



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

A MEMBER OF THE NATIONAL KIDNEY FEDERATION

Joshua's Half Marathon

Joshua Williams-Welch recently did a sponsored half marathon for AKPA and raised over £900. A pretty good achievement for anyone, but Joshua is only eight years old!

His mother, Jacqueline, said, "This was such a big decision for a small child. He wanted to raise money for AKPA because a family friend needed a transplant. He ran distances of one to two miles over an eight week period, and although he didn't find it an easy task, he completed it."

Joshua asked for sponsorship from friends and family, and was also sponsored by his father's work place. His Beaver Scout section also decided to help him by holding a sponsored walk. Jacqueline said she felt extremely humble to have such great support from the local community.

This was indeed an amazing achievement. Our most grateful thanks to Joshua, and to his family and friends for all their support.



Top photo Joshua, and below his mother Jacqueline

www.akpa.org.uk

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AKPA to Fund Fistula Therapy

Also, support for SONAR Trial

Healthy arteriovenous fistulas are a vital lifeline for Haemodialysis patients

Over the past three years infrared therapy has been successfully used to promote fistula healing in Addenbrooke's dialysis units. At present only one borrowed machine is available for use in the four units. AKPA has agreed to fund four infrared machines at a total cost of £15,200. The machines will be available for use in Cambridge Dialysis Centre and the three satellite units.

See page 6 – SONAR Trial – Fistula research at Addenbrooke's

More about the importance of fistulas in Andrew Norton's article on page 3.

Dates for 2019

Sun. July 21st
Great Graham Event
Graham Water Visitor Centre

July 25th–28th
British Transplant Games,
Newport, South Wales

Mon. 2nd September – 6.00pm
AKPA AGM
Cambridge Dialysis Centre

Sat. December 14th – 3.00pm
AKPA Carol Service
Great St Marys, Cambridge

AKPA Carol Service – Great St Mary's, Cambridge



Dr Rowan Williams with Sally Tabor

For many patients, staff and their families, the AKPA Carol Service on December 22nd heralded the start of Christmas celebrations. The bells of the old University Church pealed out across the Market Square, as the church rapidly filled to capacity.

Nicky Moncrieff (AKPA vice chair) 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 kindly agreed to officiate.

We were also pleased to again have the St Augustine's Singers directed by Philip Mead, leading the carols and performing solo pieces. Their musical virtuosity amply displayed in solo pieces – *O Magnum Mysterium* and *In Dulci Jubilo*. We were also very fortunate to have Organist David Poulter, who had recently moved to Cambridge from Liverpool Cathedral. He is not only a brilliant accompanist but also treated us to some fine solo pieces.

The traditional bible readings were given by the Mayor of Cambridge, Councillor Nigel Gawthorpe; Renal Transplant Nurse, Gill Matthews; AKPA Committee Member, Andrew Norton; Renal Counsellor, Gill Chumbley and Retired AKPA Chairman, Peter Constable. The readings were interspersed with seasonal carols sung by choir and congregation.

“Dr Williams praised the dedication of NHS staff and linked medical advances and organ donation to a heathy society.”

Dr Williams, who is always an outstanding speaker, delivered a thought provoking address. He praised the dedication of NHS staff and the brilliance of recent medical advances. Saying that, the altruism of live organ donation is a sign of a healthy society, contrasting it with the promotion of greed and selfishness much in evidence these days. The service continued with the Lighting of Candles ceremony which was touching as always.

The joyous final carol, *O come all ye Faithful* was followed by the blessing from Dr Williams, and the service ended with Philip Mead's beautiful *Christmas Bells* performed by the St Augustine's Singers and David Poulter.

Wine and seasonal nibbles were served at the back of the church and as the congregation moved slowly towards the



Monica Taylor and Nicky Moncrieff serving seasonal cheer

exit many paused for a drink and chat with friends old and new.

