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Summer is here and hopefully we will soon see an end or bigger easing to all the restrictions that have been in place for the last 15 or so months. Progress is being made as almost all the population have received their first dose of vaccinations with many more having received their 2nd as well.

Let's hope that we have a nice summer to help us all mentally feel better whilst being able to spend time with family and friends outdoors.

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.



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 and website, or if you would prefer the audio version to be emailed to you then please let us know.

Contents

News and Updates
News You Can Use
Project News
WS Clinics
Fundraising News
Ways to Support WSUK
Your News

News and Updates

UK Clinical Trial Updates



Update from Dr Ben Wright - Adult Lead

We continue to be open to recruitment to this study and are actively screening people with Wolfram's to this trial. The trial has been updated to minimise any attendance at the hospital site using more telephone contact for study appointments where possible to do so. If you are interested in learning more about the trial please contact the Neurology research nurse team directly via email to: neurologyreseachteam@uhb.nhs.uk

Update from Prof Tim Barrett -

I am really pleased to say that the TREATWOLFRAM clinical trial has now reached 48 participants! We are grateful for the fantastic support of families, and all the hard work of our international teams, led by Renuka Dias and Ben Wright in Birmingham, Gema Esteban in Spain, Agathe Roubertie and Christophe Orssaud in France, and Wojciech Mlynarski in Poland. Gema in particular has worked hard to recruit 13 participants, despite having had a Covid infection with after-effects. We need to.... read the full report [here](#).

USA Trials and Research Updates

Dear Friends in the UK,

Hello everyone. I pray you're in great spirits. Everyone in my research team has been vaccinated for COVID-19, and we are working very hard to develop novel treatments for Wolfram syndrome. Although our past has been harsh, our future looks brilliant now. I continue adhering to my three guiding principles: 1. Improve clinical care, 2. Raise awareness, and 3. Provide a cutting-edge treatment for Wolfram syndrome. Here are our updates.

An Upcoming Trial

As I repeatedly mentioned in the past, a repurposed drug could be just a sticking plaster for Wolfram. So, we need a cutting-edge treatment designed explicitly for Wolfram syndrome. We have been focusing our efforts on developing AMX0035 to treat Wolfram syndrome with Amylyx in Cambridge, Massachusetts, in the US. AMX0035 targets endoplasmic reticulum stress... Read more [here](#)



You can read all the latest research and trial updates on the WSUK website [here](#).

WS Conference

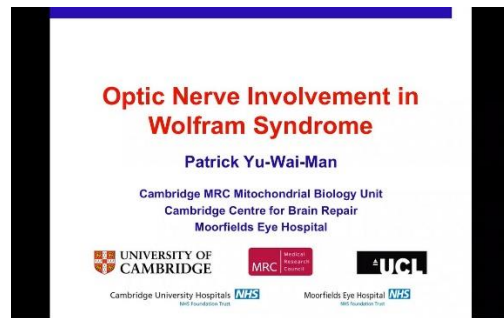
Conference will be on 2 Saturdays and in 2 different formats this year. We are still planning to hold a face to face conference, the final decision on this will be made after 21st June after the final step on the road map out of lockdown is hopefully met; but we will also be holding a virtual conference with International speakers to present to everyone without them having to travel to the UK. We plan to stream the presentations live from the face to face conference as well as record them to be put onto the website afterwards as usual for everyone to see.

The virtual conference is **Saturday 18th September**, the programme will be shared from July onwards and details on how to register will be shared from **August 20th**; and the face to face Conference is **Saturday 25th September** at Whittlebury Hall Hotel. The programme and booking forms for the live conference will be shared after the announcement on 21st June.



Further details will follow as they are finalised and will be shared on the WSUK website and WS social media pages as well as by email.

Video presentations from last year's conference, as well as all previous years, can be found on the [WSUK](#) website and the WSUK [YouTube](#) channel.



Wolfram Syndrome Global Awareness Day

A decision has been made by WSUK and 7 of the other 11 global WS organisations that we need our own day to focus on raising awareness and funds each year.

We have decided that this will be 1st October. This date is relevant to the WS community, as it is the date that the late Dr Alan Permutt from Washington University Hospital, USA had his paper published about identifying the WSf1 gene.

