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Welcome to the Autumn newsletter.

I hope that many of you have enjoyed the summer weather this year and managed to find ways to keep cool on those days where temperatures have climbed. Hopefully the sun and warm temperatures will remain with us for a while longer as we head into Autumn.

As always there is lots of information in this newsletter. For those of you not yet booked for conference, there is still time to book for the day and rooms may still be possible but can't be guaranteed, so check with the office first before making payment.

We have a new member to the WS Support team and you can find out more about her in the News and Updates section.

Remember, if you have anything that you would like to see included in future newsletters, then please send it to the office, details at the bottom of this newsletter. Likewise, if you have any questions or concerns you can contact [Tracy](#), [Phillippa](#), [Georgina](#) or [Olivia](#) about these.

Take care

Tracy



Wolfram Syndrome UK values your involvement with the newsletters, so please remember to share anything that you would like to see included in future newsletters as well as telling us what you have been doing. These can be sent to us at admin@wolframsyndrome.co.uk.

An audio version of this newsletter is posted onto our website and Social Media pages or if you would prefer the audio version or a large print printed version mailed to you, then please let us know.

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News and Updates

WS Conference



If you haven't yet booked your place for this year's conference on 21st September there is still time, up until 11th September. This is mainly for day places. If you wish to book a room to stay then please contact the office first so that room availability can be checked on.

Reminder, for those of you staying on the Friday night. Phillippa, our Adult Support Co-ordinator, will be hosting a social event which will include Bingo and a Quiz. More details can be found on the website [here](#)

Second Family Support Co-ordinator joins WSUK

We're really pleased to let you all know that Olivia Edwards joined WSUK as the second Family Support Co-ordinator on Tuesday 27th August.

Olivia will be working 22.5 h per week across 4 days, typically Monday – Thursday, and will work alongside Georgina to help support young people and their families both during and outside of the WS MDT clinics at BCH.

Olivia previously spent 10 years working as a primary school teacher and more recently in a pre-school nursery, so has lots of experience in working with children with a range of special educational needs.

Olivia will be joining the October clinic at BCH, when attending families will be able to meet her in person. Unfortunately, Olivia isn't available for this year's WS Conference on Saturday 21st Sept.



From 1st Oct, Georgina will be reducing her hours to 18.75 h per week, across 4 days, to better fit her work-life balance.

Wolfram Syndrome Global Awareness Day

1st October 2024 is our WS Global Awareness Day. We are currently working on a Top 10 WS 'Myths' that we would like everyone to share on their social media pages along with the WSGAD logo starting on 22nd September with number 10 and finishing with number 1 on 1st October. We would then ideally like you to post the full list of 10 as well.

At the time of writing this newsletter 4 'myths' have been sent to the WSUK office. An email has been sent out to all patient organisations to share and to personal emails. The request has also been shared on the Global Facebook page.

If you have a WS 'myth' you would like to share then please send it to admin@wolframsyndrome.co.uk by 10th September so that we have time to put them in order as well as posting out to everyone ready to share.

If you would like to do something to get involved, WSUK has a small selection of t-shirts and other items you can purchase with the WSGAD logo on with a percentage of the item cost coming to WSUK. The company delivers worldwide. Please have a look at the

[website](#).

One of the Spanish Patient Organisations are having a stall in their town and have the council illuminating public buildings with lilac coloured lights. Is this something you could ask your council to do next year? Could you do something to raise awareness about Wolfram Syndrome on this date this year or next? If you do something, please let us know so that we can share it in a newsletter.



Wolfram Syndrome International Researcher's Symposium

22nd-24th October will see a number of doctors and researchers from around the world come together to share research being carried out for Wolfram Syndrome and to discuss an update around clinical guidelines which will be used globally once completed.

As with last year, we will share a brief synopsis of the research work that was shared so that everyone can be kept up-to-date. This will

be shared on the WSUK website as well as with other Patient Support groups to share with their communities.



