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## **Welcome to the Autumn Newsletter.**

I hope that you have all been managing to stay cool in our record-breaking temperatures!! A bit of a change from last Summer.

We have been busy over the last few months with fundraising and the employing of some new staff. More about our new staff will be mentioned in the Winter newsletter.

There is still some time to book your place at this year's face 2 face conference if you haven't done so, but do be quick as rooms can't be guaranteed after 9th September!

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 keep hydrated!

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](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

### WS Conference



We are only a few weeks away from our annual conferences. The programme with registration links has now been sent out/shared on social media for the virtual event on Saturday **24th September**. This is open to everyone in the global WS community that would like to join. We then have our first face to face event since 2019

on **1st October** at Whittlebury Park (previously known as Whittlebury Hall Hotel), also the date for our 2nd WS Global Awareness Day.

There is still time to register your place/room for both of these events. The [booking form](#) for the face to face event can be found on our [website](#). A programme for both dates has been added to the website/emailed out.

Rooms are guaranteed until 9th September if you intend to stay over. 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.

**For those coming on 1st October we would ask that, if possible, you take a Covid test either that morning or the night before to confirm you are negative. We will do our utmost to ensure your safety. At the time of writing facemasks may be suggested to be worn on the day but this will be left to your discretion.**

## **UK Clinical Trial Updates**



## **Update from Prof Tim Barrett**

Dear friends and colleagues,

I hope everyone is keeping OK and managed to cope with the 2 heatwaves this Summer. Our hospital research teams have kept busy seeing people taking part in the TREATWOLFRAM clinical trial, and we have had meetings of the Trial Steering Committee, and the Trial Management Group. The Trial Steering Committee, chaired by Professor Marc Peschanski, commended all the study teams and participants for keeping the trial on track despite the pressures the National Health Service and international health services are under. They were really pleased that most participants are having study investigations on time, and.....Read more [here](#)

## **Update from Dr Ben Wright**

Patients continue to be seen as part of the TreatWolfram clinical trial at the QE. We are thankful for the continued commitment of all those involved with this trial.

## USA Trials and Research Updates

Dear Friends in the UK,

You are my heroes. When I am stressed and tired, I go to emails and social media posts from our patients and families. These emails and posts give me a reason to keep on going. I always appreciate your continued support and faith in me. Here are my updates.

### Upcoming clinical trial

We need new treatments and therapeutic modalities for Wolfram syndrome, including oral and injectable medications for optic nerve atrophy and neurological issues. I have been focusing my efforts on developing a new drug, AMX0035, to treat Wolfram syndrome in collaboration with Amylyx Pharmaceuticals in Cambridge, Massachusetts. AMX0035 targets endoplasmic reticulum stress and mitochondrial dysfunction (molecular mechanisms of Wolfram syndrome). The results of our pre-clinical studies using iPS cells from our patients of Wolfram syndrome were encouraging, .... Read more [here](#)



## GDPR and Data Consent Forms

We still have a number of unreturned data consent forms. Please return these as soon as you can either by post or email.

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.

If you require the forms again then please let [Tracy](#) know.

## 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 **all** do around this time to help promote our WS Awareness Day.



It is worth remembering, that all these global WS 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!

## **News You Can Use**

### **Support for Parent Carers**

If you're feeling exhausted or alone, support is at hand from ourselves here at WSUK; but for professional general support the organisations below are worth trying:



~ [parentsonline.co.uk](https://parentsonline.co.uk) offers emotional support via confidential messaging with fully trained volunteers, who also have lived experience of caring.

~ Contact your local carers' association via [Carers Trust](https://carers.org) (carers.org). The charity has a network of local offices, providing support to carers and a grants programme that offers one-off payments. (the WSUK office also has the list of local offices).

## **New laws to protect disabled people in England, Scotland and Wales when travelling in taxis and PHVs.**

New laws will ensure the 13.7 million disabled people in England, Scotland and Wales receive the assistance they need and will not be charged over the odds when using taxis and private hire vehicles (PHVs).

