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Welcome to the Spring Newsletter.

Lighter evenings and longer days are around the corner, hopefully with some better weather than the start of the year!

We are busy with the final preparations for the 8th WS International Symposium, to be held this year in the UK, for overseas researchers to come together and share their work. We are also working on the programme for our annual WS family conference later this year. You can read more below.

Georgina, Family Support, attended her first clinic, in post, in January and is looking forward to meeting more of you

at future clinics. Phillippa, Adult Support, has re-started the Emotional Wellbeing Project, which you can read about further in the newsletter. So, everything is busy here with us.

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



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

International WS Symposium

This year WSUK are collaborating with The Snow Foundation to host the International Symposium for Doctors and Researchers working in the field of WS to try to find treatments and cures.

The seven previous symposiums have been organised by the French WS Association and held in France, but this year will be held in the UK. We hope to hear about some interesting research and results which we hope to be able to share with you at some point in the future.

WS Conference



This year's conference is 29th September to 1st October 2023 and we will be at a new venue, Mercure Daventry Court Hotel. Invites and booking forms were sent out to our community in January but can also be found on the conference page of our [website](#).

Apart from the cost of triple rooms we have managed to keep the others the same price as previously. Please book your room as soon as possible. Information about conference will be updated regularly on the website.

UK Clinical Trial Updates



Update from Prof Tim Barrett

Dear friends and colleagues and participants in the TREATWOLFRAM clinical trial,

I hope everyone is keeping OK. As some of you may know, we had to change supplier of the medicine and placebo, and this caused an interruption in supply for some participants. I am relieved to say that participating centres were resupplied with medicines in December, and everyone who is still being followed up in the trial should have restarted their medicine.

I was so pleased to see some young people face to face in clinic and for study...Read in full on our website [here](#)

USA Trials and Research Updates

Dear Friends in the UK,

As spring approaches, I wanted to take a moment to thank you for your continued support and faith in me. Your encouragement has meant so much, and I am truly grateful for it. I would like to provide you with a quick update on my progress. I am happy to report that we are making steady strides and moving in the right direction.

Upcoming clinical trial

There is a pressing need for new treatments and

therapeutic modalities for Wolfram syndrome, including oral and injectable medications. One promising strategy is to target the upstream disease mechanisms and delay the ...Read full article on WSUK website [here](#)

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 Support Page

If you are on Facebook, are you aware that there is a [Wolfram Syndrome Global Support group](#) page?

This is a private page purely for those affected and their family members. You can either be invited to join or you have to request to join. It is a good place to ask questions with others that can understand what you are coping with or may have dealt with an issue you are trying to deal with at the moment

Hybrid closed loop system for Type 1 Diabetes

NICE (National Institute of Clinical Excellence) on 10th January 2023 released draft guidance recommending the use of hybrid [closed-loop systems](#) for some people with type 1 diabetes in England and Wales.

These recommendations are a significant step towards making this technology available on the NHS. If this proposal is approved in the consultation process – it would mean over time around 100,000 people with type 1 diabetes could be offered it as an option to help manage their condition. You can read the full article on the Diabetes UK website [here](#).

This article does come with some comments from both our adult and children's teams to bear in mind before approaching them about this system:

Dr Sofia Salahuddin - Diabetes Consultant at QEH

"I would fully support closed loop in Wolframs , we have 1 patient already using. I am initiating in our local patients."

Dr Renuka Dias - Diabetes Consultant at BCH

"I think closed loops as a system should be publicised to the WS community although the caveat with that is that we are not in position to offer this without funding. However, the NHSE HSS team were impressed with the improvements in

HbA1c with CGM. I am hoping to write a short report on the outcomes of our Dexcom data and HbA1c in conjunction with Prof Tim Barrett.

Support for taking Assistance Dogs on trains.

(Taken from Motability Lifestyle Magazine Issue 118. Feb 2023)

If you or a member of your family rely on an assistance dog to go out and about, you should find train travel easier thanks to a new scheme from train companies, which provides a laminated reusable 'Assistance dog under the seat' card. The card explains to other passengers why an assistance dog needs to sit under an unoccupied seat and has been tested with charity Assistance Dogs UK.

Through the scheme, people who use wheelchairs will also be able to reserve space for their assistance dog around their wheelchair.

