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## **Welcome to our Spring Newsletter.**

With the storms of last month behind us and Spring on the way, now is the time to look with some positivity to the future. We are planning our first face to face conference since 2019 and fundraising activities are back on the calendar.

With better weather, fingers crossed, coming now could be the time for you to start getting active, think of ways to raise awareness or fundraise for WSUK or to get out and just enjoy the fresh air.

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

Tracy



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Wolfram Syndrome UK values your involvement with the newsletters, so please remember to share anything that you would like to see included in future newsletters as well as telling us what you have been doing. These can be sent to us at [admin@wolframsyndrome.co.uk](mailto:admin@wolframsyndrome.co.uk).

An audio version of this newsletter is posted onto our Social Media pages or if you would prefer the audio version to be emailed to you or a large print printed version mailed to you, then please let us know.

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## News and Updates

### GDPR and Data Consent Forms

At the start of September last year, updated Data Protection consent forms were sent out to our UK community. To date only a quarter have been completed and returned. Over the last few weeks paper copies have been posted out to everyone that hadn't re-consented.

It is essential that we keep the information we hold up to date as otherwise what could be important information to you may not be received. These consent forms are essential for your involvement in any projects we run as well as communicating with you.

It is advised that we ask you to re-consent the secure storage of your information on our system every 3 years as you may have changed your mind since the original consent was submitted or moved and not notified us.

If you haven't yet returned your forms either by email or post then please do so as soon as you can. If you require the forms again then please let [Tracy](#) know.

## UK Clinical Trial Updates



### Update from Prof Tim Barrett

Dear friends and colleagues,

Hello to you all, and I hope you and your families are OK and keeping safe in these uncertain times.

Tracy asked me to give you an update on Wolfram research in Birmingham.

Starting with the TREATWOLFRAM clinical trial, as you know, this is an international, randomised controlled trial of sodium valproate to delay or prevent the progression of

vision loss in Wolfram.

As you know, participation was completed on 1<sup>st</sup> Nov 2021 with recruitment of 63 people who have kindly consented to take part. These include 25 children and adults recruited in Birmingham UK, 15 children and adults in Paris and Montpellier, France, 18 children and adults in Almeria, Spain, and 5 children in Lodz, Poland. The youngest participant is 8 years, and the oldest, 61 years. We have a good spread.... read the update in full [here](#).

## **USA Trials and Research Updates**

Dear Friends in the UK; hello,

It is always nice to “see” you. As I write this message to you, I am feeling your support, trust, and faith in me. I keep on doing my best to provide the best clinical care and develop safe and effective treatments for patients with Wolfram syndrome. Here are my updates, and I feel hopeful.

### **Upcoming clinical trial**

In the past, I looked for existing drugs that could be beneficial for patients with Wolfram syndrome. This effort led to a few clinical trials, but a repurposed drug could be just a band-aid for Wolfram, and we need a new medication for Wolfram syndrome. I have been focusing my efforts on developing a new drug, AMX0035, for the treatment of Wolfram syndrome in collaboration with Amylyx Pharmaceuticals in Cambridge, Massachusetts. They have been collaborative and generous. AMX0035 targets endoplasmic reticulum stress (a molecular mechanism of Wolfram) and mitochondrial dysfunction. A recent

clinical...continue reading [here](#)



## WS Conference



Conference this year will be a combination of a virtual event, planned for Saturday **24th September**, and a face to face on **1st October** at Whittlebury Park (previously known as Whittlebury Hall Hotel), also the date for our 2nd WS Global Awareness Day.

The [booking form](#) can be found on our [website](#) as well as having been emailed out to our UK community. A draft programme for both dates will be added to the website when confirmed.

We are asking that you kindly make payment to us for your room costs at the time of booking your place, details on how to do this are on the booking form. This should make

checking in easier as you will only have additional food and drink to pay for on checking out. If you cancel attendance **before 9th September**, then a full refund will be made. After that date, as we will still have to pay for your room, we will refund 50% of the cost.

## **Wolfram Syndrome Global Awareness Day**

We have a separate website where specialists, doctors, public can go for more information about this day [www.globalwsday.org](http://www.globalwsday.org).

This year's event coincides with our annual conference. We welcome any suggestions from our community on fundraising and awareness events that we could do around this time to help promote our WS Awareness Day.