UK Clinical Trial Updates



Dear friends and colleagues,

I hope everyone is keeping OK and managed to enjoy at least some good weather this Summer.

We are getting to the end of the TREATWOLFRAM trial, and the last participants will be having their last visits this October. We then hope to collect all outstanding data from study sites by the end of the year. The Clinical Trials Unit will then 'lock' the database so that our statistician can do the analysis. We expect to be told whether the treatment is effective or not, by the end of March or April 2025. As soon as I am told the results, I will write a report to our funder, the UK Medical Research Council; and I will of course share results

through Wolfram Syndrome UK. Our trials unit team, Amy.....Read in full [here](#)...

USA Trials and Research Updates

Dear Friends,

I hope you had a wonderful summer. As the number of patients referred to us continues to grow, our team feels an even greater urgency to develop safe and effective treatments for Wolfram syndrome. I'm pleased to share the latest updates with you:

Ongoing Clinical Trial of AMX0035 in patients with Wolfram Syndrome

<https://clinicaltrials.gov/study/NCT05676034>

We have been collaborating with Amylyx Pharmaceuticals to advance the development of AMX0035, a novel oral medication with the potential to halt or delay the progression of Wolfram syndrome, based on its mechanisms of action and pre-clinical studies. The trial began in April 2023, and the interim results were announced in April 2024. According to Amylyx, the interim analysis of the ongoing Phase 2 clinical trial of AMX0035 for Wolfram syndrome, which involved eight participants assessed at Week 24,..... Read in full [here](#)



WSUK Research Funding

A funding call has been sent out to international researchers for a small WS research grant. Details and the application form can be found on our website [homepage](#) as well as the [WSRA website](#).

If any researchers would like a copy of the grant details and the application form please contact the WSUK office [here](#). The closing date for applications is 8th November 2024.

WSUK Funded Research Projects

Wolfram Syndrome UK research grant funding of £15,000 has been awarded to Dr Sovan Sarkar at the University of Birmingham in UK. The project is related to the development of autophagy and NAD enhancers for the treatment of Wolfram syndrome (WS).

Brain diseases include common disorders such as dementia, and rare childhood-onset disorders like WS. In neurological disorders, a

biological process that is commonly affected is called autophagy, which acts like a housekeeping process of a cell by removing undesirable cellular components such as protein aggregates and damaged organelles. When this process malfunctions, unwanted cell components build up and the cell can eventually die. Brain cells called neurons are particularly affected due to defective autophagy, leading to neuronal cell death by a process called neurodegeneration. On studying further as to why this happens, we found that autophagy promotes cell survival by maintaining the cellular level of a metabolite called nicotinamide adenine dinucleotide (NAD), whereas absence of autophagy causes brain cell death by NAD depletion. Read the full report [here](#).



Orion Project - UK

The Orion Project study, mentioned in the June newsletter, which is being carried out at Cambridge University Hospital by Prof Patrick

Yu Wai Man and his team now have 7 interested participants who are currently in the process of being registered so the project can start.

WSUK hope to be able to share updates about this in a future newsletter.

News You Can Use

International Patient Registry

Have you wondered how to get involved in Wolfram Syndrome research but did not know how? Here's your chance...check out the Wolfram Syndrome Global Patient Registry at wsglobalregistry.iamrare.org.



Wolfram Syndrome Global
Patient Registry

Welcome to the Wolfram Syndrome Global Registry

[Learn more »](#)



Autumn Covid vaccine details announced

[Contact](#) published an update on their website on Monday 12 August 2024 regarding the announcement for the Autumn Covid and Flu

vaccines. Read below-

The Joint Committee on Vaccination and Immunisation (JCVI) has announced its [recommendations for the autumn Covid booster programme](#).

The JCVI's recommendation – which the government has accepted – is that the following groups receive a vaccine later this year:

- Anyone aged six months to 64 years in a clinical risk group (as defined in tables 3 and 4 of the [COVID-19 chapter of the Green Book](#)).
- Adults aged 65 years and over.
- Residents in a care home for older adults.