More information about how you can get involved will be shared soon; but if you have any ideas on events or any contacts that may be able to help with getting stories into the press, helping with social media or if you know a celebrity that would help us to promote this day then please let us know. If you would be happy to share your story this would also be a great help. Again just let us know.

It is worth bearing in mind though, that all these non-profits 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, especially after the last 15 months. So even though we are creating this significant day for everyone to join together, please do continue with your fundraising efforts

throughout the year!

News You Can Use

Using technology to help manage hypoglycaemia for the visually impaired.

Are you aware that with both the Libre and Dexcom CGM you can set up a feature that will enable the blood glucose to be read out to you.

The document can be found on the WSUK website [here](#).

FREE Just Can't Wait Toilet Card

Access the Universally Recognised Digital Just Can't Wait Toilet Card Online for **FREE**

Order the original toilet access card from the Bladder and Bowel Community today. They use the universally acknowledged W.C. signage, giving you the benefit of discreet and clear communication for those moments where you just can't wait to use the toilet.

DIGITAL TOILET CARD NOW AVAILABLE! The Just Can't Wait card is now available to download to your phone. Fill out a few details and they will guide you to download your card instantly. All you need is Apple Wallet or GPay.

To find out more and to download or order a card please visit the Bladder and Bowel website [here](#).



Wolfram Syndrome Research Alliance

This is a new website that has had collaboration from several WS groups around the world. This site is for use by Clinicians, Researchers and the WS affected community.

Wolfram Syndrome Research Alliance (WSRA) serves as a centralised portal to connect researchers and clinicians, coordinating their efforts to quickly and effectively develop treatments and a cure for Wolfram Syndrome.

WSRA supports relationships between researchers while aligning scientists, clinicians, patients, governmental and non-profit agencies to further efforts towards effective Wolfram Syndrome treatment.

Why not have a look at the site [here](#).



How is the UK Government planning on creating an advanced genomic healthcare system?

Read the [new article about the Genome UK Implementation Plan](#) on the Genetic Alliance UK website.

Venue to Virtual with a Difference from Disabled Living

Monday 28th June to Friday 2nd July 2021

Disabled Living's services, Equipz, Kidz to Adultz Events and Bladder & Bowel UK have joined forces to bring you

-

The Disabled Living Collective!

What is it?

A FREE week-long virtual event featuring over 50 of the most prestigious and award-winning companies, demonstrating their equipment, products and highlighting their services.

Who is it for?

People of **all** ages with disabilities and additional needs, older people, relatives, parents, carers, and the professionals who support them.

Why are we doing it?

In November 2020 and March 2021, Disabled Living's Kidz to Adultz team organised two Venue to Virtual events, specifically focusing on equipment and services supporting children and young adults with disabilities.

We were overwhelmed with requests not only from adults with disabilities, but also the professionals who work in adult services for a Venue to Virtual with adult equipment and products. The team love a challenge and are delighted to bring you our next Venue to Virtual event, The Disabled Living Collective, which will feature equipment, products and information for people who access all of Disabled Living's services.

Venue to Virtual will offer you an opportunity to view the

most advanced and individually tailored equipment, products and services all in one place. As we look forward to Covid restrictions easing further in June, Venue to Virtual will help you to decide which companies you may choose to contact in the future to arrange assessments or appointments.

How do I register?

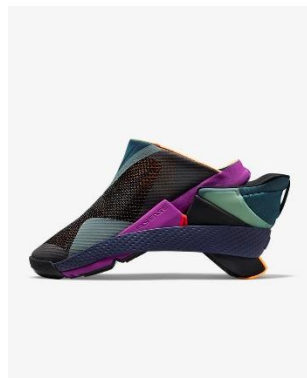
To keep up to date with the latest news on Venue to Virtual – The Disabled Living Collective, please [register now](#).



Nike launches a Hands Free Trainer

Nike were contacted by a young man with Cerebral Palsy asking them to develop a trainer that were hands free so he wouldn't be reliant on other people to tie laces. Nike took up the challenge and have developed the Nike Go FlyEase trainer range.

The entire heel hinges open and closed with a midsole tensioner for flexibility to help get the trainer on and off easily; just slip in and step down. Prices are from £104.95. For more information go to their [website](#).



RealSAM Smart Speaker

You can now use your Google Home or Alexa device to access the world's first dedicated smart speaker information hub for blind and visually impaired people.

Offering masses of content from UK sight-loss charities, the subscription service includes books, newspapers, podcasts and radio stations, all in one place for the first time.