The AKPA Carol services seem to become more popular every year, and our thanks to all the all who contributed and made this event so successful. To Dr Rowan Williams, Philip Mead and the St Augustine's Singers and organist David Poulter who all gave their services freely: to all the readers and those who worked hard to serve the food and wine.

But very special thanks must go to Mike Ruggieri and Sarah Oughton for their months of hard work organising and arranging all the many elements that enabled this service to run so smoothly and successfully. (Mike and Sarah have already started planning this year's service for Dec.14th! Details on front page.)

A sad note: we heard shortly after Christmas that the Mayor of Cambridge, Councillor Nigel Gawthorpe sadly died in a swimming accident while on holiday.

Where the Money Goes

AKPA are constantly looking for projects to fund that will improve medical treatment and the quality of life of Kidney patients treated at Addenbrooke's Hospital.

During the last year we have funded:

- Four Infrared fistula treatment lamps for the Dialysis Centre and Satellite Units at a cost of £15,200.
- A research post to develop a handheld potassium measuring kit for patients on home dialysis at a cost of £13,395.
- Welfare and holiday support for sick and needy patients and their families totalling £3,534.
- Therapeutic massage for patients in the Transplant Ward. £1,741.
- Support for Addenbrooke's team to take part in the Transplant Games £1,362.
- Patient comforts for Hinchingsbrooke Satellite Unit including: Jigsaw table, furniture and games at a total cost of £250.
- A drug handbook for Cambridge Dialysis Centre at a cost of £198.

Full details of projects funded by AKPA will be available at our AGM.



Choosing to Donate Blood May Have Saved Andrew Norton's Life

The conversation went something like this:

Nurse: "We can't take your blood, you're anaemic."

Andrew: "No I'm not!"

Nurse: "We're still not going to take your blood and you'd better see your GP."

A visit to Andrew's doctor confirmed the anaemia: and further tests led to an eventual diagnosis of Chronic Kidney Disease (CKD).

"You are going to need dialysis..."

Those words are guaranteed to send the majority of CKD patients into a state of horror and anticipation of their lives being a continuous trail of needles, wasted time and discomfort at the very least.

I know – that was my reaction in summer 2016. I speak now from 30 months down the road and life has gone on surprisingly OK. So don't panic – read my experience of that period.

I had been diagnosed with C3 glomerulopathy in about late 2013, my kidney function was then about 40 %. I was being careful with diet, attending the clinics and feeling fine: it all seemed pretty manageable and I felt I could cope indefinitely.

By summer of 2016 I was attending the 'Low Clearance' clinic where monitoring of my condition showed it was now Stage 4 CKD and heading for stage 5. In July the nephrologist at the clinic said those words at the top of the article and I was very upset.

I went home and Googled all about dialysis and living with end-stage failure. None of it looked good.

At the following clinic they said you will need to have an arteriovenous fistula created in your arm so that when (if?) you need to dialyse you will be prepared in time, as the fistula takes about 6–8 weeks to mature enough for dialysis.

I was adamant I could survive ages yet. Reluctantly the doctors said "OK" as I was about to go on a foreign holiday. "When you return we need to do this for your sake" they said, as the alternative is an emergency line in the chest which is not as reliable and you would not like it!

So reluctantly, I was duly at the operating theatre the following month. The operation was not as bad as it sounded, I was awake and even plucked up courage to look at what was going on. All sorted out, I went off to recovery on my trolley...but a large lump like half a tennis ball had appeared! I said to my nurse "It should not look like that should it?" Correct, so the trolley was turned round back to theatre where they opened it up and sorted out bleeds. All stitched up again, I was fine and discharged.

"The impact on partners and loved ones is something we don't often consider but dialysis impacts everyone in the immediate family."

Plenty of bruising ensued but it settled down and all was well. I now had a big vessel showing on the venous side of the fistula and to my delight it buzzed like an electric shock. This is called the 'thrill'. All the friends and family were treated to a surprise of course. Its still a good party trick!

