



Welcome to the Spring newsletter.

Welcome to the first newsletter of 2025. The mornings are getting lighter and the days are getting longer, fingers crossed warmer and sunnier weather is round the corner.

Spring and Summer start the ball rolling for our regular fundraiser events and hopefully some of you will also think about how you might be able to support us as well. Please share anything that you do with the office or the Support Co-ordinators, so that we can share it with the rest of the community.

Friday 28th February was Rare Disease Day and on 27th Phillippa attended the Rare Disease Day Reception at Westminster Palace where she met up with other RD Groups.

2025 is a bit of a special year as we mark 15 years this month since Paul and I started WSUK as a support group for the small number of known families in the UK. Three years later we became a registered charity, with even more families known to us and the numbers slowly growing. We have seen so much happen in that time.

Thank you to the WSUK team; Trustees, past and present; our volunteers; fundraisers; doctors and all of you for helping us get to where we are today.

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



This year's conference is **Saturday 20th September**, at the same venue in Daventry. Information, the booking form and a draft programme can be found on the [website](#). There will be further updates to the programme which will be updated as they become known. There will be a social evening event on Friday 19th held by Phillipa and Olivia, two of our Support Co-ordinator's. Details of this will be included in a future newsletter.

I'm afraid, there is a very slight increase this year for single and double room prices; but we continue to subsidise the cost of the rooms, pay the conference day costs and the dinner on Saturday night.

Please book your place and room if required as soon as possible. The last date to book is 28th August.

WSUK Research Funding

Our Scientific Advisory Board met on 20th January to discuss the three grant applications we received. The Board came to a decision to fund a research project in Montpellier, France which will be funded for 18 months.

Information about this project will be shared at points throughout its duration.

WSUK Funded Research Projects

In the next few months, we hope to get an update on the work carried out by Dr Sarkar and his team at University of Birmingham on their project which is **related to the development of autophagy and NAD enhancers for the treatment of Wolfram syndrome.**

Dr Sarkar will also be talking about this at the conference in September where you will be able to ask questions.



Research Updates

TREATWolfram Trial Update



Dear friends and colleagues,
I hope everyone is keeping OK and escaping the winter bugs that are going around.

TREATWOLFRAM international randomised controlled trial

I would like to give a short update on our next steps now that the TREATWOLFRAM trial has finished. The last participant finished the trial during November 2024. We are currently collecting all the outstanding data from study sites (in France, Poland, Spain, and UK). We hope to complete this by end February or beginning of March. The Clinical Trials Unit will then 'lock' the database..... Read more [here](#).

USA Trials and Research Updates

Ongoing Clinical Trial of AMX0035 in patients with Wolfram Syndrome

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

We continue working with Amylyx Pharmaceuticals to evaluate AMX0035, an encouraging oral medication aimed at slowing the progression of

Wolfram syndrome. The Phase 2 clinical trial began in April 2023, with interim results announced in April and October 2024. The latest analysis in October included assessments at Week 48 and continued to show encouraging outcomes. Among the eight participants evaluated, sustained improvements were observed in pancreatic.... Read in full [here](#)

Please see the [newsletter](#) from The Snow Foundation which has updates on the research that is happening around the world.

Development of new Clinical Guidelines for Wolfram Syndrome

WSUK and The Snow Foundation are working alongside a group of WS clinicians from the UK and USA as part of a core group to develop comprehensive guidelines for the diagnosis and treatment of WS for those affected around the globe.

These guidelines aim to provide clear guidance on the criteria and decision-making processes related to the diagnosis, management, and treatment of Wolfram syndrome across various areas of healthcare.

Doctors and Patient Organisations, from around the globe, are from around the are being invited to contribute to the development of the guidelines as each stage progresses.

News You Can Use

Renaissance Legal launches artwork competition to mark 15th anniversary

Renaissance Legal, who have attended a few of our conferences, have launched an art competition to celebrate their 15th anniversary at their current premises. The competition is open to children and young adults, aged between 4 and 25, with a disability or SEN. For full details and to access the entry form click [here](#).

The closing date is Friday 18th April 2025. We would love to hear from you if you enter.



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 »](#)



It is also possible for parents and siblings who are carriers to enter their details to the registry and to answer questions relevant to them. All this information will be helpful to researchers in the future. Thank you for contributing.

Medical Exemption Certificates

As I'm in the process of renewing my daughter's Medical Exemption Certificate (MEC), I thought it would be worth reminding you about the possible need to renew yours, it needs renewing every 5 years, or to apply for one if you don't already have one.

