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Welcome to the Winter Newsletter.

Well, the weather has finally decided to turn colder and more in keeping for this time of year, although I'm still wearing shorts when out walking my dog.

This newsletter has some articles that I hope will be useful following on from the First Aid training session run at conference, as well as lots more news about what you have been doing and how you can get involved.

At this time of year, we all tend to reflect on the year and the year ahead. I would just like to take this opportunity to thank my team and the Trustees for all the work they have done this year. I would also like to thank those from the WS community who have supported me through a tough few months when my daughter Jennifer was in hospital earlier this year. Support like that really helps when you need it, so thank you.

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.

The WSUK office will be closed from 12.00pm on Thursday 21st December and will re-open 9.00am Tuesday 2nd January 2024. Any emails or phone messages received during this time will be responded to when we are back in the office.

Take care 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 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



It was great to see so many of our community at this year's WS conference. We had a few new families attend as well, and it was great to see them getting involved and meeting others from our community.

Thank you to all the Medical Professionals from the children's and adult clinics for coming along to take part in workshops and to chat with delegates. Thank you to Dr Fumi Urano for travelling over from USA and to Prof Patrick Yu Wai Man and Prof Tim Barrett for their presentations.

We had a new speaker this year, Beth Marshall who is a Qualified Teacher for the Deaf, who presented and ran a couple of workshops, and we also ran a couple of First Aid courses giving training on Basic Life Support, Defibrillators and Choking. Everyone who took part in these courses received a certificate of attendance.

From the feedback we received it appears that all workshops, presentations and the new venue were well received, despite a few technical and teething issues.

Presentations have been uploaded to the [WSUK website](#).

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

UK Clinical Trial Updates



Update from Prof Tim Barrett and colleagues

Dear friends and colleagues,

I hope everyone is keeping OK and are keeping warm enough in this cold weather. Our research teams have kept busy and I would like to use this letter to keep you updated on our progress.

The TREATWOLFRAM trial is now in its final year. It has been a long journey to get here, navigating medicine manufacture problems, BREXIT, Covid, and supply issues. Thank you to all the participants who have supported the trial with their involvement. Our trials unit team, Amy Lamb, Lewis James Victoria Homer and Darren Barton, are working hard to make sure all the information that participants have kindly supplied, will be ready to be analysed when the trial ends in October 2024. There has been an update from the UK Medicines Regulator (MHRA) to remind patients Read in full [here](#)

USA Trials and Research Updates

Dear Friends,

As we near the end of another remarkable year, I would like to express my gratitude for your unwavering belief in and support of our quest for a cure for Wolfram syndrome. Your continued encouragement has been a guiding light throughout our journey, just like the fading sunlight in these waning days of the year. As we prepare to say goodbye to this year, I am thrilled to share some exciting updates on our progress in the fight against Wolfram syndrome. Our therapeutic development has made significant

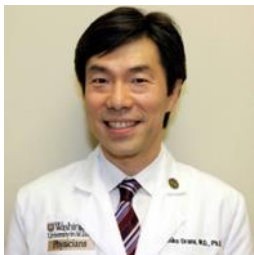
advances, and I am eager to reveal all the intricate details to you.

Research Progress in Wolfram syndrome this past year includes:

Ongoing clinical trials

In collaboration with our partners at Amylyx Pharmaceuticals, we're actively advancing the development of AMX0035, an innovative oral medication designed to delay/halt the progression of Wolfram syndrome. In 2020, the US FDA granted AMX0035 orphan drug status for Wolfram syndrome. Using previous clinical study data,...

Read in full [here](#)



Wolfram Syndrome Global Awareness Day

This year on 1st October, WSGAD, the AFASW - Association of Spanish WS families, prepared a visual event to raise awareness of Wolfram Syndrome.

They illuminated the public buildings in green, read their manifesto, accompanied by their public representatives (mayor and councillors). They also sent a press release to the main media in the area.

Their hope was to help to make Wolfram Syndrome visible and raise awareness, to fight to improve the quality of life of people suffering from Wolfram Syndrome and to collaborate to continue advancing in the research of the disease.



