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Welcome to the Winter Newsletter.

The last few months have been busy here at Wolfram Syndrome UK. We have employed 3 new members of staff to work alongside Tracy.

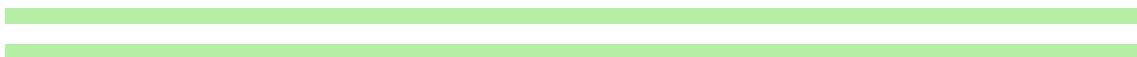
You can read about them further on in this newsletter.

There is also some information that may be helpful during the current times we are all experiencing with rising costs on food and fuel.

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.

Stay safe and happy holidays!

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 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



Thank you to everyone who joined us at our first face to face conference since 2019. Thanks go to our speakers and a big thank you to the WSUK team of Trustees, volunteers and new employees who had to step in at the last minute,

quite literally, to take over the running of the day.

Next year conference will be 29th September to 1st October 2023 and we will be at a new venue, Mercure Daventry Court Hotel. Invites to our WS clinicians and potential speakers have been sent out. Further details will be sent out in the New Year.

UK Clinical Trial Updates



Update from Prof Tim Barrett

Dear friends and colleagues,

I hope everyone is keeping OK and warm in these challenging times. Our hospital research teams remain busy seeing people taking part in the TREATWOLFRAM clinical trial, and we are well on the way to completing the study. As some of you may know, we have had to change supplier of the medicine and placebo, and this is causing an interruption in supply for some participants. We are very sorry about this, but are having weekly meetings with the supplier, and have been assured that new packs of medicine and placebo will be distributed end November/beginning of December.

Several of us attended the face-to-face Wolfram syndrome UK conference in Whittlebury Hall in October, and really enjoyed meeting families.....
Read in full on our [website here](#).

USA Trials and Research Updates

I hope you are well. I always feel your continued support and faith in me, which I appreciate. Here are my updates. We are making steady progress.

Upcoming clinical trial

We all know that we need novel treatments and therapeutic modalities for Wolfram syndrome, including oral and injectable medications. One of my strategies is to target the upstream disease mechanism and delay the progression of symptoms related to Wolfram syndrome, including optic nerve atrophy, neurodegeneration, and diabetes, using oral medication. I have been focusing on developing a new oral medication, AMX0035, to treat Wolfram syndrome in collaboration with Amylyx Pharmaceuticals in Cambridge, Massachusetts. AMX0035 targets endoplasmic reticulum stress and mitochondrial dysfunction Read full article on WSUK website [here](#)



Additions to the WSUK Team

At the end of the summer, we have had some new members of staff join WSUK to assist with the work we do to support our community. Below you will find an introduction from each of them.

Gina Isherwood - PhD - Contracts Manager

Hi, I'm Gina Isherwood, the new Contracts Manager at WSUK. I've been part of the WSUK team since Jan 2019 working initially as a consultant in the role of Grants Coordinator. My focus at that time was to secure grant funding

from external providers (such as the National Lottery Community Fund) and to manage these projects to help WSUK expand the services and support that we provide to the WS community (such as the Wellbeing packs during the COVID pandemic). You may have met or spoken to me if you were part of our Breaking Down Barriers project or attended the WS Conference in 2019 (Unfortunately I missed the 2022 conference due to testing positive for COVID!)

As the Contract Manager, I'm now fully a part of the WSUK team, working 2 days per week, typically across 4 mornings. My role still includes grant funding and projects but has expanded to include managing the new contract that WSUK has recently been awarded by Birmingham Children's Hospital (BCH) and our new Support Co-ordination team. Through the BCH contract, WSUK has been able to employ a Family Support Co-ordinator, Georgina King, who will be at the WS clinics at BCH to assist families and provide broader on-going support outside of

these clinics. In addition, we have our new Adult Support Co-ordinator, Phillippa Farrant, who will provide additional support to WS affected adults, which includes the Emotional Wellbeing for WS affected adult's project.

Although I won't be in regular contact with you, I will be busy working behind the scenes to help ensure that our team can deliver the very best support and that as a charity we offer services that help you to manage the many challenges that WS can bring.