The RealSAM smart speaker is a fully voice controlled media player tool that you can add to your home.... continue reading [here](#).



Project Updates

Caregiver's Wellbeing Project Update

This Caregiver's project, being funded by the National Lottery Community Fund, re-started on 12th April with the 2nd stage of lockdown easing .

We have 20 people enrolled in this Pilot Project with 17 who have actively started, 3 of those have completed their funded projects and a couple are close to finishing. We have 3 Caregivers still to start which hasn't been helped by the lockdowns and limitations when things have been open.

We hope to have everyone completed by the latter part of this year so that we can report back and hopefully

apply for another grant which will enable us to open this project up to even more of our WSUK caregivers.



Wolfram Syndrome UK Breaking Down Barriers Year 2 Project Update

WSUK is part of a network of over 40 organisations working together to improve the lives of families from diverse and marginalised communities, so they have equal access to health services.

One objective of Breaking Down Barriers (BDB) is to strengthen the ability of patient organisations and support groups such as WSUK to develop more supportive and inclusive services for individuals and families affected by genetic disorders e.g. Wolfram Syndrome.

In March 2021, WSUK received our new grant of **£5,000**, which has enabled us to launch our new BDB project.

New activities happening this quarter:

1) New BDB webpage –

A new webpage is currently under development which will include information, links and videos from our project and broader work e.g. a dual language leaflet (English / Urdu) – Understanding WS. We will let you all know when the new webpage is available.

2) Your experiences –

WSUK will be inviting members of the WS community to share your experiences and top tips on different aspects of living with WS. Your input can be provided by phone, email, photos and / or video. We will collate this information, which will be shared on our BDB webpage and in future Newsletters.

If you would like to share your experiences, you can contact us: Tracy – admin@wolframsyndrome.co.uk or Marie - mariemcgee@wolframsyndrome.co.uk; or respond to our invitations which will be shared with everyone in the WS community.

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



WS Clinics

Clinic Dates 2021

All clinic dates have currently been moved to a virtual clinic/telephone call format; it is hoped that face to face clinics will return soon but probably with a slightly different format. Please be aware that clinics may have to be cancelled at short notice in this current climate.

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

16th July

24th September

26th 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 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 June

4th-5th October



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, especially at the moment, 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 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.

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.



Fundraising March by Mathsoc at University Dublin

For the whole of March, the Maths Society at Dublin University were raising funds for WSUK and the Irish Cancer Society. One of their committee members, who is also part of our WS community gave a virtual presentation explaining about what WS is and how WSUK helps.

This event involved participants walking/running/cycling as much as they feel comfortable with during the whole of the month of March. Participants then recorded the distance they had travelled (using a fitness watch, phone etc.) and input this value, alongside their name to the fundraising page. They could donate any amount.

We have now received our share of the funds, they were also raising for the Irish Cancer Society. We received **£132.94** and thank everyone that took part in raising these funds for us.

Return to the Office Charity Bake Sale

The Shah's, parents of one of our younger members, organised a bake sale at work at the end of March, as the first phase of restrictions eased and they were able to return to the office to work. They raised funds for WSUK and WellChild. We have received a **£153.40** from this.

Thank you so much for all the work you put into organising this. The cakes look lovely.



Donations in Memory

WSUK were chosen as the charity to benefit from the passing of a WS affected adult by his family. Friends and family donated **£1437.32** in his memory. We thank them all for their generosity at this time.

This gentleman hadn't been known to WSUK before his passing but on speaking to his father we were told that he had worked in the Foreign Office when he was younger before having to 'retire' early. This is proof that you shouldn't let WS define who you are or restrict what you can do.



Charity Golf Day

Following on from having to cancel our Annual Charity Golf Day last year, I'm pleased to announce that this event will be happening this year on 1st October. This is a popular event with many of the teams have been taking part since the start. Within the space of a few hours of the invite being sent out we had 14 teams sign up for the day.

Penfold Verrall will very kindly be sponsoring this event

once again. This is always a great day for all that take part whilst raising funds for us at the same time. This year it also coincides with our first International WS Awareness Day.



80's music night

Our 80's night is back this year in Worthing, with local 80's tribute band, Synthony 101 providing the music. This is another popular event locally for raising funds for us. This will be taking place on Saturday 30th October.