Anyone over the age of 18 and no longer in fulltime education will need to pay for prescriptions unless they have a MEC.

You're entitled to a medical exemption certificate if you have either:

- a permanent fistula (for example, caecostomy, colostomy, laryngostomy or ileostomy) which needs continuous surgical dressing or an appliance
- a form of hypoadrenalism (for example, Addison's Disease) for which specific substitution therapy is essential
- diabetes insipidus and other forms of hypopituitarism

- diabetes mellitus, except where treatment is by diet alone
- hypoparathyroidism
- myasthenia gravis
- myxoedema (that is, hypothyroidism which needs thyroid hormone replacement)
- epilepsy which needs continuous anticonvulsive therapy
- a continuing physical disability which means you cannot go out without the help of another person
- cancer and are undergoing treatment for either:
 - cancer
 - the effects of cancer
 - the effects of cancer treatment

These are the only conditions that entitle you to a medical exemption certificate. If you're not sure about the name of your condition, speak to your doctor.

If you're entitled to a certificate because of your medical condition, speak to your GP or doctor. They'll give you an application form.

You'll get a certificate in the post within 10 working days of them receiving your application.

Without a valid MEC you are liable to a fine if you don't pay for a prescription.

Financial Support Checklist from Contact

- Six top tips for parents/carers of children with a disability

Did you know it costs *3 times more* to raise a disabled child? That's why it's vital that these families claim all the financial support they can, but many don't know what's available to them.

To help, [Contact](#) have created this handy checklist that we can share with any parent carers who might be struggling with extra costs.

1. **Use the Benefits Calculator:** Parents you can check if you're claiming everything you're entitled to by using [this online Benefits Calculator](#) – it takes just 10 minutes and can make a *huge* difference
2. **Try Contact's Grants Search:** [The online Grants Search tool](#) will show parents what charitable funding you could get towards specialist equipment, therapies, home adaptations, white goods and even holidays
3. **Get help with household bills:** Take a look at the [schemes and grants available](#) to help families with water, fuel and other utility bills
4. **Look at our energy saving tips:** With disabled families already facing higher energy bills, [these practical tips](#) can help parents cut down on heating, fuel and appliance costs

5. Apply for help with extra costs: Contact's website lists [several support schemes](#) available to help parents with [education](#), [health](#), and [transport and leisure](#) costs

Read Contact's Money Matters guide: Parents will find detailed advice on benefits, vouchers, discounts, loans and other sources of financial help in their [Money Matters guide for England & Wales](#)

Affordable, adaptive clothing ranges

This article won't be relevant to everyone in our community, but it is worthwhile including it for future knowledge.

Primark have recently unveiled a new affordable 49-piece adaptive clothing range for men and women that includes wardrobe staples based on Primark's bestsellers. The new collection ranges from trench coats and tees to jumpers and jeans, all with features designed around the needs of disabled people or those experiencing temporary disability.

The collection's adaptive features are designed to make dressing simpler, from magnetic zippers and snap fastenings to waist loops that help to pull up trousers and hidden openings for tube, stoma, or catheter access.

There is also a range of options for people who are seated, such as wheelchair users. Created to reflect a diverse range of needs, the collection was shaped through a series of focus groups and hands-on fit sessions with members of the disabled community. To read more about this click [here](#).

For our younger community - In February 2023, Asda launched an 'Easy on Easy Wear' collection of clothing for children, an affordable, adapted clothing range to support independent dressing for children and young people with disabilities.

Following the success of its Easy on Easy Wear school uniform range, George at Asda has created a collection of everyday casualwear that has been adapted to make independent dressing easier for those with additional needs and reduced mobility.

The Easy On Easy Wear range features 24 items of clothing for ages 3 to 16 years old and is available in Asda store and [online](#), with prices starting at £3.00. Garments feature discreet and practical adaptations that make day-to-day dressing easier for children and young people with special requirements. An article about this range can be found [here](#).

Water Rates Rising

Household water bill prices in England and Wales

[will rise on average £10 a month from April](#), according to new figures from Water UK.

The trade association representing water companies in the UK says that while price rises will vary across different regions, the average annual bill will be £603.

Families and individuals will be worried about the impact on their finances. For some families with disabled children, there will be help available.

This includes the WaterSure (Wales) schemes and assistance from your supplier, including social tariffs and debt support schemes.

Read [Contacts water bills news story](#) to find help with water and other household bills or have a look at the WSUK website [Benefits and Grants](#) page which will also have some helpful information.