Gina

Georgina King - Family Support Co-Ordinator

Hi, my name is Georgina King, and I am the new Family Support Co-ordinator for Wolfram Syndrome UK. I have three children, two of which are autistic and my eldest suffers from a skin condition that affects his daily life. Because of my personal experiences that come from

having children with complex medical conditions, I understand the challenges facing the families that I am supporting at WSUK.

I have previously supported families in many roles, from volunteering to family support; working for the NHS as part of Royal Derby's Children's Hospital to being a mentor for vulnerable young people who are at risk. I have a passion for working within communities and strengthening them. I will utilise my expertise to make a difference to the Wolfram Syndrome community.

As the family support coordinator, I will be supporting children, young people and their families affected by Wolfram Syndrome to ensure they feel fully supported by the professionals working with them. So far in my role I have actively supported families with food bank referrals, occupational health referrals, referrals to other local charities to receive support locally and supported families with

claiming expenses from Birmingham Children's Hospital (BCH). I am also in the process of transitioning two families to the WS adult services at Queen Elizabeth Hospital (QEH) via the transition clinics and pathway. I work very closely with the teams both at BCH and QEH and will be attending the WS clinics at BCH and transition clinics at QEH to support you.

Please feel free to contact me on georginaking@wolframsyndrome.co.uk my phone number is 07592 629813. I will be working 25hrs a week, Monday to Friday. If you contact me and I'm not available, please leave me a message and I will get back to you as soon as I can.

I'm really looking forward to getting to know you all.

Georgina.

Phillippa Farrant - Adult Support Co-Ordinator

My name is Phillipa, I live in Eastbourne and I am 56 years old. I was recently appointed Adult Support Coordinator for Wolfram Syndrome UK, a role I am really enjoying already.

I have for the past 25 years, worked in the charity sector and specifically with rare diseases, running a small charity supporting families with Duchenne Muscular Dystrophy, which is a life limiting muscle wasting disease. This mainly affects boys and means that by adulthood, they are generally wheelchair bound and needing lots of interventions including ventilators to help with their breathing and PEG's to help with feeding.

I am currently learning more about Wolfram Syndrome and the range of issues that can affect families. I am also enjoying beginning to get to know some of you and look forward to meeting more of you and helping when and

where I can.

I will be working mainly Mon, Tues, Thursday and Friday mornings, however within that there will be some flexibility, and so with the help of the team I will be able to answer your queries as soon as I can if I am not in the office.

I am currently arranging 1:1 and group sessions for the Emotional Wellbeing Project for WS affected adults, which some of you are involved in, so if you haven't yet heard from me I will be getting in touch with you soon. If you are not currently involved but would like to know more, please get in touch with me:

phillippafarrant@wolframsyndrome.co.uk or you can call 07752 193635

If you have any suggestions on how I could best support you or the broader WS adult community, please get in touch.

Having met some of you at the conference and

seen and heard about the great work happening globally, here in the UK, and the work at WSUK, I am very excited to be part of the WSUK community.

Best wishes to you and your families,

Phillippa

News You Can Use

Mental Health

Here are some links that may prove useful that were also mentioned at this year's conference.

- www.youngminds.org.uk
- <https://www.nhs.uk/every-mind-matters>
- www.mind.org.uk

There are also some helpful links and information to be found on the [Our Projects](#) Page under the Emotional Wellbeing Project heading, in the online version of the [WSUK handbook](#) to be found under the 'Our Services' heading and also listed amongst the [Helpful Organisations](#) found under the 'Resources and Helpful Links' heading, all on the [Wolfram Syndrome UK](#) website.

Diabetes Information

Dr Dias shared some information from conference that some of our community may be interested in learning more about.

- [Diabetes UK](#) - Information on Pumps and AIDS:
- [Dexcom](#): Continuous Glucose Monitoring Systems.

10 Ways to Beat Rising Energy and Food Bills

Grants and benefits available to help get you through the winter. (Information taken from issue 117 November 2022 Motability Lifestyle magazine.)

1. British Gas Energy Trust - offers grants up to £1500 to anyone in energy debt - not just its customers - to support families and individuals who are struggling to pay their bill. You need to be spending more than ten per cent of your income on energy, which is quite likely to be the case. For more details go to britishgasenergytrust.org.uk.