It is worth remembering, that all these non-profit organisations need funds to be raised throughout the whole year to enable them to keep functioning and to be there to support the WS Community now and in the future.



So even though we have created this significant day for everyone to join together, please do continue with your fundraising efforts throughout the year!

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**News You Can Use**

## Medical Exemption Certificates

People over 18 out of full-time education with certain medical conditions can get free NHS prescriptions if they have a valid medical exemption certificate.

A medical exemption certificate:

- entitles you to free NHS prescriptions only
- doesn't cover dental treatment or help with other health costs
- should be shown when you collect a prescription
- is valid for five years (or until your 60th birthday, whichever is sooner)

It's your responsibility to check the expiry date, and if you claim free prescriptions after your certificate expires, you could have to pay a penalty charge of up to £100.

If you're entitled to a certificate because of your medical condition, you need to ask your doctor to give you an application form to complete and then return to them for sending off.

You should expect to receive your certificate within 10 working days of us receiving your application.

For more information about Medical Exemption Certificates, how to get a refund if required, go to the NHS website by clicking [here](#).

## Focus on Sight Loss

These organisations may or may not be known by yourselves. They might have some sight loss related



information and equipment that may be helpful to your daily lives. More organisations can be found on our website [here](#).

### [The Partially Sighted Society](#) -

A national charity to help anybody living with sight loss

Their specialist services focus on helping you to make the best use of your remaining vision and a friendly team are at the end of a phone if you or someone you know is affected by sight loss.

[Royal Society for Blind Children](#) - The Royal Society for Blind Children offers a range of services including emotional support and practical advice for families, opportunities for children and young people to build confidence and skills through activities, and a specialist further education college.

### [Sight Village Exhibitions](#) -

Here are the 2022 dates, with further dates to follow shortly.

**South-West 26th April 2022 - Sandy Park Stadium, Exeter**

**Central 28th & 29th June 2022 - Cranmore Park Conference Centre, Solihull**

**North-East 21st September 2022 - Royal Armouries, Leeds**

**South-East 8th & 9th November 2022 - Kensington Town Hall, London**

Are you thinking about the next step in education after exams? You might like to consider the following:

### [Royal National College Hereford](#) -



The Royal National College for the Blind (RNC) in Hereford. The UK's leading college for further education and training for the visually impaired.

Being a national centre of expertise for people with visual impairment, RNC provides a broad curriculum which is underpinned by specialist skills for life.

The College experience is more than vocational and academic qualifications. It's about achievement beyond the classroom - developing self-confidence, personal independence and communication skills that are needed for the future.

[Queen Alexandra College](#) - Queen Alexandra College (QAC) is a Specialist College based in Birmingham. They welcome students who come to their college from all over the country – as well as many who are local to them.

## **Disability Related Expenses**

### **What are disability-related expenses?**

If you care for someone with a disability or a medical condition, there may be extra costs involved in helping them manage this. These are called disability-related expenses. There are many examples of these and they could vary from special dietary requirements to certain types of medication not available through the NHS.

### **Having a financial assessment**

When a local authority or trust (in Northern Ireland) carries out an assessment of someone's care needs, they will also need to carry out a financial assessment to see if they can

potentially contribute towards their care costs. The amount varies but usually there is a flat rate that will be allocated by the council or trust to help cover extra disability-related expenses (for example £15-20 per week).

To read the full article go to the Carer's UK website [here](#).

**Make sure you're claiming everything you're entitled to.**

From the recent [Contact](#) newsletter.

As the cost-of-living crisis continues, make sure you're claiming everything you're eligible for. Use [our benefits calculator tool](#) to check your entitlements and [our grants search tool](#) to see if you can apply for support. Visit our pages on [benefits and tax credits](#) and on [money and debt advice](#), including other sources of financial support. This information and more can be found in their '[handy checklist of 6 steps every parent carer should take now](#)'.

Contact have an all-in-one book which has all the information and help you need to enjoy family life. [Get your free copy of their Helpful guide for families with disabled children](#) straight to your letterbox.

## **Wolfram Syndrome Patient Registry Update**

The Snow Foundation, USA is currently partnering with the National Organisation for Rare Disorders "NORD" to implement the first ever WS global patient owned registry, a priority in the field of rare disease..