Support Co-ordinator's Updates

Family Support Co-ordinators

Hello everyone,

Welcome to 2025! As we are stepping into a much needed spring, I am happy to announce the continued use of Ronald McDonald House for the Sunday evenings prior to the WS clinics at BCH. For those of you that came to clinic in October 2024, and

January 2025, you will know that we used Ronald McDonald House on the Sunday evening, and it was used by a number of the families attending clinic. I am really pleased that this will continue.

Ronald McDonald House is a separate building, that sits behind Waterfall House at Birmingham Children's Hospital. Whilst children are in BCH as inpatients, Ronald McDonald House serves as a hotel for their families, with a working kitchen and washing facilities. The hotel is strictly for inpatient's families; however, the day room can be used for anyone connected with BCH. As part of the Wolfram Clinic, we are able to use the day room free of charge and bring our own refreshments to share with you. We hope by using this space more families can connect with each other during the clinic experience.

Further to this, WSUK purchased some VI friendly games, and as a result we are able to share these with you during clinic times in order to ease the boredom. We do appreciate that there are long waits between clinic appointments, and this can cause frustration and boredom. Please let either myself or Olivia Edwards know should you wish to use the games within the clinic day.

As I head into my 3rd year of working for WSUK I am excited around what this year can bring; and I hope to bring more connectivity and communication between families to help bridge that social isolation

gap. Please let me know if you would be interested in a community visit throughout the coming year.

Have a great 2025!

Georgina

Email: georginaking@wolframsyndrome.co.uk



Mobile: 07592 629813

If I haven't had the chance to wish you a Happy New Year yet, then *Happy New Year* - even though we're now into March already! I hope 2025 is off to a great start for you all.

I had my second clinic in January, and it was such a lovely opportunity to meet some new families. I really enjoyed getting to know everyone and hearing more about their lives - from education to hobbies, it's always wonderful to learn about what makes each family unique. One particular highlight for me was looking at a young person's ceramic artwork – it was so inspiring! If anyone else has any creative achievements, special hobbies, or opportunities that they would like to share with me, I would absolutely love to hear about them!

Over the past few months, I have been supporting families in various ways, including helping with

EHCP annual reviews, assisting with DLA applications, or providing a listening ear whenever it's needed. I now support 27 young people and since I began in September, I have had the pleasure of meeting 12 of you. It has been rewarding to provide guidance and support where I can, and I always look forward to continuing to help families navigate their journeys.

A big thank you to all the families for their warmth and generosity during my visits, I was especially touched when a new family introduced me to *panjiri* - a delicious traditional treat! I am definitely going to try making this at home with my children so I will keep you updated with how that goes!

As I prepare for my third clinic in March, I'm excited to meet both new and familiar faces. I can't believe that I'm already approaching my sixth month with Wolfram Syndrome UK - the time has truly flown by. I look forward to continuing to support you and your families in any way that I can.

Olivia

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Mobile: 07756 778454



Family Support Co-ordinator Page -

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



Adult Support Co-ordinator

We are now heading into spring, and the sun is actually shining today! I am looking forward to not having to have the lights and heating on all the time! I even got to my allotment at the weekend for a tidy up.

2025 is going to be a busy one for me, as our community continues to expand and so there will be more of you to visit and support. I have quite a few visits pencilled in my calendar already from local to me in Sussex to as far away as Scotland, along with attending the clinics in Birmingham. Please reach

out if you feel that a face-to-face visit from me would be helpful; whether for emotional support and being able to chat to someone in person or whether you need help with paperwork/forms. If I can manage a visit, I will do my best to do so. However, I am always at the end of the phone and/or zoom/teams/WhatsApp- whichever platform is best for you and I am happy to support in this way.

As I write this, we are approaching another Rare Disease Day at the end of February. This is where many organisations shine a spotlight on their conditions and rare diseases in general. There will be plenty of information on social media and in the press. As part of this, Genetic Alliance UK put together a creative anthology of people's stories about living with RD, and a song I wrote with my partner about having to fight the system was accepted, as soon as we get the link to the anthology, we will put it on the WSUK website. The song is called 'It will not grind us down'. On the 27th February, I will be representing WSUK and the Rare Disease Community in Parliament at a reception for Rare Disease Day.

Some of you may be wondering what is happening with the Adult Support project. I have been thinking, chatting with some of you and working on a plan going forward. There are still some concrete plans to develop, but I hope to be starting with a pilot social event in the Southeast in the summer. From there, if

it is successful, I will look to explore logistics and develop plans for other areas. Watch this space!

I am looking forward to seeing some of you over the course of the year, whether through visits, WS clinics in Birmingham or at the annual WS conference in September.