This year, the JCVI is not recommending the booster for unpaid carers and household contacts of people with immunosuppression, as it has done in the past.

If your child is eligible, the NHS will contact you to book an appointment online, attend a walk-in service or arrange the vaccine with your GP.

Flu vaccine details

Details for the 2024 flu vaccine programme are [also available online](#).

From 1 September 2024, the flu vaccine will be available to:

- All children aged two or three years on 31 August 2024.
- Primary school-aged children (from Reception to Year 6)
- Secondary school aged children (from Year 7 to Year 11)
- All children in clinical risk groups aged from six months to less than 18 years.
- Pregnant women.

Usually, two and three-years olds are eligible for the nasal vaccine, which they'll receive at the GP surgery.

School age children up to the age of 15 will be offered the vaccine nasal spray at school.

Babies aged six months to two years with a long-term condition will be offered the injected vaccine at the GP surgery. The nasal spray is not licensed for under-tuos.

Read more about [the flu vaccine](#) and [the covid vaccine](#).

Neuropad

Neuropad is a patented 10-minute screening test for the early detection of diabetic foot syndrome. The test is completely painless and is an early warning system for your feet. Nerve damage to feet is a common complication of diabetes but is often not noticed until it

becomes quite advanced. Neuropad helps to solve this problem with a simple colour change test.

For some years this has been available to purchase from several online retailers, and still is available to purchase, VAT free when a code is applied or a declaration submitted. This comprises of two test pads; but now there is good news that neuropads are now available to diabetics free on a GP prescription.

Here's how it works - damage to the nerves in the feet can result in the sweat glands not producing enough moisture which leads to dry and cracked feet (called sudomotor dysfunction). A Neuropad is stuck to the sole of each foot like a small sticking plaster and left in place for 10 minutes. The pad is blue to start and should turn pink in the presence of moisture from sweating to indicate a normal result (many will obviously require assistance with the colour change). If the Neuropad test patch stays blue or turns patchy blue/pink, this indicates that you MAY have diabetic peripheral neuropathy and your sweat glands are not working properly because there is not enough moisture to complete the colour change. In clinical trials, the sensitivity and specificity of Neuropad was comparable to well established hospital based tests.

Note: If you would like to purchase online then these can be

purchased from IDDT [online](#) or by phone on 01604 622837 or from [Neuropad UK](#)

Resources to help with transitioning from Paediatric to Adult Care

T-KASH (Transition – Knowledge And Skills in Healthcare) are FREE resources which were originally created in 2015 by young people from the Alström Syndrome UK (ASUK), Hear My Voice Youth Forum.

The resources are designed to support young people, families, and healthcare professionals, to help everyone understand the transition journey and the things that are important to young people.

At the end of 2022, the process began for updating the T-KASH resources to ensure they are inclusive and represent the needs of young people within the rare disease community. Find out more [here](#).



Be My Eyes

Be My Eyes connects blind and low-vision users who want sighted assistance with volunteers and companies anywhere in the world, through live video and artificial intelligence.

There is also a Be My Eyes for workplaces.

Be My Eyes for Work is a suite of tools that makes the workplace more accessible for the people working in it who are blind or have a low level of vision. From AI-powered software that describes on-screen content, to automatic connection to designated sighted colleagues for assistance, or even a fully outsourced service of support, Be My Eyes for Work is a full-stack solution for corporate accessibility and workforce accommodations.

To learn more about this App or even to volunteer if you are a fully sighted person go to their website - <https://www.bemyeyes.com/>



European Deafblind Youth Camp

One of our WS community, from the UK, attended this year's Deafblind Youth Camp in Germany in July. He said he had an amazing time and learnt a lot about living with a Deafblind identity and about self-advocacy.

If you/your child are Deafblind in the 18-35 age group in 2026, living in Europe and would like to attend the next 'camp', this will be held in Malta, go to their website to find out more - <https://edbyouth.org/>.