To get an Assistance Dog Under Seat Card email customer.relations@nationalrail.co.uk

Assistance Dog Statistics at a glance:

More than **7,000 people** rely on assistance dogs.

It costs Support Dogs **approx. £36,000** to train and support a dog throughout its working life.

Diabetes alert dogs alerted their owners to **83% of low blood sugar episodes**, according to a 2019 study.

It takes **20-24 months** to train a disability assistance dog.

Help with Mobile Phone and Broadband costs

(Taken from Motability Lifestyle Magazine Issue 118. Feb 2023)

Are you finding it hard to afford your mobile phone or broadband? Social tariffs could possibly help. They are cheaper broadband and phone packages for people claiming Universal Credit, Pension Credit and some other benefits.

Ofcom (the regulator for communications services) is encouraging more companies to offer social tariffs to help customers on low incomes. Most tariffs offer superfast broadband. If your provider offers a social tariff, you can switch to it at any time, free of charge and the price won't go up mid-contract.

Visit [ofcom.org.uk](https://www.ofcom.org.uk) for more information.

Children's books shine a light on blindness

(Taken from Motability Lifestyle Magazine Issue 118. Feb 2023)

A new children's book, *Better Places: Nicky and Candy's Street*, by Ben Andrews and illustrated by Charlotte Jenkins, shows how small things can become big barriers for blind or partially sighted people. It follows the story of Nicky, who has a white cane named Candy and asks readers to think of ways to make the street more accessible. The book was published on 23rd February.

Ben, a disability rights advocate, is registered blind and is writing further *Better Places* books, featuring a young wheelchair user and a girl with autism.

Another inspirational author is nine-year-old Betsy Griffin who is registered blind from a rare brain tumour. She has written her first book, *'Out of The Woods': A tale of positivity, kindness and courage*, with illustrations by Emanuel Santos. It is also available in Braille.

Great Savings to get you out and about this Spring and Summer.

(Taken from Motability Lifestyle Magazine Issue 118. Feb 2023)

1. Free Bus Travel - Bus passes for disabled people are issued by your local council and can be used anywhere in the country. You can travel at any time weekends and Bank Holidays and

from 9:30am to 11:00pm on other days. Some local authorities extend the pass to selected free train services. If you are unable to travel by yourself you can also apply for a companion pass so that person can travel for free with you.

For more information got to - [gov.uk/apply-for-disabled-bus-pass](https://www.gov.uk/apply-for-disabled-bus-pass).

Scotland: mygov.scot/disabled-bus-pass

Wales: [gov.wales/apply-bus-pass](https://www.gov.wales/apply-bus-pass)

Northern Ireland: nidirect.gov.uk.

2. Train takes the strain - If you are more of a train user, then disabled people are eligible for a Disabled Person's Railcard for £20, which gives you a third off train travel for you and an adult companion. Over a year you could save an average of £91 on tickets. You could save more with a three-year-railcard for £54. If you register the card online you'll get a third off a London Oyster card. For more information disabledpersons-railcard.co.uk.

3. Max savings for families - Available to families of children with additional needs, the Max card can be used at venues across the UK such as Legoland, castles, zoos, trampoline parks and bowling alleys to get free or discounted admission. Cards are available from local authorities and selected charities. For information about the Max card - <https://mymaxcard.co.uk/>

4. Take in a show - Many British theatres offer discounted tickets for disabled people with a carer getting in for free. See theatre websites for further details.

The [Society of London Theatres](#) run Access Schemes for disabled people for shows in the capital with details on its website, including discounted tickets. Shows often hold special matinees or performances for people with learning disabilities, as well as specific audio described performances, often at a discounted rate. officiallondontheatre.co.uk/access for further details.

5. A trip to the movies - The well-established CEA Card entitles you to one free cinema ticket for someone to accompany you. You'll have to purchase a full price ticket to get the free one. Approximately 90% of cinemas accept the card. Ceacard.co.uk.

6. Covered when you travel - The UK Global Health Insurance Card (GHIC) lets you get medically necessary state healthcare, including for existing conditions, in the EU at a reduced cost or sometimes for free. If you have a European Health Insurance Card (EHIC) it will be valid until the expiry date on the card. Note that the GHIC and EHIC do not replace specialist disabled travel insurance. You cannot use the cards in Norway, Iceland or Lichtenstein. The card is free but do be careful - some websites charge to help you apply; don't use them. nhs.uk/using-the-nhs/healthcare-abroad.