2. Charis Grants - Runs charitable funds on behalf of many major energy providers, including

E.ON and EDF. Their schemes provide financial assistance towards paying for bills and essential household items.

For more details got to charisgrants.com

3. Warm Home Discount Scheme - you could get £150 off your electricity bill, or £150 added to your pre-payment meter. The scheme is changing for 2022/23 and reopened in November. The Government website will be updated with details of who is eligible. Or, you can check your energy supplier's website. For more information gov.uk/the-warm-home-discount-scheme.

4. Food Banks - get a minimum of 3 days' emergency food and additional support. Food banks work with professionals, such as social workers, to issue vouchers. If you need help

getting food home, ask the food bank about deliveries. Trussell Trust has the largest network nationwide.

For more details trusselltrust.org/get-help

5. Local Authority help - your local council could help with energy and food bills through welfare assistance schemes, also known as 'crisis support'. You just need to ask. Many schemes provide support with utility bills, petrol and food as well. Also, ask about their crisis fund, emergency supermarket vouchers and emergency payments.

Find your local council on: gov.uk/find-local-council.

6. Membership Food Clubs - often called social supermarkets, membership food clubs offer reduced price products for a small charge. You'll

usually have the choice of getting shopping worth many times your contribution but availability may limit the choice. [Local Pantry](#) has 70 shops around the UK.

For more details go

to yourlocalpantry.co.uk/pantry-listings/ or ask [Citizens Advice](#) for more information.

7. OLIO app - it connects you with neighbours and businesses looking to share surplus food. OLIO says it has over 1.2 million users across the UK. many items on the app come from people emptying out their store cupboards and donations from supermarkets, cafes, bakeries and shops.

For more information olioex.com.

8. Energy improvements - ECO is the main scheme for supporting energy efficiency

improvements for disabled people. It's funded by energy suppliers and installs energy improvements and reduces bills for households in need. You may qualify if you claim certain benefits. Offers mainly are for cavity wall and loft insulation, but they may replace a boiler.

For more details ukenergysupport.co.uk/eco4-scheme.

9. Zero-interest Loans - supermarket Iceland is part of a scheme to offer zero-interest loans of up to £100 to buy everyday groceries. The Iceland Food Club is a link-up between the chain and a charity owned lender, Fair For You. The funds are available on preloaded cards with repayments set at £10 a week. Anyone can apply for the scheme and you can use the card in-store or on the Iceland website.

For more information fairforyou.co.uk/food-club

[card](#)

10. Charity Help - here are some examples of the many charitable trusts that can help disabled people with small one-off grants and fund household essentials:

- [The Florence Nightingale Aid in Sickness Trust](#) - provides grants to people with medical conditions, disability, or poor health.
- [The Glasspool Trust](#) - issues small one-off grants to individuals in need on a low income.
- [Heinz, Anna and Carol Kroch Foundation](#) - provides £100 to £500 grants for individuals suffering from on-going medical conditions.
- [Linking Help with Hope](#) - offers grants for household items if you have certain health conditions.

- [The National Benevolent Charity](#) - makes grants to help with household items and supplies vouchers for goods and services.

All details on [Turn2us](#) website - grants-search

Disability Grants News

Here are a few highlights from the [Disability Grants](#) website and resources for anyone with a disability, caring for or working with disabled adults or children.

If you are new to the website and searching for grants please read the following pages before starting your search....

Adults- [About Grants](#) section

Children and Young People - [Grants for Disabled Children - An Introduction](#)

Here are some of this month's updates and additions. More can be found on their [website](#)....

Cost of Living Grants

For Individuals check out our pages **“Grants for Household Items”** and **“Energy Grants”** for grants towards essential items and energy support.

Grant News

National

- The Family Fund support disabled and seriously ill young people aged 18-24 years living at home through their **“Your Opportunity” Fund**.
- **Inclusion Grants** for deaf children and young people aged 5 – 18 years to be

involved in events and activities. The grant is for up to £150 from the National Deaf Children's Society.