Please help us improve patient care, strengthen our voice, and improve the chance for quicker drug development. Support The Snow Foundation's vision of “a world without Wolfram syndrome.”

The registry should be up and running by April 2022. You can [sign up](#) today to receive critical information about treatment, research, resources, and other initiatives. We will contact you once the registry is live to sign up to officially. If you have any questions, please email Pat Gibilisco - [pat@thesnowfoundation.org](mailto:pat@thesnowfoundation.org).



## **Planning for the future and Decision Making**

Renaissance Legal specialise in planning effectively for the future with Wills, Trusts, Powers of Attorney, Court of Protection applications and Inheritance Tax Planning. Their team are friendly, approachable and understand that planning for the future can be a complex and emotional process. They make sure their clients' needs are met in the most effective, forward thinking and economic way.

### **Specialist experience**

They specialise in working with families and carers of disabled and vulnerable individuals, helping them plan effectively for the future. Their team has built its excellent reputation on understanding the needs of parents and carers – all of whom are dealing with complex, often challenging

lives, where it's vital that they can understand their options.

[Renaissance Legal](#) presented to our community at conference in 2018 and will be attending again this year. They have some webinars about 'Planning for the Future' and 'Decision Making' coming up in March. If you are interested you can find them [here](#).



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## WS Clinics

### Clinic Dates 2022

WS clinics are returning to face 2 face where possible although some, especially in the adult clinic are still running as virtual. Please be aware that clinics may have to be cancelled at short notice.

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

25th March 2022  
27th May 2022  
15th July 2022  
23rd September 2022  
25th November 2022

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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:

7th-8th March 2022  
6th-7th June 2022  
3rd-4th October 2022



If you or your child would like to be seen for either clinic, please contact [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 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.

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## **Fundraising News**

Upcoming events can be found listed on the events page of the Wolfram Syndrome website

[www.wolframsyndrome.co.uk](http://www.wolframsyndrome.co.uk)

Remember to keep checking the website for upcoming

events, any recent news articles & links.



## **Continued Support!**

A fantastic couple continue to support us with donations and fundraising.

At the beginning of December Colin and Rosy Gray paid £400.00 into the WSUK charity bank account, which we were also able to collect Gift Aid on. £100 was a donation and the other £300 was raised through the sales of a book and DVD they produced of a Land's End to John O'Groats cycle ride that Colin did during the summer.

Since they started fundraising for us back in 2018, they have raised over **£6500** including Gift Aid for WSUK. Thank you to you both and to your friends and family who have sponsored and supported you in the raising of funds for WSUK.

## **Ultra Action Challenges**

We are now registered with the organisation Action Challenge UK. They have lots of ultra challenges happening throughout the year that you could sign up to as an individual or as a group.



Push Yourself Further, there are 15 great events in 2022.

Are you a regular walker and new to endurance events? Perhaps a seasoned trekker looking for testing adventures? Or even a marathon runner wanting to 'up' your distance? Whether it's along magnificent coastal scenery, or in stunning open countryside, there's an Ultra Challenge for you. Walk, Jog or Run at **YOUR** pace on the Ultra Challenge Series event of your choice.

Join 30,000 others of all ages & experience in 2022 for an unforgettable Challenge. It will be rewarding, fun, and absolutely achievable with your resolve and determination alongside first class support. Push yourself further - 100km Full Challenge, with Half & Quarter options also available

We have one WS family member who is taking on the half distance of the Jurassic Coast challenge this May. Why not have a look at the Ultra Challenge website and see if there is anything that catches your eye, that you fancy having a go at.

You can visit their website [here](#) or find information about events on our Events page on the WSUK website.



## Charity Football Match

25th March will see a charity football match take place at Horsham Football club, organised by FJN Solutions in Horsham after they took part in last year's charity golf day.

They have players from international companies they work with coming along to test their football prowess on the pitch. After the game there will be an opportunity for people to donate to take part in a penalty shoot-out or a cross bar challenge.

This will be a great way to raise funds and awareness in a new area.



## Charity Golf Day

Our Annual Charity Golf Day will take place on 29th July at Mannings Heath Golf and Wine Estate sponsored by Penfold Verrall and Northern Commercials.

Invitations have already been sent out to teams that have played previously with a couple already signing up and more to come in the next few weeks.

This is always a great day for all the teams that take part whilst raising funds and awareness for us at the same time.