Support Co-ordinator's Updates

Family Support Co-ordinator

Hello everyone,

I hope you all managed a bit of sunshine over this summer! I have had an update from one of the families up in Yorkshire that have done a fantastic job of growing their own vegetables and salad! I have requested some photos of these which you will find below in the 'Your News' section.

I have really enjoyed catching up with some of you over the

summer, and hearing about your travel plans, also. Remember, if you want to share your achievements and stories, we always welcome them.

As we move into September, I am delighted to be working with Olivia our newest member of the family support team. Some of you will meet Olivia at both the virtual and face to face clinics in October, unfortunately she is unable to make the conference; but I am sure you will all make her feel as welcome into the role as you have done me.

Speaking of the conference, if you are attending and wish to have a catch up with me, please let me know and I will put some time aside for you. I will be there on Saturday only.

October sees my 10th face to face clinic and the final clinic for 2024. What a milestone! I am genuinely surprised how fast those clinics have come round and how settled I feel in the role. I am looking forward to Olivia joining me on October's clinic and sharing with her the joy I feel when supporting you all in the clinic environment.

Best wishes

Georgina

Email: georginaking@wolframsyndrome.co.uk

Mobile: 07592 629813

Family Support Co-ordinator Page -

<https://wolframsyndrome.co.uk/family-support-coordinator/>

Adult Support Co-ordinator

I can't quite believe that we are now heading into September, the autumn equinox and evenings beginning to draw in. Let's hope we might just get a bit of an Indian summer yet!

I have managed a few days off here and there over the summer, mainly long weekends connected to me playing with the band, but it has been nice to get out of the office from time to time. As I catch up with some of you over the coming months, it will be good to hear about your holidays/top tips on travel etc.



I would like to give a big thank you to all of you that completed the survey for the Adult Support Project recently. I know what a nuisance surveys can be, but your responses have been extremely

helpful. Please bear with us as we analyse the results and consider how we could improve our support activities. Our current ideas include organising specific topic webinars, one to one sessions with myself, and / or group sessions. We are also exploring the possibility of running face-to-face social events. As all of the new activities will need to run alongside my current clinic commitments and day-to-day support with yourselves, we will look at working out what is achievable for both us at WSUK and for the community.

If you are attending the conference this year and are arriving on Friday (20th Sept), I will be running a social evening, with bingo, quiz and possibly some other activities. This is a great opportunity to meet others in the community and have some fun together and there might even be some PRIZES!

September is a busy month for me, as the week after conference is our penultimate adult clinic this year so I will be back up in Birmingham again. Our last clinic this year is at the end of November when I am sure the weather won't be so accommodating!

Don't forget if you need some support, help with specific issues or just need a chat, please do get in touch. My contact details are below.

Best wishes to you all! (It will soon be Christmas! 😊)

Phillippa

Tel: 07752193635



Email: phillippafarrant@wolframsyndrome.co.uk

WS Clinics

WS clinics are generally face-2-face, but if requested can be done virtually if there are reasons why you can't travel to Birmingham.

Adult's Clinic



Adult clinics are run from the Centre for Rare Diseases in the Heritage Building at The Queen Elizabeth Hospital, Birmingham.

If you are no longer able to attend the date you are invited to, **PLEASE** let the clinic team, [Tracy](#) or [Phillippa](#), our Adult Support Co-ordinator, know so that someone else can be invited in your place. There is always someone ready to take a slot if you can't. Due to hospital policy, a clinic appointment can only be changed once for a patient as there is now a larger WS community than previously. **Failure to attend will mean you will be discharged from the service.**

Please ensure contact details are kept up to date with both the hospital, whichever one you attend, and the Wolfram Syndrome UK office!

Dates 2024

27th September

22nd November

Clinic dates 2025

24th January

29th March

23rd May

25th July

26th September

28th November

Children's Clinic



The Children's Clinic is run from Waterfall House, the Rare Disease Centre at Birmingham Children's Hospital.