- Register your interest for 2023 accessible holidays for people with complex disabilities. **The Sense Holidays** are for adults and children. Each holidaymaker will be expected to pay £800 out a total cost of £2,500. Sense also offers short breaks.
- **Ambitious about Autism** connects and supports young people with Autism aged 16 to 25 years with an EHC Plan with an online community and supported internships.

Resources

- **Sight loss toolkit** providing advice for people with sight loss and healthcare professionals.

- New Easy Read Guides: - **Help with the Cost of Living Guide** and [Employment Support Allowance](#).
- From Contact – **Universal Credit for disabled students** – what parents can do when their child is 16.

WS Clinics

Clinic Dates 2023

WS clinics have returned to face 2 face but in some situations can still be done virtually.

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

27th January 2023 TBC

March

May

July

September

November

Dates are still to be confirmed and will be added to our [events page](#) when they are received.



If you are no longer able to attend the date you are invited to, **PLEASE** let the clinic team or [Tracy](#) know so that someone else can be invited

in your place. There is always someone ready to take a slot if you can't.

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:

9th - 10th January 2023

6th - 7th March 2023

5th - 6th June 2023

2nd - 3rd October 2023



If you or your child would like to be seen for either clinic, please contact our Family Support Co-ordinator, [Georgina](#) or [Tracy](#). We can't guarantee you will be seen straight away but will let it be known.

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.

If you are unable to attend then **PLEASE** let Georgina, Tracy or the hospital know 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.

We have recently added a '[Who's who at the WS Clinic](#)' page to the website, as it was thought this would be helpful to our newer diagnosed individuals and families who are attending a clinic for the first time or our Young Adults who are transitioning across to adult services. It isn't complete yet but is being updated as information is received from the different clinicians.

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.



Continued Support!

Thank you to those members of the WS community and their friends 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 that can be printed off and sent back to us).

Charity Golf Day

We have received the sum of **£2000** from Adler Shine, following their Corporate Golf Day held in September. The father of one of our WS teenagers works for the company, so thank you for putting us forward as a beneficiary.

Charity Month

G & K Heating in Hove, East Sussex supported us during the month of August by donating £1 to every invoice they issued during the month. We received **£177.00** from them. Thank you.



Manchester Half Marathon

The colleague of one our father's ran the

Manchester Half Marathon in October for WSUK.

He raised **£120.00**.

Thank you for supporting us this way



Family Fundraising

One of our families, whose son was diagnosed earlier this year, have kindly made a donation to WSUK in the last month of **£1250**. We thank them so much for this generous donation.

Project Updates

Emotional WellBeing Project

Some of you signed up to participate in the WS affected adults Emotional Wellbeing Project earlier this year, which I will now be leading as part of my role as the new Adult Support Co-ordinator for WSUK. This project is all centred

around our emotional wellbeing, and how we can help support ourselves and each other in various ways.

I will be running some one-to-one support sessions, with each WS affected adult participating in the project and also some group sessions with lots of discussion for those of you looking to connect with others within the community I will soon be getting in touch with participants to arrange our first session and to ask you to complete a Wellbeing questionnaire, if you haven't yet done so.

If you are new to Wolfram Syndrome UK, and haven't heard about the project and would like to know more then please contact me and have a look at the project page on the WSUK [website](#)

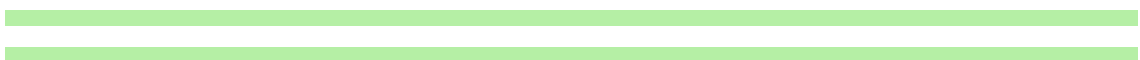
for tools that may help and for regular updates on the project.

This project is aiming to be user led, and for the benefit of our community so all ideas and thoughts are welcome.

My email address is

phillippafarrant@wolfram.syndrome.co.uk, and I

mainly work Mon, Tuesday, Thursday and Friday mornings.



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](https://paypal.com/gb/fundraiser/charity/76200)

WSUK Charity Christmas cards

All our charity Christmas cards have sold out this year. We will have more stock with new designs in next year.

Other Ways to Support WSUK

Why not get involved with fundraising for WSUK?

There are many ways to get involved with fundraising. Some are very simple and easy to organise. Why not try thinking outside of the box?

You could host a virtual quiz, try a virtual sing along, or have a virtual Big Night In and donate what you would have spent on going out to charity?