For help in finding travel insurance see: [Money Helper](#). (This site is a suggestion; we don't advocate any one site or company to be used apart from official sites like NHS or Gov.UK.)

7. Travel back through time - Both the National Trust and English Heritage offer free entrance to carers who accompany disabled visitors. The National Trust's Essential Companion card makes it simple to bring one or two carers or companions with you, free of charge.

English Heritage will supply a letter of authority for free access for carers. If you're not a National Trust or English Heritage member, you will need to pay for your own entry. For further details on these schemes and membership - [National Trust](#) and [English Heritage](#).

Experiences for Children and Young Adults with VICTA

VICTA provides extensive opportunities throughout the year for children and young adults to take part in activities and short breaks around the UK. Please check out the [activity calendar](#) on their website for full details of activities currently open for application.



Over The Wall - a serious fun camp

Experience the mischief and magic of Over The Wall's free and transformative activity camps.

Over The Wall help children and young people reach beyond the boundaries of their health challenge. They offer both residential camps and Camp in the Cloud, which is their camp-at-home experience. All of their services enable their campers to build confidence by trying new things, creating friends, having fun and making lifelong memories!

To find out more go to their website [here](#). To see the dates of their camps for 2023 click [here](#).

For more recreation and holiday ideas have a look at the Recreation page on the WSUK website [here](#).

Looking for the post 16 options?

The Royal National College for the Blind (RNC) is holding an open day Friday 24th March 2023 please see website for more information [News \(rnc.ac.uk\)](https://www.rnc.ac.uk/news)

Sense College in Loughborough is holding an open day on Saturday 20th May 2023 for more information [Open Day - Sense](#)

New College Worcester has a number of activity days. Please use the links to book with the college directly.

[Summer Activity Break - New College Worcester \(ncw.co.uk\)](#)

[Family Day May 2023 - New College Worcester \(ncw.co.uk\)](#)

[Outreach Open Day - New College Worcester \(ncw.co.uk\)](#)

Royal Society for Blind Children

The Royal Society of blind children has an activity calendar and access to assistive technologies please

email: connections@rsbc.org.uk

Activity calendar: [Calendar of Activities - RSBC](#)

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:

24th March

26th May

21st July

22nd September

24th November



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:

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 Football Match

FJN Recruitment Solutions in Horsham, West Sussex are once again organising their Charity Football Match, 31st March, for which we will be a beneficiary. We thank them for supporting us in this way.



80's Night

Our popular 80's night with Synthony 101 and DiscoKings is back once again on Saturday 1st April.

For those that are local, in the area tickets are £16.50 each (inc handling fee by provider) and can be purchased online [here](#). It is always a great night.



Charity Golf Day

Our charity golf day is back for its 10th year. Once again sponsored by Penfold Verrall and Northern Commercials

Limited, invited teams of golfers will play at Mannings Heath on Friday 28th July.

We are sure it will be another fantastic day of golf and fundraising alongside the awareness it raises with any new players.

Awareness days for your calendar 2023

You might like to know about some of the awareness days being held. Some of the organisations sometimes have events around these days that you can be involved in.

- World Hearing Day – 3rd March
 - Autism Awareness Week – March 28th - 3rd April
 - World Autism Awareness Day – 2nd April
 - DeafBlind Awareness week – 27th June - 3rd July
 - National Carers Week (UK only) – 6th - 12th June
 - Wolfram Syndrome Global Awareness Day – 1st October
 - World Diabetes Day – 14th November
 - Hidden Disabilities Day – 3rd December
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Support Co-ordinator's Updates

Family Support Co-ordinator

Hello everyone, if you haven't already met/know me, I am Georgina King the new Family Support Co-ordinator for WSUK.

I started this role in August last year and since October, I have supported 11 families in the WS clinics at Birmingham Children's Hospital (BCH). I have helped with securing hotel accommodation for our families and reclaiming their travel and meal expenses so you can have the best clinic experience possible. In preparation for the clinic, I contact each family to confirm their attendance and assess their needs. This includes what will they need to come to clinic and how I can support them best. All our families are individual therefore have individual needs. You can count on me to respect this and do my utmost to support your family during clinic.

