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## **Welcome to the Spring Newsletter.**

Well, we've had a real mixed bag of weather to start the year off already. Hopefully it can only improve as we move forward into Spring.

There is lots planned for this year, all of which are mentioned in the newsletter content. The first thing coming up is next month, with the virtual global conference. We have four WS researchers from around the world giving us updates on their work. Full details on how to register and take part are to be found in the newsletter.

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](#) or [Georgina](#) about these.

Take care

Tracy



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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](mailto: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



This year's conference has been booked for the same venue as last year, Mercure Daventry Court Hotel, Daventry for Saturday 21st September 2024, so please save the date in your dairy.

There is a slight increase to room costs I'm afraid but it is minimal, Booking forms to reserve your place and room if required can be found on the [website](#) and will be sent out shortly.

Further details will follow.

## **Wolfram Syndrome Global Virtual Conference**

On 13th April there will be a global virtual conference for all those interested, hosted by Wolfram Syndrome UK and The Snow Foundation.

There will be 4 presentations on the Saturday afternoon starting at 2:00pm (BST).

The programme and the links for registering will be sent out nearer the time either by email or posted on social media.

Each presentation will be recorded and added to the WSUK website afterwards. We will try to have time for some questions and answers on the day, but any others we will ask to be emailed to the WSUK office, who will then send them to the relevant presenter for answering. The answers, once received, will then be sent to the person asking as well as then being added with the video on the website.

We hope that this will help everyone to know some of the research that is being done for WS around the world. The plan is for this to be a bi-annual event.

# UK Clinical Trial Updates



## Update from Prof Tim Barrett

Dear friends and colleagues,

I hope everyone is keeping OK. I have 3 items to update you on.

Firstly, the TREATWOLFRAM trial is continuing to progress well. We had an independent Data Monitoring Committee meeting in January. This is chaired by Professor Karen Morrison, an honorary consultant in adult neurology, who previously led the highly specialised service for adults with Wolfram syndrome. The Data Monitoring Committee reviewed the unblinded data. I am pleased to say that they had no safety concerns, and were happy for the trial to continue to completion. Following this meeting, our Trial Steering Committee met, chaired by Professor Marc Peschanski, Director of INSERM, a large research institute outside Paris. We discussed the trial progress so far, and plans for acting on the results at the end of the trial. The last participant will complete the trial at the end of October 2024. We will then have 2-3 months to collect any outstanding data from study sites.

The Clinical Trials Unit.....

read in full [here](#).

## **USA Trials and Research Updates**

Spring is just around the corner, and our dedicated team continues to work tirelessly on advancing safe and effective treatments for Wolfram syndrome. Here's the latest update:

### **Rare Disease Day at National Institutes of Health 2024**

I'm excited to share some fantastic news with you. I've received an invitation to present our research on Wolfram Syndrome at the Rare Disease Day event held at the National Institutes of Health on February 29, 2024. This event is widely regarded as one of the most prestigious gatherings for rare diseases, offering an excellent platform for us to raise awareness about Wolfram Syndrome. Even if you can't attend in person, you can still participate by watching my presentation remotely. Here is the link to access it: <https://ncats.nih.gov/news-events/events/rdd>

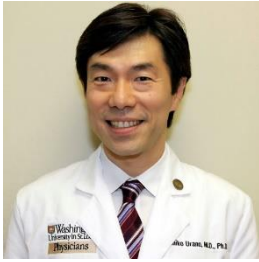
### **Ongoing clinical trials**

We have been collaborating with Amylyx Pharmaceuticals to advance the development of AMX0035, a novel oral medication that has been designed to halt.... read in full [here](#)

With grace and gratitude,

Fumi

Fumihiko Urano, MD, PhD, FACMG



## **WSUK Research Funding**

Our Scientific Advisory Board (SAB) recently held a meeting to discuss some research proposals for a funding call we announced last year. The SAB is made up of a mixture of doctors and researchers, so we have a good mix of expertise and knowledge.

We have listened to their input and recommendations which have then been put to the Board of Trustees before the release of funds to the successful project, which we will name in our next newsletter.

Once our research budget has been set for our next financial another funding call will be announced around summer time.

## **Snow Foundation Newsletter**

The newsletter from The Snow Foundation was emailed out on 16th February. It has lots of information about research that is

currently taking place around the world. If you would like to read the newsletter, click [here](#).

## **Data Consent Updates**

WSUK are currently in the process of updating the way we hold and store personal data for our community. This is to ensure we continue doing everything required to keep the information we hold secure.