If you are unable to attend **PLEASE** let [Georgina](#) or [Olivia](#), Family Support Co-ordinators, [Tracy](#) or the hospital know asap, so that the place can be offered to someone else, even if you are having a virtual clinic appointment. There will always be someone ready to take up that slot if you can't.

Places for both clinics whether virtual or face to face are by invitation only.

Please **DO NOT** book or make any travel arrangements until you have received confirmation of your clinic invite and have heard from

the hospital as to whether you need to attend in person or will be having a virtual clinic appointment.

Dates 2024

7th and 8th October

We have a '[Who's who at the WS Clinic](#)' page on the website, as well as a [Family Support Co-ordinator's](#) page with information from Georgina and Olivia.

There is a map of the [Queen Elizabeth Hospital](#) site and a floorplan of [Waterfall House](#) for new visitors, on the clinics page of the WSUK [website](#).

Fundraising News

Upcoming events can be found listed on the events page of the Wolfram Syndrome website www.wolframsyndrome.co.uk

Remember to keep checking the website for upcoming events, any recent news articles & links.



Charity Football

FJN's 6-a side tournament was another fantastic day raising **£1364.38!** The total raised this year from the 3 events organised by FJN is **£3514.38.**

Thank you to everyone involved and who took part.



Charity Golf Day

Our 11th annual charity golf day sponsored by Northern Commercials this year, was held at Mannings Heath Golf Club and Wine Estate on 19th July.

We would like to thank everyone who donated prizes to our auction

and to everyone who took part, there are too many to list them individually.

The total amount raised this year was **£17,050!**



Continued Support!

Thank you to those members of the WS community and their friends/families who donate regularly, through monthly standing orders/direct debits, to support the work that we do.

Would you consider making a monthly donation to us? If so, then

please contact Tracy in the [office](#) for bank account details.

Why not set yourself a task of asking **3 friends or family members** if they would like to do the same? Can they spare £2.00 a month? Less than the cost of a fancy coffee shop coffee.

Don't forget to the office know if we can Gift Aid your/their donation. We just need a name and address to do this (forms for [single](#) or [multiple](#) donations are on the website, these can be printed off and sent back to us). Why not get involved with fundraising for WSUK?

Let us know if you do something and we can include it in a future newsletter.

All the fundraising sites we are registered with can be found on the WSUK [website](#).

If you have any event that you would like to share or possibly promote please let us know in the WSUK office.

Ways to Donate to WSUK



Facebook Donations

We continue to be thought of by WS members and their families when it comes to their birthdays or they are doing a fundraising event through creating [Facebook fundraiser pages](#).

A big thank you to everyone who supports us in this way.



PayPal Giving Fund

PayPal Giving Fund is a way of donating to Wolfram Syndrome **without** any fees being **deducted** by the fundraising platform like many of the others do. The link for this page is paypal.com/gb/fundraiser/charity/76200.

PayPal Giving Fund



This QR code can also be used to make a donation to WSUK. Please feel free to share with friends and family.

Other Ways to Support WSUK

PayPal - Give at Checkout



Want to support WSUK when you shop online? Set us as your favourite charity, then click to donate £1 when you checkout with @PayPal for your purchases.

There are 2 ways to do this.

1. By using the link below, select us as your favourite charity and then log in to your account to complete the process.

paypal.com/gb/fundraiser/charity/76200

2. Log in to PayPal. Click " Set your favourite charity", type in our name Wolfram Syndrome UK. Confirm this is your favourite charity and we will appear on your homepage.

Make your online shopping count!



Want to help us raise more just by shopping online? Well now you can! It's very easy to do.

We are registered with online shopping portals [Give as You Live](#) and [easyfundraising](#).

Shop at your favourite stores and many more as usual, using one of these portals, and when you check out a donation from that store will be paid to WSUK at no extra cost to you. You can also raise funds when shopping for things like holidays and insurance.