Outside of clinic, I have supported families with EHCP referrals, OT referrals, and referrals to sensory services. I also work with their local community to ensure that effective support is being provided at a local level. Please get in touch if you feel I can speak on your behalf or support your family with anything in your local community.

In this newsletter, you will see included in the 'News You Can Use' ,some upcoming events and news for children, young

people and their families. Some of this information will soon be added to the new Family Support Coordinator webpage on the WSUK website. This new page will also include information on inspirational people (e.g., Molly Burke a VI YouTube content creator). I hope you will enjoy learning about people who have overcome challenges with their disabilities to be recognised as inspirational in society and their community. Please let me know if you want me to feature your favourite star!

The March clinic is just one week away, I look forward to seeing the families who are attending.

Best wishes,

Georgina King

Family Support Coordinator, WSUK

07592629813

Georginaking@wolframsyndrome.co.uk

I work part-time on Monday, Wednesday, Thursday and Friday.

Adult Support Co-ordinator

Hi everyone, if you haven't already met/know me, I am Phillippa Farrant the new Adult Support Co-ordinator for WSUK.

Emotional Wellbeing Project – 1:1 and group sessions

I am pleased to say that I am making progress with the Emotional Wellbeing Project, which has been set-up by WSUK to help support WS affected adults to improve their emotional wellbeing. I am enjoying talking to members in our adult community, getting to know some of you and being able to put some support in place to help your emotional wellbeing.

If are not yet involved but would like to have regular 1:1s with me, I currently have some capacity. Please reach out to me via phillippafarrant@wolframsyndrome.co.uk or 07752193635. I will be happy to talk through what it involves and how I might be able to help you. (Suffice to say there are no lengthy in-depth counselling sessions!). We can connect via zoom, phone or whichever platform works best for you.

In addition to 1:1 support, I will be starting some group sessions very soon. Each group will include a small number of WS affected adults who will connect on a regular basis. Each session will have a theme for the group to discuss and run with in the direction that suits them best, with a little guidance from me. Again, if you would like to be involved or know more, please do contact me.



Social events

- Poll to gather your views

I will soon be emailing a short poll to all WS affected adults to gather your thoughts on the type(s) of on-line social event(s) that you may like to participate in. I am open to your suggestions and am happy to be guided by the community.

- WS Conference social event – Friday 29th September

I am also planning to run an informal social event on the Friday evening of the WS conference weekend, which will be open to all members of the WS community who are staying at the venue. My initial thoughts include bingo, beetle drive, or quiz, but have yet to make a final decision. Your ideas are very welcome!

Braille – are you using Braille?

I will be starting to learn some basic Braille soon, so it would be helpful for me to understand how many of you currently use Braille and whether it works well for you or not. If you are using Braille, please get in touch, so we can arrange some time to connect on your experiences.

Need on-going support – get in touch!

I am available to support the WS adult community on any subject that you may be struggling with, emotionally, mentally and / or physically, so please just ask.

I look forward to getting to know more of you over the coming months.

Best wishes,

Phillippa

Adult Support Co-ordinator, WSUK

phillippafarrant@wolframsyndrome.co.uk

M: 07752193635

I generally work Monday, Tuesday, Thursday and Friday mornings but am happy to be flexible wherever possible.

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

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 online shopping count!



Give as you Live®

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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 OSOS 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 has closed!

After 10 years of supporting thousands of charities including WSUK, AmazonSmile closed on 20th February.

You can still earn cashback to support WSUK by signing up to [Give As You Live](#) and [EasyFundraising](#), accepted at thousands of retailers.

Whenever you make a purchase - doing your weekly shop, booking a holiday or booking your train tickets – the retailer will send WSUK a free donation without any additional costs to you.

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 Summer newsletter is 22nd May 2023.

King Charles III's visit to Royal National College, Hereford

King Charles III visited the RNC, Hereford to celebrate their 150th anniversary in December. One of our young adults River is a student there and got to meet the King and give him a demonstration of using a Brailier. You can see the news coverage on our website [here](#)



Congratulations!!

Congratulations to Eric & Helen who are getting married on 6th April

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 later in the year.

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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