This odd feeling is your sign that the fistula is doing its job and hopefully continues a very long time. I had to get used to wearing my watch on the right hand and also to having a little band on the fistula wrist telling anyone not to take blood samples or blood pressure from that arm.

Hopefully you will get to this stage and still be okay but dreading the moment it comes to the first time on the machine. I was really dubious and asked if I could visit someone who was similar in age and able to carry on regardless after the dialysis was needed. This was most reassuring as I think he was carefully chosen and I left more comfortable.

I had blood tests as usual about two weeks after the fistula was created and on the Saturday of that week my wife and I were catering for a big party for which I was the transport when my phone rang – "You have to start dialysing now! Come in as soon as possible and a machine is waiting for you." My creatinine level was 1000 or so and potassium was 7 – this was it – no more hiding!

"Guess what? You are going to start feeling well again!"

Now I saw the wisdom of making the fistula earlier – mine was less than three weeks old and the vein was pretty tender and small. A special lamp was brought out to shine on it which helps develop it and the nurse carefully needled me. It was still a shock. This would now be my life three days a week for ever or until a transplant might appear.

Now the dialysis has become the routine – three days a week. At first I was on a 'twilight' session for three hours. I got used to the schedule but found it messed up my life at home.

The impact on partners and loved ones is something we don't often consider but dialysis impacts everyone in the immediate family. Nice thing is you can visit with your partner or relative: watch TV, or take a tablet, laptop smartphone or whatever and make some use of that 'downtime'.

Guess what? You are going to start feeling well again! You will probably eventually go to 4 hours like many people do but you will absorb the time and you may, like me, come to regard it as your 'part-time job' to keep well. I changed to the morning shift when a chair became available and it does just feel like a job for 15 hours a week and home for lunch. You can start to think about getting back on a holiday again. It takes work to organise but anything is possible. *Its not the end of the world after all, just a new world.*

**Andrew Norton
March 2019**

Winter Fair Fundraising



Raj Garhu and his family

Raj Garhu and his family sold their delicious homemade Indian snacks in aid of AKPA at the Mill Road Winter Fair and raised an amazing £1,180.

Over the years the Fair has grown to be a major event and every year they have

had a food stall in front of their shop raising money for AKPA.

Our thanks to Raj and his family for all their hard work and for the stream of very well filled collecting tins they regularly send to AKPA.

Moira's Riverside Fundraising



Moira Boughtwood

Moira Boughtwood recently raised a total of £116 for AKPA from collecting boxes at her Chandlery in Westview Marina on the River Ouse.

The chandlery is in an old steel wide-beam boat where she sells all manner of things a boat might need, plus drinks and ice creams. There is an area in the shop for donated books and DVDs, sold at 50p for AKPA. Moira said, "Many folk come in on their way up to Bedford or down to Ely and Cambridge, get a few books to read, then donate them again on their way back."

Moira's husband is a transplant patient and they regularly support AKPA. She said, "I tell everyone about the excellent work AKPA does by supporting Kidney patients".

Our thanks to Moira for all her fundraising and continuing support.

Haig Court Bring and Buy

Residents at Haig Court Chesterton once again supported AKPA with their annual Bring and Buy sale. The sale raised a magnificent £118 for AKPA. Our thanks to the residents for their generosity and to House Manager Adrian Livermore for organising the sale and again supporting AKPA.

Volunteers Needed for Garden Centre Collection

At Scotsdales Garden Centre in Great Shelford on Saturday July 27th.

Please contact Janet Man

Tel: 01223 660312,

email: fundraising@akpa.org.uk

Waitrose in Ely have included us in their Green Token scheme. If you shop there please look out for the AKPA box.

AKPA Christmas Cards

Sales of AKPA Christmas cards were again very successful, with the new designs for this year selling well and raising a total of £3,320. Our thanks to Carol Slattery for all her hard work in selecting, organising and distributing the cards. AKPA cards sold well in Clinic 12, the Dialysis Centre and satellite units. Our thanks to all who bought our cards.