[The new Taxis and Private Hire Vehicles \(Disabled Persons\) Act 2022](#), which came into force on 28 June, is the most significant change to taxi accessibility legislation since the Equality Act was introduced 12 years ago.

The 2022 Act amends the [Equality Act 2010](#) to place duties on taxi drivers and PHV drivers and operators, so any

disabled person has specific rights and protections to be transported and receive assistance when using a taxi or PHV without being charged extra.

As part of the amendments, taxi and PHV drivers could face fines of up to £1,000 if they fail to provide reasonable mobility assistance to disabled passengers taking a pre-booked vehicle.

This will also ensure that visually impaired passengers will be assisted by drivers to help them identify or find the vehicle. There will also be a duty for local authorities to publicly identify wheelchair-accessible vehicles in their fleets.

The measures will apply to drivers in England, Scotland and Wales and will help to provide consistency of experience for affected passengers.

The act was a Private Members' Bill introduced by Jeremy Wright QC MP. Another change will mean that even drivers granted exemption from assistance duties on account of medical needs must still accept the carriage of disabled passengers and will not be able to charge them more than

others.

Read the [Access to taxis and private hire vehicles for disabled users guidance](#).

## **Positive changes to private parking**

**(From Motability magazine)**

Lower parking fines, permitted grace periods, a single appeals service, and no fine if you forget to display your disabled badge are among the measures in a new code of practice for operators of private car parks.

Intended to clean up the private car parking sector, a new code outlaws opaque parking rules and heavy handed demands for payment, and permits innocent errors.

### **What the new Private Parking Code of Practice says:**

~ In England (but outside London) and Wales, charges will be reduced from £100 to £70 or £50, depending on the seriousness of the breach.

~ The current £100 fines cap will remain in circumstances such as abusing Blue Badge Bays, or if a motorist is trespassing on private land. Motorists will be offered a 50% discount if they pay within 14 days.

- ~ Parking debt collectors will be banned from adding additional excess fees to the level of the parking charge.
- ~ A compulsory ten minute grace period will be granted before firms can issue a late fine.
- ~ A five minute cooling off period will be included, in which a motorist can change their mind about parking.

The full Motability article can be found on the WSUK [website](#) or you can go to gov.uk to read more.



## **New NICE guidelines recommend wider access to Flash and CGM**

(article from Diabetes UK website 30th March 2022).

We are celebrating the publication of new guidelines by the National Institute of Health and Care Excellence (NICE) which recommend wider access to Flash and continuous glucose monitoring (CGM) for people living with diabetes on the NHS.

These new guidelines represent a shift towards a better understanding of technology as an integral part of diabetes management, rather than an added luxury.

We have been campaigning for better access to these technologies for many years and has been actively involved in responding to NICE's consultation on this guideline update. We're thrilled that our response to their consultation and our wider work pushing for better access to Flash and CGM has been heard - including via our more recent [Diabetes is Serious](#) and [Cheque for Tech](#) campaigns.

The [new guidelines](#) recommend that:

- all adults with type 1 diabetes should have access to either Flash or CGM
- all children with type 1 diabetes should have access to CGM and that
- some people with type 2 diabetes who use insulin intensive therapy (2 or more injections a day) should have access to Flash, for example if they experience recurrent or severe hypos, if they have a disability that means they cannot finger-prick test or if they would otherwise be advised to test 8 or more times a day.

We are also pleased to see the new guidelines recommending that the health system addresses the inequalities in Flash and CGM access that already exist – something we called for them to do in our response to the consultation on these guidelines.

While NICE only provides recommendations for the NHS in England and Wales, we think that the health service across the UK should adopt these tech recommendations as the minimum standard.

See detail on what these [tech recommendations and other guidelines are from across the UK](#). To read the rest of the Diabetes UK article please click [here](#).

## **WS Clinics**

### **Clinic Dates 2022**

WS clinics are returning to face 2 face where possible although in some situations are virtual.