News You Can Use

International Patient Registry

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

Wolfram Syndrome Global Patient Registry

Welcome to the Wolfram Syndrome Global Registry

[Learn more »](#)



Following on from the First Aid workshops held at this year's conference, here are 2 news posts that you might find helpful:

999 by Text Message

Deaf people can text emergency services, but only if our phones are registered for the service in advance.

Don't wait until you need to call, it will be too late. Do it now.

How to register

Write an SMS text which just says "register" and send it to 999.

They will reply with a message telling you more about the service.

When you have read their message reply with “yes”.

Shortly afterwards you will get another reply message. This one will say you are now registered, or tell you there is a problem and how to solve it.

Information needed in a 999 text

1. Do you want fire, police or ambulance?

2. In just a few words, what is happening?

3. Where is help needed? Give the full address if you can, or a street name and landmark. Make it easy for the emergency services to find you.

When to use 999 text

- Life is at risk
- Crime/trouble is happening now
- Someone is injured or threatened
- Person committing crime is near
- There is a fire or people trapped
- You need an ambulance urgently
- Someone is in trouble, or missing, at sea
- Someone is in trouble on the cliffs or on the shore

Here is a [video](#) produced by Nottinghamshire Police.

ReviveR Programme by British Heart Foundation

RevivR is our free, interactive, online CPR training course. In just 15 minutes, you can learn how to save a life and receive your very own CPR certificate. It couldn't be simpler – you just need your mobile phone or tablet and a cushion to practise on.

Start the training now, or save it for later and get it sent straight to your inbox, ready when you are.

To find out more about this free course and to start your free training,

go to the BHF website [here](#).

Useful Equipment to buy

The first aid trainer from the conference course recommended two pieces of equipment that can be purchased for use at home. See the links below:

CellAED (Defibrillator) - <https://cellaed.io/uk>

Suction device - <https://www.sja.org.uk/first-aid-supplies/specialist-equipment/resuscitation-equipment-airway-maintenance-and-oxygen-masks/suction-devices-and-accessories/evac-s-hand-held-single-use-suction-device/>

Just Can't Wait Card

Do you find that there are times when you need the toilet urgently? This card can help.

The Just Can't Wait Card is recognised and supported by many retail and service organisations, giving you access to toilets not normally available to the general public. Just show your card.

Although access is not guaranteed, the cards are widely accepted and acknowledged.

To find out more and to order your card, go to the Bladder and Bowel



UK website [here](#).

Better Gyms - Inclusive UK Membership

With a New Year round the corner, some of you might be starting to think about getting healthier especially if there is a bit of over indulging during the Christmas period. Then membership at a Better Gym might be just what you are looking for.

Better say "We believe everyone should be able to enjoy staying active, no matter what your access needs are.

That's why our Inclusive UK membership gives people who are registered as disabled access to our gyms, swimming pools, fitness classes and more for a reduced price . This gym and leisure membership for those with disabilities also provides access for you and your carer/personal assistant*, so you always have the support that you need."

To find out more about the Inclusive Membership, the Membership Benefits, who is eligible etc then go to the Better website [here](#).



'Every Body Moves' Initiative

The 'Every Body Moves' initiative which was developed in partnership by ParalympicsGB and Toyota, sets out to connect disabled people with more opportunities to get active. It is an evolution of the award winning Parasport platform, which is the nation's largest online platform that connects people with thousands of inclusive physical activities.

Visitors to the ['Every Body Moves'](#) website can search by their postcode and view a wide range of virtual workouts and tips.

One of the coaches involved says "there is a sport or activity out there for everyone. No matter what that person's age, gender, religion, ethnicity or impairment - our message is simple, get out there, find your thing and have fun!"

Why not have a look and see if there is anything that catches your eye to have a go at.

Braille Gift Cards

Following a consultation with the RNIB, Marks and Spencer have recently launched a first of its kind 'Happy Birthday' gift card. Joining this gift card is a range of three braille greetings cards covering different celebrations.