Phillippa

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WS Clinics

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

Adult 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, [Phillippa](#), our Adult Support Co-ordinator, or [Tracy](#) know so that someone else can be invited in your place. There is always someone ready to take an appointment 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!

Clinic dates 2025

29th March
23rd May
25th July Transition Clinic
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 appointment 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.

Clinic Dates 2025

10th- 11th March

16th - 17th June

25th July Transition Clinic at QEH

6th - 7th October

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

There is 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.

A map of the [Queen Elizabeth Hospital](#) site and a floorplan of [Waterfall House](#) for new visitors, can be found 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.



Christmas Hamper Draw

A boutique restaurant, The Parsonage, very local to WSUK founders, Tracy and Paul, held a Christmas Hamper Draw to raise £500 for WSUK. They weren't sure what the uptake would be like, so limited it to 100 tickets at £5 each. It proved popular and they could have certainly sold more tickets they said. Tracy drew the tickets for the hampers on 20th December so each winner received their hamper in time for Christmas.

A big thank you to Wayne, Connor and the rest of The Parsonage team for organising and running this event for us. Not only did this raise funds for us but

also awareness as a number of people were asking about WS as they purchased their tickets.



Christmas crafts for WSUK

The 85 year old great uncle of one of our WS teens has been busy crafting again, making wooden models for Christmas which he then sold at a craft fair raising £150 for WSUK. Thank you for doing this once again for us.

Do any of our community or a family member have a craft that you could use to make and sell to raise funds at craft fairs? Why not ask them? Craft fairs will quite often give a table for free or a reduced rate if you are selling to raise funds for charity.

Charity Football returns

4th April sees the first of the charity Football events organised by FJN Solutions in Horsham. We look forward to updating you with the amount raised in the next newsletter as well as via social media.

50km Coastline Ultra Marathon!

On March 22nd 2025, Alice Hurt will be taking on a 50km ultra-marathon to raise money for Wolfram Syndrome UK. She will be running from her family home, down the Lancashire Coastline from Fleetwood to Lytham, before finishing at Stanley Park.

Her sister Charlotte is affected by WS and will be running the last few Kms with Alice to spur her on to the finish line. Alice has also managed to persuade her parents and some friends to run parts of the course with her.

Alice has previously run in the 2023 Leicester half marathon raising £935 for WSUK. Her aim for this event is £1000 for which she is already well on her way. At the time of writing, Alice's total raised was **£625**.

If you, family or friends would like to help Alice reach her target please go to her GoFund Me page [here](#).
Thank you



HYROX Competition

Katie Lynch, niece of co-founders Paul and Tracy, is taking part in her first ever HYROX at Wembley on 5th May.

[HYROX](#) combines both running & functional workout stations, where participants run 1km, followed by 1 functional workout station, repeated eight times. Accommodating both professional athletes, and everyday fitness enthusiasts looking to take their training to the next level, HYROX is the sport for everybody.

Katie has chosen to raise funds for WSUK as she has seen how her cousin, Jennifer, has been affected by the condition since her diagnosis in 2010.

If you or any family and friends would like to support Katie in this challenge then please click here to [donate](#). At the time of writing, Katie's total raised was **£320**.

Annual Charity Golf Day

This is returning for its 12th year on Friday 18th July. We will update you with amount raised in the Autumn newsletter and on our social media pages.

Continued Support!

Thank you to all 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. By donating this way, we get the full amount of your donation without losing any funds from "processing charges" from the online giving platforms.

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 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). If you can Gift Aid this increases your donation to us.

Why not get involved with fundraising for WSUK?

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, or you take part in an event to raise funds please let us know in the WSUK office and we can share it on our social media pages and the newsletter.

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**, unlike many of the other fundraising platforms, including normal PayPal. 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 to purchase; all raising funds for WSUK. You can access the shop page [here](#).

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. (At the end of each month they usually offer free UK P&P as well.)

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 you could look to see 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 Summer newsletter is **27th May**.

WSUK Co-Founders become first time grandparents

Tracy and Paul became grandparents on 14th January when their eldest son and his partner welcomed their first born to the world. Baby Noah

arrived safely weighing 9lb 5oz.



More than you can imagine: an anthology of rare experiences

Congratulations to one of our young adults, Evie West, from the WS community on having a written piece of work included in the 'Anthology of Rare Experiences', produced by Genetic Alliance UK for Rare Disease Day. This was published yesterday, 28th February. You can see this publication by clicking [here](#).

As mentioned in her update, Phillippa, our ASC, has also had a song she and her partner wrote accepted and published in the anthology.

Congratulations to them both!

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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