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

23rd September 2022

25th November 2022



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:

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.

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](http://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

On 24th June the second charity football match took place at Horsham Football club, organised by FJN Recruitment Solutions, Horsham.

They again had players from companies they work with

coming along to test their football prowess on the pitch.

This event rose **£1180.00** for us! Thank you to everyone that took part, FJN Recruitment Solutions for organising it and GBG for sponsoring it.



## Charity Golf Day

Our 9th Annual Charity Golf Day took place on 29th July at Mannings Heath Golf and Wine Estate sponsored by Penfold Verrall and Northern Commercials.

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

This year there was a slight change to the format and comedian Adger Brown hosted the charity auction before the prize giving.

This year was amazing, we beat the previous record raising

the grand total of **£18,505.87!!!**

Thank you to both Penfold Verrall and Northern  
Commercials for sponsoring the event, all our hole  
sponsors and all the golfers who took part who have  
become great supporters of WSUK over the last 9 years.

Everyone within the WS community thank you for your  
continued support.





## Project Updates

**Breaking Down Barriers Y2 project is now complete!**

### Video clips of experiences

**12 members of the WS community** have recorded video clips of their experiences of living with WS, which are now available on the WSUK website at:

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

They cover a range of topics such as WS symptoms, living independently, recreation and leisure, a parent's view, finding employment among others.

Thank you to each of our 12 contributors for sharing your stories with us – you are truly inspirational!

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



## 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.

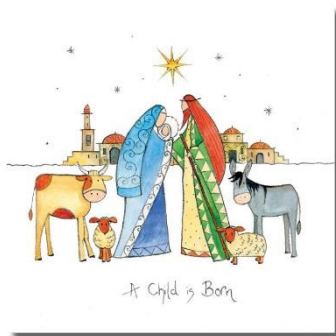


## Christmas Cards

I'm very sorry to say but that time of year is approaching. Our popular Charity Christmas Cards have been added to our [website](#) and will be available to purchase at conference.

Some designs are very limited so be sure to get them quickly.

Cards are £2.95 per pack of 10. There is one design in each pack. All the profits go directly back to the charity.



## 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](https://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!**

A teal banner for 'easyfundraising' with the tagline 'feel good shopping'. It encourages users to 'Raise free funds for us every time you shop online' and includes a pink 'Find out more' button. Below the banner, a grid of logos for partner retailers is displayed, including Amazon.co.uk, John Lewis, eBay, M&S, Boden, GAP, Argos, Booking.com, Debenhams, Next, Screwfix, Sainsbury's, ASOS, Viking, Moonpig, and Just Eat.

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.

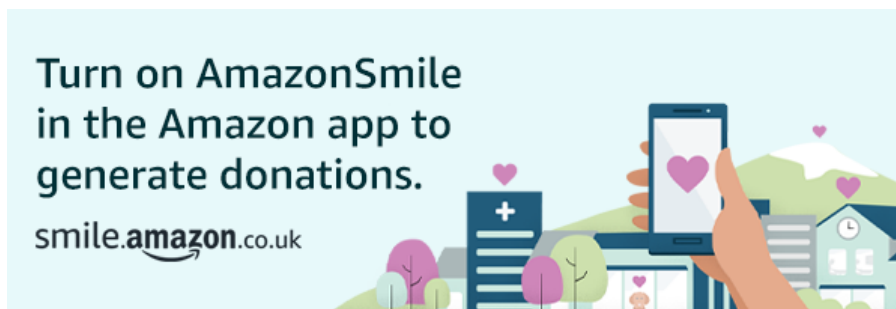
Links to register can be found [here](#); or you can click on the relevant image above to be taken straight through to the registration page. Install the reminder link so you will be asked if you want to raise a donation when you go straight to the retailer's website, so you don't need to worry about 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 the Winter newsletter is 29th November.

## **Birthdays (UK and worldwide)**



Happy birthday to everyone that has a birthday to celebrate during September, October and November.

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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