The industry-first braille gift card features an embossed outer sleeve to communicate the 'Happy Birthday' message and an embossed gift card enclosed within the sleeve which can be used online or in over 700 M and S stores. Each greeting card and gift card design is plastic-free, made of FSC Certified paper and fully recyclable (customers just need to remove the glue dots from the gift card).

Support Co-ordinator's Updates

Family Support Co-ordinator

Hello everybody,

Well, we have reached the end of 2023 and I have completed my first full year in post as family support coordinator for WSUK! What a wonderful 12 months it has been.

In October, I had the opportunity to speak with Neil Balmforth who is the IBTA (International Blind Tennis Association) world champion of 2023. You can read more about his story and how his visual impairment affects him on the [FSC webpage](#). If you would like to contact Neil, or require information about attending a VI tennis session, where held around the UK, please let me know.

Last month, I had the pleasure of attending my first adult WS clinic at University Hospital, Birmingham. As YP start to transition into adult services, I will be making an appointment with the family to talk through the process. If you want any additional information on transition to adult clinics, please let me know. I will be partnering with Phillippa, the WSUK adult support coordinator to deliver some helpful resources around transition clinic in 2024.

Please check out the [FSC webpage](#) on our website for details of accessible activities available over the holiday period:

My final working day for 2023 is Tuesday 19th December and I will be back in the office on 2nd January 2024.

Have a Happy Holidays, however you celebrate, and I will see you in 2024.



Georgina

Tel - 07592629813

Georginaking@wolframsyndrome.co.uk
[Family Support Co-ordinator Page](#)

Adult Support Co-ordinator

Winter Greetings – I can't believe that I am writing this coming up to December 2023, and celebrating the fact that I have been the Adult Support Coordinator at WSUK for just over a year now! Time seems to go so fast. It has been a very eventful year, and I am looking forward to new challenges in 2024 and hopefully getting to meet more of you either at the clinic or in the community.

I would like to say a big thank you to all those who came and

supported the social event at the WS annual conference in September. It was good to meet you in person in an informal setting. Bingo was a great success, although next year I will possibly be looking at a different way of calling the balls as I kept dropping them on the floor! I may also change the quiz as it seemed to be a bit tricky for some. Apologies! Any ideas for future events then please let me know. But I think we all had fun.

As I write this, I am gearing up to attend the November adult clinic in Birmingham and of course I will also be there in January, well trains and weather permitting of course! It is always good to meet you in person, to find out what support you might be needing and helping with conversations with the clinical team. So, looking forward to seeing you in person if you are attending November or January clinics, and if you have a specific query then please get in touch with me, and we can address it whilst at the clinic.

For 2024, I will be looking at new ways of supporting our adult community, and finding out what might be most helpful. If you have any ideas on future projects or would like to get involved with the next one, either in helping shape what we do or as a participant then please do get in touch with me by email or phone. With all our projects we want them to be led by what you - our community - want and need.

I'm always glad to hear your ideas and it doesn't matter how big or small, or how silly they may seem to you, just let me know.

Let's hope that the weather over the winter months is not too severe, and those in areas prone to snow don't get cut off. Mind you, my roses at the allotment are still blooming and I had apple blossom on my apple trees recently, so nature seems - a bit confused at the moment! Here are a couple from my allotment earlier in the year...



Enjoy whatever you do over the festive period if you are celebrating. If you need any support over the coming weeks then please reach out.



Phillippa

Adult Support Worker

phillippafarrant@wolframsyndrome.co.uk

Tel: 07752 193635

Working part-time on Monday to Thursday mornings.

WS Clinics

Clinic Dates 2024

WS clinics are back to 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:

26th January
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.

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:

15th and 16th January
4th and 5th March
10th and 11th June
7th and 8th October



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 **PLEASE** let Georgina, 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.

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](#).

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/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 that 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](#).

One family's fundraising continues

Along with friends, the Mason family are continuing to fundraise for WSUK.

At the end of August a friend and her work colleagues at Community Housing did a fundraiser, raising £250.



Then on 1st October, they organised a Car Treasure Hunt from Kidderminster Carolians Rugby Club. This raised £1505.00.