You will shortly be receiving forms asking for your consent or re-consent to hold this information as well as asking for consent on what information you would like to receive from us. Those that have consented since January 2023 won't be asked, although we may ask for you to provide us with any information that is missing from the forms.

We would appreciate it if you could return the signed and completed forms as soon as possible.

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## **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](http://wsglobalregistry.iamrare.org).

## Wolfram Syndrome Global Patient Registry

Welcome to the Wolfram Syndrome Global Registry

[Learn more »](#)



## Updated NICE quality standard on the transition from children's to adult services.

As part of a commitment in the England Rare Disease Action Plan, NICE have recently published an [update to their quality standards to improve transition of care between child and adult services](#).

## Guide Dogs Tech for All Scheme re-opens March 2024.

Children from the ages of 3 - 18 with a Visual Impairment are eligible to claim a free iPad, Assistive Equipment, Sensory Equipment or an iPhone for older children.

<https://www.guidedogs.org.uk/tech-for-all/>

Even though the scheme may not yet be open, parents can register their interest by using the link - [Guide Dogs Tech for All](#)

**Keeping your Blue Badge safe!**

It is now possible to purchase a double or single blue badge protector from Halfords stores. The protector features a steel based sleeve with a clear Perspex slide cover. Users can lock it to the steering wheel with a 1.2m cable which is provided.

### **Cheap and fast social broadband.**

Vodafone has introduced its first social tariff broadband from just £12 a month.

With download speeds of up to 38MB per second, it claims to be the UK's cheapest and fastest social broadband plan and will be available to all existing and new customers.

Eligible benefits for this tariff include Disability Allowance, Universal Credit, Reduced Earnings Allowance and Personal Independence Allowance.

Sign up on Vodafone's website and they will call you to confirm eligibility.

### **Decision to close rail ticket offices reversed.**

Following a public consultation and around 750,000 responses, the plans to close almost 1,007 of the nation's ticket offices has been cancelled.

Transport Secretary, Mark Harper, says” they will continue their work to reform our railways with the expansion of Pay As You Go ticketing, making stations more accessible through their Access for All Programme and £350m funding through their Network North Plan”.

The RNIB said it was “delighted the voice of blind and partially sighted people has been heard”.

## **Useful Links for those with a Hearing Impairment**

These links will be added the Helpful Organisations document found on the Helpful Organisations (<https://wolframsyndrome.co.uk/helpful-organisations/>) page of the WSUK website.

**SignHealth** – has loads of useful resources and provides psychological therapy service for Deaf adults delivered in BSL: [signhealth.org.uk](http://signhealth.org.uk)

**SHOUT** – a free text messaging support service available 24/7. Text'DEAF' to 85258.

**Deaf Action** – offers BSL, deaf awareness and lipreading courses: [deafaction.org](http://deafaction.org)

**National Deaf Children's Society** – has a list of helplines and

websites for younger ones: [www.ndcs.org.uk](http://www.ndcs.org.uk)

**National Deaf Services** – has a 24/7 Mental Health Support Line – 0800 028 8000 or visit the website for more information: <https://swlstg.nhs.uk/deaf-services>

**The Royal Association for Deaf People** – offers a live chat and wellbeing groups: [royaldeaf.org.uk](http://royaldeaf.org.uk)

**Follow Asha Hylton** – a top Paediatric Critical Care Sister and Deaf Awareness Advocate – Instagram: [@justmecameil](https://www.instagram.com/justmecameil).

## **Free Workshops organised and run by Contact**

### **Free workshops for parent carers in the Midlands**

Contact are running a series of free online workshops for parent carers in the Midlands with young disabled children (aged 0-5).

The sessions will cover advice on financial support options for your family, handling meetings with your child's professionals, and managing issues with your child's sleep.

[Book your place on Eventbrite.](#)

**Wellbeing: Thursday 21st March 19.00 - 21.00 via Zoom.**

What causes you stress and how do you cope with it at present? Parenting can seem full of challenges and stressful times. Supporting the needs of a child with a rare condition can

lead to a sense of isolation and affect your wellbeing in many different ways.

This online workshop will give you an opportunity to:

- understand clearly what stress is and how it affects you
- identify those factors which cause you stress and establish how you cope with these at present
- learn about coping mechanisms and each other's coping styles

To find out more and to secure your place please book via [Eventbrite](#)

### **How to Handle Meetings: Thursday, 11 Apr 2024 19:00 - 21:00 via Zoom**

This online workshop will help you to handle meetings to discuss your child's specialist needs and get the right support for them. You'll learn about preparing for meetings, develop your skills for online and in-person meetings and learn how to feel more confident to help you reach the best outcomes for your child.