Pearce's Farm Shop in Buntingford sell a huge amount of our cards every year. This year they sold a record amount, raising a total of £1,345. Our thanks to all at Pearce's Farm shop for another brilliant contribution.

Cambridge Cards for Good Causes shop also sells our cards and this year raised £423. Our thanks to Janet Man for her work as AKPA volunteer in their Cambridge Card shop.

Internet Fundraisers

Thanks to all the people who have raised money through the **JustGiving**, **easyfundraising** 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 Addenbrooke's Kidney Patients when you shop on-line.
Visit: www.akpa.org.uk/easyfundraising for more information.

Souled Out Summer in Newport

A charity music festival held in Newport raised £1,500 for AKPA in June last year. The event was organised by Paul and Natalie Emuss, and Steve and Sasha Bellamy to support AKPA and Addenbrooke's Breast Cancer Appeal.

The audience enjoyed live music from the Adaptones, The Mod Cons, Zoot Money and his Band, plus DJ sets from some of East Anglia's top DJs. The event was sponsored by local businesses, with Tescos supporting the BBQ and Susie Diggins, their Community officer cooking for the whole event. Kelly Thurston volunteered and provided Glitter tattoos for the guests.

Natalie Emuss said, "The Souled Out Summer team spent six months planning this event and we are so pleased with the result." She went on to thank their host, Jon at the Coach and Horses in Newport and sponsors Tescos, Ambassador Marquees and Mullucks.



Our very grateful thanks to Paul, Natalie, Steve and Sasha, and all the Souled Out Summer team and supporters.

Bric-a-Brac Stalls

In December Sue Oates and Monica Taylor held a bric-a-brac stall in the Outpatient's Hall and raised £198. Over the last year the bric a brac stalls have raised a total of £838 for AKPA. Our thanks to Sue and Monica and all who donated items.

We have been unable to arrange stalls in the coming months due to refurbishment in the Outpatients Hall but are hoping to find alternative venues in the near future.

Our thanks to Sue and Monica and all who donated items for the stalls.

Collecting Tins

AKPA has collecting tins in several shops, the Dialysis Centre and Hospital clinics. They are a very useful source of fundraising for AKPA. Committee member Mike Ruggieri is collecting tin co-ordinator and if you know of a shop, pub or any other venue to place an AKPA collecting tin, please contact Mike.

The Lyke Wake Walk –

AKPA/NKF/MNDA joint fundraising event – 6th July 2019

This will follow the traditional **Lyke Wake Walk** route, a 40-mile (64km) walk with about 4000ft of ascent across the highest and widest part of the North York Moors National Park. It will be well organised and supported with six support points. Completing this event will be a serious personal challenge as it is 40 miles of mixed walking, as far from civilisation as it gets in most parts of England.

For more details contact:
Andrew Norton, email:
andrew.j.norton@pdmassociates.co.uk

Great Grafham Event Joint AKPA/MNDA Fundraising Event – 2019

Sunday 21st July.

Location: Grafham Water Visitor Centre, Marlow Car Park, Grafham, Huntingdon PE28 0BH.

Last year's event was a great success and we are hoping for even more support this year. Again there will be two events.

The Dam Stroll – a two mile level walk/cycle on hard surfaces across the dam, start: 10.30 am.

The Full Circle – a nine mile walk/cycle around the reservoir on hard tracks, start 10.00 am.

Entry fee: £5 each, children under 12 free. Further information and sponsorship forms from andrew.j.norton@pdmassociates.co.uk:
A J Norton, 13 Dunstal Field, Cottenham, Cambridge CB24 8UH:
Tel: 01954 251353

**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



Fistula Research at Addenbrooke'

A multi-centre medical trial to evaluate the role of ultrasound in creating healthy fistulas was described by Mr Hossain Mohammad, (Speciality Registrar) and Regin Lagaac, (Clinical Nurse Specialist, Vascular Access) at our AGM last year.