Well done to you all and keep up the great work!!

Leicester Half Marathon

On 1st October 2023, Alice Hurt, sister of WS member Charlotte ran Leicester's Half Marathon in aid of Wolfram Syndrome UK.

Alice says " My older sister, Charlotte, was diagnosed with WS at the age of 13. She is the most inspiring person I know (although, she will hate me for saying this). Charlotte's drive & aspirations have never been limited by her diagnosis, but Wolfram Syndrome continues to make daily tasks more challenging."

Alice raised **£935.00** for WSUK. Her official completion time was 2 hours, 28 seconds. Thank you so much and well done!



Both events on 1st October coincided with the Wolfram Syndrome Global Awareness Day, so a great way of raising awareness.

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.

Donations will from 1st November be paid across to us from Facebook Meta via PayPal Giving Fund instead of through Facebook Payments. We have done what is required by us to ensure that payments to us continue without interruption.



PayPal Giving Fund

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

PayPal Giving Fund



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

Other Ways to Support WSUK

PayPal - Give at Checkout



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

There are 2 ways to do this.

1. By using the link below, select us as your favourite charity and

then log in to your account to complete the process.

paypal.com/gb/fundraiser/charity/76200

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

Make your online shopping count!



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

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

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

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

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

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](#)



WSUK Charity Christmas Cards

There is still time to buy any extra packs of Christmas Cards. Go to the [shop page](#) on our website to see the designs available.

One-off Pieces of Art

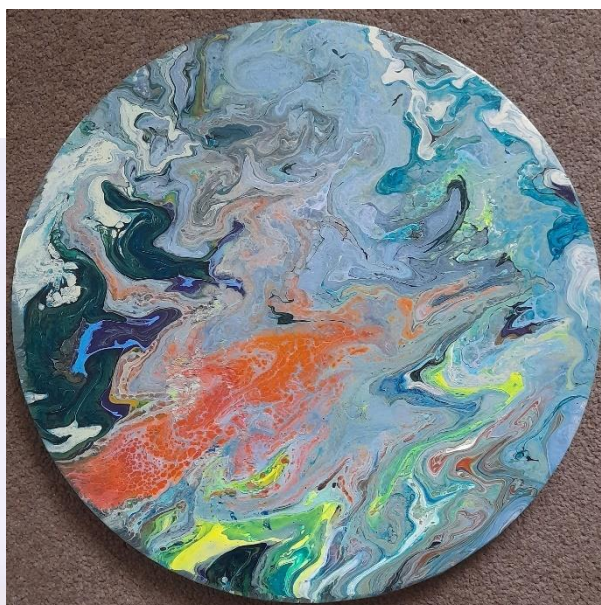
22-year-old, Jennifer Lynch, has been busy creating individual pieces of Art this year.

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 staff from hospital when she was there earlier this year, by some of you at conference and by others who have seen the artwork on Facebook.

The artwork has now been added to the [WSUK shop](#) page for others to look at and purchase if they wish. 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.



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 26th February 2024.

Sad News

It is with sadness that we have another passing of a WS member to tell you about.

Amy Hawkins passed away on 19th September with her family around her. Amy along with her mum, Sam, were two of the original Trustees for WSUK when we became a Registered Charity in 2013.

A living gift of a rose plant, called 'Sweet Amy', was sent to the family by WSUK in remembrance.

The family asked for donations instead of flowers. Donations were shared equally between 'Make A Wish', VICTA and Wolfram Syndrome UK as all 3 charities had supported Amy at some point or throughout her life. We have received £3598.87 so far with a further donation to come. We would like to thank the family of thinking of us at this difficult time.



Congratulations!

Congratulations to Joh & Braedyn Lennox from Australia. Joh gave birth to a baby girl, Stella Kerris Lennox on 12th November, at 32 weeks. She weighed 1975g (about 4lbs 3 oz) and measured 43 cm long. Joh says, "Stella is already bright, alert and is kicking goals already".

Joh has confirmed I can share this news as well as a picture with the



WS community.

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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