To secure your place book via [Eventbrite](#).

### **Siblings workshop for parent carers: Tuesday 16 April 10.00 -12.00 via Zoom**

This online workshop offers a non-judgemental, confidential space to explore common issues parent carers face with managing the different needs of their children and hear strategies that could help.

To secure your place book via [Eventbrite](#).

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## **Support Co-ordinator's Updates**

### **Family Support Co-ordinator**

Hello everyone,

In January and February, I went on a number of family visits in the community to meet some new and existing families. I supported new families starting their WS journey, PIP applications and EHCP support. I want to thank you all for your generosity allowing me to support you in your homes, lifts to and from the station and for feeding me and keeping me hydrated. It's so wonderful to work with such a compassionate community.

In February, I had the delight of meeting Evie West, a member of our community with cochlear implants. Evie wrote a poem around her journey for cochlear implants which won the Worcestershire Poet Laureate for age category Y9-11. Well done Evie!

You can read the poem on the FSC page on the WSUK [website](#), in the Inspirational People section, Hearing Impairment tab, or in the 'Your News' section at the end of this newsletter.

Guide dogs have re-opened their project Tech for All, for young people with a visual impairment aged between 3-18yrs. Please register your interest [here](#).

Excitingly myself and Phillippa, the adult support coordinator, are working on a project to host regional meet ups, hoping to bring our community together socially. However, if you would like me to visit you at home during the Easter and summer holidays, please don't hesitate to contact me.

If you have anything you wish to share with us, such as the poem Evie wrote, please get in touch. We are happy to share your achievements on the website and in future newsletters.

I will be moving to three working days a week from April to allow me to complete the SEND Law training programme.

Parents can complete this training, if they so wish, at a heavily reduced cost. For more information click [here](#).

I hope you all have a wonderful Easter, looking forward to seeing some of you in March clinic.

Georgina

Tel - 07592 629813

[Georginaking@wolframsyndrome.co.uk](mailto:Georginaking@wolframsyndrome.co.uk)

[Family Support Co-ordinator Page](#)

## **Adult Support Co-ordinator**

I am writing this looking out at grey skies and rain, but hoping for better days ahead- it always makes us feel better when the sun shines and the days begin to lengthen again. I try and get out, but it can be hard work to get motivated sometimes.

At the end of January, I attended the WS adult clinic in Birmingham, where it was good to meet some new members of our community. We also tried a new way of doing things, where each patient was assigned to a room and the health professionals moved between rooms to see patients. We all agreed that this led to a much better flowing clinic, with more privacy to talk to those who attended.

Going forward, I will also have a separate room so - if any of you attending clinic have any issues that you want to talk to me about, we can meet there in between seeing other health professionals, which will be more private than talking in an open waiting room.



This year I will be developing a new project, focused on building the engagement within our adult community. I will be reaching out to some of you for input to help the project be as community focused and beneficial as possible. Watch this space!

Based on last year's success, I will be running a social event again this year on the Friday night before the annual conference (Friday 20<sup>th</sup> September). This may involve more bingo! but any ideas will be gratefully received (within reason!)

I have a few home visits already pencilled in for the coming year for those who may need face to face interaction and support, which I am looking forward to. The favourite part of my role is meeting you all, chatting to you, and hearing your stories. If anyone needs any specific help, advocacy or just a chat, then please do get in touch via my email

[phillippafarrant@wolframsyndrome.co.uk](mailto:phillippafarrant@wolframsyndrome.co.uk) or my phone :  
07752193635.

There are lots of exciting times ahead, and I look forward to getting to know you all better this year. Hopefully the sun will shine soon!



Phillippa

Working part-time on Monday to Thursday mornings.

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## **WS Clinics**

### **Clinic Dates 2024**

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 clinics are run from the Centre for Rare Diseases in the Heritage Building at The Queen Elizabeth Hospital, Birmingham on the following dates:

**22nd March**

**24th May**

**28th June**

**27th September**

**22nd November**



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!**

The dates for the Children's Clinics, run from Waterfall House, the Rare Disease Centre at Birmingham Children's Hospital are:

**4th and 5th March**  
**10th and 11th June**  
**7th and 8th October**



If you are unable to attend **PLEASE** let [Georgina](#), Family Support Co-ordinator, [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.

Birmingham Children's Hospital fully launched their DrDoctor Notification system in January 2024. This is used to improve ways of communicating with patients, families and service users about your appointments, for example by sending letters digitally.