Known as, **SONAR** (Surveillance Of arteriovenous fistulae using ultrasound) it will provide information to help surgeons and medical staff create healthy fistulas, and treatment to stop them failing.

The trial began at the end of last year and AKPA committee member Andrew Norton joined the steering committee at the invitation of transplant surgeon and Chief Investigator Gavin Pettigrew.

Andrew, who is himself a Haemodialysis patient, said: "Healthy arteriovenous fistulas (AVF) provide a vital lifeline for Haemodialysis patients. The SONAR trial is using non-invasive ultrasound to monitor the growth of fistulae in new patients. As mine was created two years ago, I can't join the trial but in my role on the steering committee I'm very keen to promote the research to other patients. I was lucky in that my fistula didn't fail even though it was only two weeks old when I had to start dialysis! Up to half of all AVF fail within the first year and researchers want to know why this happens and if it can be prevented."

AKPA to Fund Trial Patient's Travel Costs

In his role on the steering committee Andrew Norton supported AKPA's offer to fund travel costs for SONAR participants.

Taking part in the SONAR trial means an extra four hospital visits for patients in the first 10 weeks – and the extra expense could put some patients off, even if they wanted to take part. The AKPA funding will hopefully encourage more patients who are about to have fistulae created to join the trial.

Andrew explained: "My fistula has literally been my lifeline and any research that can make its benefits even better for more patients has to be worthwhile."

- SONAR is sponsored by Cambridge University Hospitals NHS Foundation Trust and the University of Cambridge. It is managed by the Clinical Trials Unit at NHS Blood and Transplant.
- To find out more about SONAR visit their website: www.sonartrial.org.uk
- SONAR is also on Twitter: [@SONAR_TRIAL](https://twitter.com/SONAR_TRIAL)
- The SONAR trial is funded by a £1.8m grant from the National Institute for Health Research (NIHR) Health Technology Assessment programme. Funding from the Addenbrooke's Kidney Patients Association (AKPA) will help fund patients' travel expenses.

Claire Leaves CDC

We are sorry to hear that Social Care Practitioner Claire Joyce is leaving Cambridge Dialysis Centre. Claire has been at CDC for almost five years. She took over and expanded the post of Welfare Officer, which was originally supported by AKPA before NHS funding was available.

In that time she has created a vital service for patients and their families; giving advice on benefits, debts, housing, grants and psychological support, as well as acting as an advocate for patients and their families. We have been very grateful for Claire's advice when patients in urgent need of support have applied to AKPA for welfare grants.

Claire is moving away to live in the village of Netley Abbey near Southampton in Hampshire. All the AKPA committee send best wishes and thanks for the work she has done for patients and their families.



NKF Helpline

Please note: new number is FREEPHONE

Tel. 0800 169 09 36

E-mail: helpline@kidney.org.uk

Website: www.kidney.org.uk

NKF Debates "Deemed Consent"

Ralph Slattery, Chair of AKPA attended the recent NKF (National Kidney Federation) AGM in Warwick, along with delegates from many other KPAs.

Ralph reports that a key topic of the meeting was "Deemed Consent", which will come into force in spring 2020. This is also known as "donation opt-out", or "Max and Keira's law".

After that date, if someone has not registered to opt-out they will be deemed to have consented to be a donor, although the wishes of the family will continue to be respected. A public awareness campaign will be starting in May this year. A similar scheme pioneered in Wales has seen organ transplants increase by 20%.

Volunteers Needed for the Cambridge Dialysis Centre

To help serve refreshments to patients receiving haemodialysis, spend time listening, chatting or reading to patients, escort visitors to appropriate areas, keep magazines etc. tidy and well stocked and engage in activities within the Centre, for example, art project and jigsaws.

