely
- 2. £150 Ms F. Kingsley, Market Rasen
- 3. £100 Tracey Ward, Roydon
- 4. £75 Mrs S. Tigue, Kings Lynn
- 5. Hamper Marie Sanders, Royston
- 6. Outdoor Coat John Cann, Cambridge
- 7. Double Bed Quilt Mr D. Daw, Kings Lynn
- 8. Patchwork Blanket Mr T. A. Griffin, Newmarket
- 9. £30 Ridgeons Voucher Adrian Williams, Fordham
- 10. £15 Voucher Mrs Rose Buckle, Gt Dunmow
- 11. Bottle Brandy Paul Mythen, Arlesey
- 12. Parker Pencil L. Cole, Bedford
- 13. Leather Wallet Marnie, Sudlow
- 14. Bottle Whiskey B. Street, Gt Dunmow
- 15. £20 Tesco Voucher Mrs B. Hughes, Horringer
- 16. £20 BHS Voucher Ron Cundall, Newport
- 18. Bottle Wine H. Hussey, Bury St Edmunds
- 19. Bottle Wine Joyce Wilson
- 20. £10 Tesco Voucher Dr N. Taneja, Welwyn
- 21. £10 Tesco Voucher S. Mitchell, Braintree
- 22. £10 Tesco Voucher Mr & Mrs White, Comberton
- 23. £10 Tesco Voucher Mrs Heavinghan, Santon Downham
- 24. £10 Marlow Voucher C. Harragan, Colchester
- 25. £10 Scotsdales Voucher Ralph & Carol Slattery, Cambridge
- 26. Spaghetti Jar Mr G. Stephens, Ridley
- 27. Jamie Oliver Book L. Hilton, Bedford
- 28. Breakfast Set Miss D. Graves, Saffron Walden
- 29. Bottle Rosé Wine Jean Gray, Hinchingbrook
- 30. Three Pack Baileys Maddy, Dialysis
- 31. Toiletries Maricel, Dialysis
- 32. £10 Tesco Voucher Richard Kellan, Thorpe St Andrew
- 33. Hand Cream Mrs C. A. Tye, March
- 34. Greetings Cards Val Hill, Sawbridgeworth
- 35. Shortbread Tony Brookes, Dialysis
- 36. Bath Bombs Chloe Tilbrook, Dunmow
- 37. Hand and Nail Creams J. A. Day, Sandy
- 38. After Eights Annie Johnson, Newmarket
- 39. Candy Cane Mug Nicki Sly, Stukely
- 40. Wine Tony Newman, Hinchingbrook
- 41. Tray Angi, Dialysis
- 42. Hand Kit M. Wilson, Ely
- 43. Wine & Biscuits J. Fossey, Bedford

The raffle, which was organised by Sarah Rook was a great success and raised £2,215 for AKPA. Thanks are due to Sarah for all her hard work.

Our thanks to everyone who generously donated prizes and to all those who bought and sold tickets.

Are You a Member or Friend of AKPA?

To join or receive more information about AKPA please complete the form below and return to

AKPA, PO Box 608, Freepost RRKT-RBGX-AETR, Cambridge CB1 0GJ.

I Name
Address
Telephone

Join AKPA

Subscriptions are **optional**, the suggested amounts are £2 single or £3 family. They are used to pay for NKF membership, and printing *Newsflash*. We are very grateful if you can help us to cover these costs.

Please send information

Benefits of membership are:

- NKF membership, which includes:
 - Kidney Life Magazine
 - Access to NKF helpline
 - NKF Conference

Plus eligibility for:

- AKPA holiday and welfare assistance
- Sponsorship for Transplant Games
- Sponsorship for NKF Conference
- Newsflash

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

It contains a large amount of information about AKPA and many other topics of importance to renal patients.

You can e-mail us at: info@akpa.org.uk

For general enquiries to the AKPA.

fundraising@akpa.org.uk

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

questions@akpa.org.uk

For questions relating to kidney disease – we will try to forward these to somebody who can help you.

webmaster@akpa.org.uk

For suggestions, comments or requests for the website. Remember we are happy to advertise your fundraising event if you can supply us with a photo.

Postal Address:

PO box 608 Freepost RRKT-RBGX-AETR Cambridge CB1 0GJ

Newsflash **Contributions**

We would love to hear from you, letters and articles for publication in Newsflash are always welcome. Send them to the editor: Brian Wood, address, phone and e-mail see Committee Members list.

Help Us Raise More - Fundraise on JustGiving

AKPA has joined JustGiving, the online fundraising and sponsorship website, to make raising money quicker, easier and more effective.

You can set up your own personalised JustGiving fundraising page to tell everyone what you are doing and why you are raising money for AKPA. The JustGiving team then gives you everything you need to reach more sponsors faster.

You can also make a one-off or regular donation to AKPA via JustGiving.

Also, JustGiving will collect Gift Aid from any eligible donors, enhancing any gift by up to 28%. The donation is a 100% secure, spam-free experience. They will never sell or share your personal details and won't try to sell you anything.

To start raising money for us on JustGiving, please visit www.justgiving.com/akpa

JustGiving^{*}

AKPA Patient Representatives

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

Addenbrooke's Dialysis Centre - Richard Fossey E-mail: rd.fossey@ntlworld.com Telephone: 01234 213546

Kings Lynn - Colin Gant

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

Hinchingbrooke - Geoff and Cilla Gidley E-mail: geoff@geoffgidley.co.uk

AKPA Committee Members 2012

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Renal Welfare Adviser Social Services Dept

Tel: 01223 714408

Richard Jarvis

Website

Tel: 01353 675066

Julia McCarthy

West Suffolk Hospital

Hardwick Lane

Bury St Edmunds

Suffolk IP33 2QZ

Tel: 01284 712920

Nicky Moncrieff

Staff Representative Dialysis Centre

Box 118

Addenbrooke's

Hospital

Hills Road

Cambridge CB2 0QQ

Tel: 01223 217827

Jenny Ridgeon

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