Some of our families are receiving email or text notifications that they are on a waiting list for a WS clinic, which is causing a bit of confusion. This isn't a guarantee that you will be seen at the next upcoming clinic, but are on the list to be seen at some point.

**If you have been told you are attending a clinic already, please ignore the reminders as they are auto generated.**

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.

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](#).

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## **Fundraising News**

Upcoming events can be found listed on the events page of the Wolfram Syndrome website [www.wolframsyndrome.co.uk](http://www.wolframsyndrome.co.uk)

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



## **Charity Football**

Regular supporters, FJN Solutions in Horsham, have once again organised two charity football matches.

April 19th will see them playing a regular football match and on 14th June there will be 12 teams taking part in a six-a-side tournament, just like last year.

FJN Solutions sponsored Horsham FC in this season's FA Cup, and have kindly donated one of the three signed and framed FA Cup shirts they were presented with to be raffled off to raise funds for us. This will be raffled off at a Home game against Lewes on 1st April.

We would like to thank FJN for their continued support.

## **80 Mile Cycle on 80th Birthday**

Ongoing supporters, Colin and Rosy Gray, will be cycling 80 miles in April on Colin's 80th birthday for WSUK.

They are friends of one of our initial families and have supported us for over 5 years with cycling fundraisers, one of which was linked to their 60th wedding anniversary.

At the time of this newsletter going out, with over a month to go, the total raised so far is £992.50.

If anyone would like to support Colin and Rosy here is the link to their [page](#)

Thank you to them for their continued support!



## Charity Golf Day

Our 11th annual charity golf day sponsored by Penfold Verrall and Northern Commercials is being held at Mannings Heath Golf Club and Wine Estate on 19th July.

This is a popular event with all teams that are invited to take part and a great day is had by everyone involved.

## 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 let me 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.**

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## **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](https://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

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## 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](https://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!

## **One-off Pieces of Art**

22-year-old, Jennifer Lynch, has been busy creating individual pieces of Art this year.

Jennifer has no real vision remaining, but with some assistance using pouring/fluid paint she has been creating art on box canvases and canvas boards, which can be framed.

These pieces of art have been capturing attention and have

been purchased by some of you at last year's conference and by others who have seen the artwork on Facebook.

The artwork has now been added to the [WSUK shop](#) page for you to look at and purchase if anyone wishes. A lot of them are brighter in real life, photos don't really do them justice.

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.



Information about ways to raise funds can be found on our website [Funding Inspiration](#) page

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## Your News

Please send in anything you would like to share with the WS community. The deadline for sending to be included in the summer newsletter is **24th May**.

## **Scars of sound- By Evie West**

**(WS Young adult)**

They are a reddish hue in colour.  
faint but visible to the naked eye,  
weaved and intercrossed with thread  
a day I so fearfully anticipated with dread.  
They do not make me shed a tear. Nor cry  
but are instead a reminiscence of my story.

The battle I fought to hear again;  
they are my scars, my scars in all their glory.  
My scars of sound. Till' the end

of  
forevermore

my spirit dances with them;  
lifts up my heart. And soars.

To be gifted my magic ears,  
was worth the scars-  
Almost ethereal. A planet like Mars.  
Spinning, spinning. Vertigo is winning-  
My head laced in white, plasters shall be off tonight-  
oh' my scars.  
My scars of sound.  
The beauty fills you,

with Earth's most utmost splendour,  
Never fails to astound.  
The queen of scars is crowned.

Have courage, I was told.  
By all those, young and old-  
But how. Could they ever know?  
How much it terrified me,  
to think  
I could live  
or go.

I wear my scars with dignity, complete pride;  
They make me complete; laced on either side;  
a part of me that shall never forsake;  
they remain, with all their hurts and aches,  
a momentary flashback;  
the injection of the cannula;  
barely audible, a grunt of pain.  
Outside, God sent down his rains.  
Pitter  
patter.  
Darkness.

Sudden light.

My scars show my fight.

And I'll love them  
-for all my life.

## **Donations in memory of Amy Hawkins**

**£12345.54** was the total amount raised in memory of Amy Hawkins. This money has been split as per the families wishes towards Research, Conference which Amy loved to attend and our day to day costs.

We would like to thank all Amy's family and friends as well as the work colleagues of her parents for being so generous in remembering such a lovely person.

## **Birthdays (UK and worldwide)**



Happy birthday to everyone that has a birthday to celebrate during March, April and May.

We hope that you all have a great day!



**Happy birthday to you all!!**



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You are receiving this newsletter as you have either subscribed, previously joined the WSUK forum or attended a families' conference

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