We are looking for sensitive people who can offer three to four hours during the day or in the evening.

To find out more please contact: Gerrie Millar, Renal Counsellor, Telephone: 01223 400186 or Email: gerrie.millar@addenbrookes.nhs.uk

Transplant Games 2019

Addenbrooke's will again be sending a team to compete in the **British Transplant Games**, July 25th–28th in Newport, South Wales.

Sporting venues being used will include the Celtic Manor Hotel and Golf Resort where the 38th Ryder Cup was held in 2010, and the Geraint Thomas National Velodrome.

There will be numerous sporting events suitable for all ages and abilities ranging from racket events to lawn bowls. For more information please visit www.britishtransplantsport.org.uk/ or email Addenbrooke's Transplant Games Team addenbrookesgamesteam@yahoo.com

To compete please register before May 3rd 2019.

Our selected athletes are also gearing up for the **World Transplant Games**, August 17th–24th to be held in Newcastle and Gateshead. Venues are to include Gateshead International Stadium and Newcastle United FC, as well as Sunderland Aquatics Centre. For further information please visit www.worldtransplantgames.org

Val Cooper

More Handmade Quilts

The Barton Mills Quilting Group recently donated more of their beautifully handmade quilts; this time for patients dialysing in satellite units.

The group also make quilts for the neonatal unit but after hearing that patients sometimes had difficulty keeping warm when dialysing the group started producing slightly bigger quilts for patients in the Dialysis Centre.

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

AKPA XMAS RAFFLE 2018

Drawn at 2pm on Wednesday 19th December
at Cambridge Dialysis Centre

List of Prize Winners

- 1 £300 cheque 04145 Colbrook, Gamlingay
- 2 £150 cheque 09725 Streater, Wisbech
- 3 £100 cheque 00021 Hughes, Chatteris
- 4 £10 John Lewis voucher 06242 Griffin, Newmarket
- 5 £10 John Lewis voucher 03575 Booker, Royston
- 6 £10 John Lewis voucher 09645 Tibbutt, Cambridge
- 7 £10 John Lewis voucher 08787 Williams, Cambridge
- 8 £10 John Lewis voucher 16930 Coxall, Hardwick
- 9 £10 John Lewis voucher 09548 Dellow, Great Dunmow
- 10 £10 John Lewis voucher 08992 Man, Cambridge
- 11 £10 John Lewis voucher 07183 Wenn, Sedgeford
- 12 £10 John Lewis voucher 02740 Heffer, Lakenheath
- 13 £10 John Lewis voucher 08158 Wilson, Ely
- 14 Bath Set 07950 Tibbutt, Ryde

Our thanks to Carol and Ralph Slattery for organising another very successful raffle that raised £1,271 for AKPA. Thanks also to all who generously donated prizes and to all those who bought and sold tickets.

200 Club – Winners

SEPTEMBER 2018

First prize £102 • Mrs Josie Fossey
Second prize £62 • Mrs Jane Giddings
Third prize £41 • Mrs Celia Bruce

NOVEMBER 2018

First prize £102 • Mrs B. Goldstone
Second prize £62 • A & R Johnson
Third prize £41 • Mrs L. Watkins

JANUARY 2019

First prize £102 • Mr & Mrs P. Owen
Second prize £62 • Miss Bridget Brady
Third prize £41 • P. & M. Tattershall

MARCH 2019

First prize £102 • Mrs Celia Bruce
Second prize £62 • Mr John Dilley
Third prize £41 • Mr Simon Pitts

*The new year for 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 contact Janet Man:
Tel: 01223 660312 • Email: fundraising@akpa.org.uk



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

Would You Like to Support AKPA?

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.

If you would like to receive regular copies by post or email please email: info@akpa.org.uk.

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 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.

Mary Dullea – 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

Kings Lynn – Colin Gant

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

West Suffolk Hospital, Bury St Edmunds – John Smitherman

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

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April 2019