If you are working from home why not donate the cost of one day's commute to us each month. We appreciate that times are hard for everyone but whatever you can do to help fundraise will be greatly appreciated by us all.

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](#).

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 shopping online count!



Give as you Live®

easyfundraising
feel good shopping

Raise free funds for us
every time you **shop online**

Find out more

amazon.co.uk John Lewis ebay M&S Boden GAP
Argos Booking.com DEBENHAMS next SCREWFIX
Sainsbury's ASOS Viking moonpig JUST EAT

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.

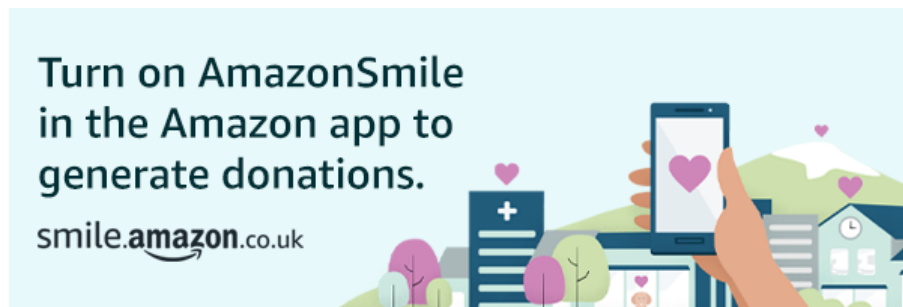
Links to register can be found [here](#); or you can click on the relevant image above to be taken straight through to the registration page. Install the reminder link so you will be asked if you want to raise a donation when you go straight to the retailer's website, so you don't need to worry about forgetting. Simple!

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

Amazon Smile

AmazonSmile customers can now support Wolfram Syndrome UK in the Amazon shopping app on iPhones and Android phones!

If you do not have the latest version of the Amazon Shopping app, update your app. Click [here](#) for instructions.



EasyPhotobook

Does a family member or a close friend have a special birthday this year? Are you struggling to think of a present for them? Why not create a beautiful photo book, sharing those special moments we all take for granted, especially after the last couple of years we have all had? You can help to raise funds for WSUK by creating and sharing a beautiful photo book for that special person.

It's so simple to support us, just click the [link](#) to go to the [website](#) and create your beautiful A4 glossy perfect bound 30-50 page photo book for just **£18.99** with **NO** postage to pay, even internationally, use the code on the page and we will receive **50%** of the proceeds to fund our work and keep those affected by WS, at the centre of everything we aim to do.

Remember, your book can be of any memories you wish, a holiday, family and friends, or create one as a wonderful gift. For more information or to place an order go to the website [here](#).



Raise funds by collecting used stamps

You can all help to raise funds for us simply by collecting stamps from your mail. Ask friends,

family and work to collect for you. They need to be left on the backing paper with a small border left around the stamp. Save them up until you have a good quantity in weight to post off.

For more details as well as details of where to send them go to the WSUK website [here](#)



Your News

Please send in anything you would like to share with the WS community. The deadline for sending to be included in the Spring newsletter is 2nd February 2023.

Open University Degree for Georgina Carolan

After five and a half years of study with the Open University, on 25th October 2022 Georgina got her results for her degree. For her dissertation on optic atrophy in WS, she got 81%. For her degree she earned a 2:1 BSc in Health Sciences.

Well done, Georgina!!

Read Georgina's dissertation by clicking [here](#).



Congratulations!!

Congratulations to Eric & Helen. They have decided, after many years together, to 'tie the knot'. They have set the date of 6th April and will get married at a hotel by the shores of Loch Earn

in Stirlingshire, which is a favourite spot of theirs.

They have decided to ask their guests to make donations to WSUK in lieu of gifts, which we thank them for doing. The link to their page should anyone wish to make a donation to celebrate their marriage is [Wonderful.org | Eric and Helen's Wedding](https://www.wonderful.org/eric-and-helen-wedding)

We will look forward to seeing them as Mr and Mrs at conference next year.

Birthdays (UK and worldwide)



Happy birthday to everyone that has a birthday to celebrate during December, January and February.

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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