Players from 2021 charity golf day

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## **Project Updates**

### **Wolfram Syndrome UK Breaking Down Barriers Project Update**

#### **Video clips of your experiences –**

The first video clips from members of the WS community are now available and can be viewed on the WSUK website at:

[www.wolframsyndrome.co.uk/bdb-community-videos/](http://www.wolframsyndrome.co.uk/bdb-community-videos/)

Thank you to everyone who has taken part! Your stories are amazing!

We are continuing to edit videos from other community members, so this page will be updated regularly. Please keep checking back to view more new videos.

**If you have already recorded your video**, Thank you! We will contact you to approve your final video clip(s) before uploading onto the website and we will also let you know when it is available for everyone to view.

**If you've not yet recorded a video, but would like to, please contact Tracy** ([admin@wolframsyndrome.co.uk](mailto:admin@wolframsyndrome.co.uk)) as we have scope to include 1-2 more within the current project.

Please remember appearing on camera is optional, you can simply speak instead. Your video will be edited before it is uploaded, so you don't need to be word perfect!

“Breaking Down Barriers” is part of an initiative for patient organisations being run by Alstrom UK and funded by the Sylvia Adams Charitable Trust.



## **Emotional Wellbeing Project**

In January 2022, WSUK received a grant from the National Lottery Community Fund (£9,995) to deliver a new project for WS affected adults (16+ years).

In this new project, WSUK aims to help WS affected adults

improve their emotional wellbeing over the next 12 months by providing support focused around the 5 factors that can improve health:

1. Connect with others
2. Be physically active
3. Learn new skills
4. Give to others
5. Take Notice

We are currently inviting WS affected adults to participate in:

~ Personalised 1:1 monthly support sessions (via phone/Zoom) for up to 25 WS affected adults.

AND / OR

~ Interactive group/peer wellbeing support sessions to provide a safe and welcoming space for WS adults to connect and help each other (via phone/Zoom).

If you are a WS affected adult and would like to participate in either or both activities and have not yet returned your completed Registration of Interest Form, please contact [support@wolframsyndrome.co.uk](mailto:support@wolframsyndrome.co.uk) as soon as possible.

## **Wellbeing workshops for the community**

As part of this project, we will be running Wellbeing workshops that will be open to everyone in the WS community (e.g. activities for wellbeing; Zoom). Further information will be shared in advance of each session.

We are also re-developing the project page on the WSUK

website, to include this project, where information including regular updates and workshop topics/recordings will be available.

Regular project updates will also be shared on our social media pages and future E-Newsletters.



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## Ways to Donate to WSUK

### Facebook Donations

We continue to be thought of by WS members and their families when it comes to their birthdays or they are doing a fundraising event through creating [Facebook fundraiser pages](#).

A big thank you to everyone who supports us in this way.



### Monthly Donations

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).



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## 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](#).

## Make your shopping online 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.

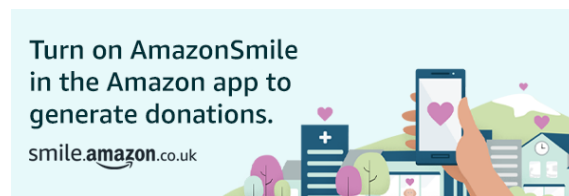
Links to register can be found [here](#); or you can click on the relevant image above to be taken straight through to the registration page. Install the reminder link so you will be asked if you want to raise a donation when you go straight to the retailers website, so you don't need to worry about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



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**Your News**

**Sad News**

It is with great sadness that I tell you about the passing of Andrea Millership, not WS or Covid related. We were told just after the last newsletter was sent out.

Andrea was one of our oldest UK community members and was sister to Sheila Kelly who we lost at the start of 2021. Sheila was unaffected.

The family asked for donations to WSUK instead of flowers and we thank them for donations, that totalled over nearly £400.

WSUK sent an indoor Christmas Rose to Andrea's husband as a living gift so that it will flower each year in her memory.



## Birthdays (UK and worldwide)



### March

Shiffa  
Adam  
Tom  
Krystal



### April

Sadiya  
Anne  
Haidar  
Amy B  
Taybah A



**May**  
Faisal  
Naomi  
Jason  
Lisa  
Charlotte  
Selina  
Clara

**Happy birthday to you all!!**



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