Links to register can be found [here](#); or you can click on the relevant

image above to be taken straight through to the registration page. Install the reminder link so you will be asked if you want to raise a donation when you go straight to the retailer's website, so you don't need to worry about forgetting. Simple!

Sometimes it may be a few pence, other times it can be up to £40 for a retailer donation. Help us by signing up today!

WSUK Shop Page

As well as our WSUK branded items, which now also include a 330ml travel cup with lid, you will find some other items now available; all raising funds for WSUK. You can access the shop page [here](#).

Unique Art Work

Unique pieces of art by Jennifer Lynch can be found on our shop page for you to purchase. If you would like to purchase a piece of art then please contact the office for P&P to be calculated and to make payment. Jennifer has donated the cost of materials so 100% of the sale price goes to WSUK.

Blank Greetings Cards

We have also added some blank greetings cards to the shop page. There are 5 designs, copies of Jennifer's paintings. Cards are available individually for £1.50 with P&P of £1.00. Please contact the office if you would like to purchase any.



Charity Christmas cards

It is that time of year when Christmas starts arriving in the shops and I'm afraid it's no different here.

We have 5 new designs which we are adding to the 9 designs from last year. Some of these designs are very limited in stock so once they are gone that is it.

Each pack has 10 cards of the same design in with our logo inside and on the back. Each pack costs £3.00 with P&P starting from £2.95. If you are attending conference on 21st September you will be able to purchase packs then as well.



You can access the shop page [here](#) for any of the items and more mentioned above.

WS clothing and accessories website

WSUK has created a new website for WS branded clothing and some accessories such as tea towels, bags and mugs. There is a link to this site from our shop page.

The products are made from organic cotton and printed in a renewable energy powered factory. When they are no longer wearable or wanted the items have instructions on how to send the product back to be re-milled and remade.

Delivery can be made to almost every country, just check the bottom of the website for delivery details and answers to any

questions you may have.

WSUK will receive funds from the sale of each product. Currently we have a minimal range of products available. There are three logos to choose from - Wolfram Syndrome UK; WS Global Awareness Day for anyone that would like to help raise awareness every October 1st and the Wolfram Syndrome UK and Snow foundation joining together logo. The two organisations work closely together putting on the virtual global events and for the last two years the International Researchers Symposium.

Please send us any images of you wearing or using any of these products if you make a purchase.

Go to the website [here](#) where you can also read a bit about the company we are using.



Information about ways to raise funds can be found on our website

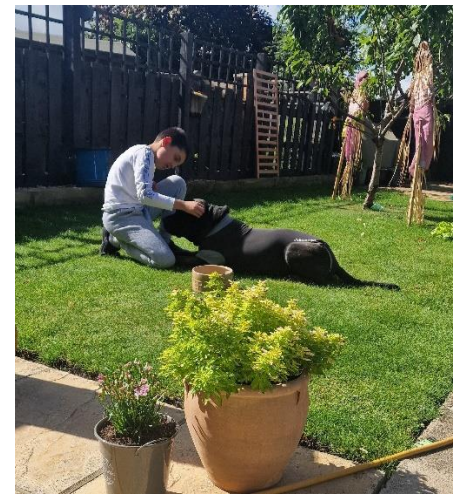
[Funding Inspiration](#) page.

If you are arty or crafty and have something that we might be able to sell to raise funds then please let us know in the office. Or think about selling them at a craft fair as a way of raising awareness and funds. Let us know and send pictures so we can share this in future newsletters.

Your News

Please send in anything you would like to share with the WS community. The deadline for sending to be included in the Winter newsletter is **25th November**.

Here are some pictures from the family in Yorkshire that Georgina mentioned in her update above, that have been growing salad and vegetables over the summer. Well done!



Birthdays (UK and worldwide)



Happy birthday to everyone that has a birthday to celebrate during September, October and November.

We hope that you all have a great day!



Happy birthday to you all!!



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