Ways to Donate to WSUK

Payroll Giving

Payroll Giving is a flexible scheme which allows anyone who pays UK income tax to give regularly and on a tax free basis to the charities and good causes of their choice.

Payroll Giving donations are deducted before tax so each £1.00 you give will only cost you 80p, and if you're a higher rate tax payer it will only cost you 60p.

Payroll Giving (workplace giving) is a valuable, long term source of revenue, providing regular income to help charities budget and plan ahead more effectively. Employees can choose to support Wolfram Syndrome UK with a regular donation direct from their pay.

It's cheaper because its tax free – for example, a donation of £5.00 per month costs the basic rate tax payer £4.00 (the taxman pays the rest!)

Higher rate taxpayers- the only way to pass on your 40% or 50% tax to charities. Only 28% can be recouped via other ways of giving.

Birthday Donations



We continue to be thought of by WS members and their families when it comes to their birthdays; either through creating [Facebook fundraiser pages](#) or just from personal donations.

A big thank you to everyone who supports us in this

way.



Monthly Donations

Thank you to everyone that makes monthly or one off donations, fundraises for us or raises funds while they shop online. It all helps.

If you would like to set up a Direct Debit or Standing Order to make a regular monthly donation to WSUK, then please contact Tracy in the [office](#) for bank account details.

You could ask 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 (Gift Aid forms for [single](#) or [multiple](#) donations are on the website that can be printed off and sent back to us).



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 and do something different?

We are all learning to do things differently so 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 WSUK?

If you are still 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 us 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 our [website](#).

Website Shop

We have various items available for purchase on our website shop. All profits go straight back to the charity. Postage and packing charges are applied at the checkout for which we use PayPal. Why not have a look at the [shop page](#)?



Make your shopping count!



Want to help us raise more just by shopping online? Well now you can! It is 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!

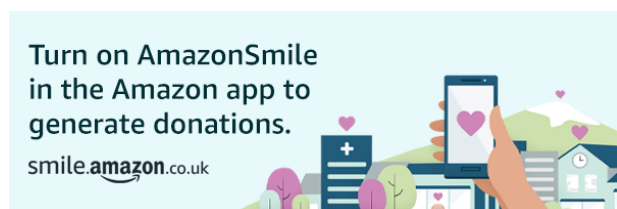
To date we have had over **£1054.00** paid to us just by people using these portals when they shop online. Help us increase this amount by signing up today!

Amazon Smile

AmazonSmile customers can now support Wolfram Syndrome UK in the Amazon shopping app on iPhones and Android phones! Simply follow these instructions to turn on AmazonSmile and start generating donations.

1. Open the Amazon Shopping app on your device
2. Go into the main menu of the Amazon Shopping app and tap into 'Settings'
3. Tap 'AmazonSmile' and follow the on-screen instructions to complete the process.

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



EasyPhotobook

At the very heart of our charity's soul is a driving force, a passion and vision to improve the lives of those with

Wolfram Syndrome. You can help us continue our work by creating and sharing a beautiful photo book, maybe of your family, friends or of those special moments we sometimes take for granted.

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, 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 and then post them to:

Wolfram Syndrome UK - 1152445
DCD Philatelics,
45 Wiltshire Lane,
Pinner,
Middlesex, HA5 2LY

You will be required to pay postage to send them but that amount will be added to the weight of the stamps when we are sent our payment.

I know that stamps aren't used as much nowadays, but birthdays and Christmas are still good times to collect them. You could save them up to send them off once or twice a year to ensure you have a good amount to send.



Your News



I am sad to report that Daniel Mulhern one of our members sadly passed away on 18th March 2021 with his mum Angela at his bedside.

On behalf of all the WS Community we sent the family a rose bush called 'Sweet Memories' as a living gift to help with memories of him. His mum is planting the rose under his bedroom window.

Starting a new college

by Georgina Fleming

I started at RNC, Hereford in September 2020, and have thoroughly enjoyed my time here. I have enjoyed having a community of people with similar visual impairments that can share experiences and advice.

Since starting here, I have grown in confidence, independence and knowledge. I study Biology, Maths and Literature A-level as well as a course in level 2 braille, IT, mobility and independent living skills. I have found the courses I am doing enjoyable and engaging as all resources are adapted to the needs of each individual student.

The social side is great, however due to Covid some activities have been limited but I have been able to participate in new sports, cooking and crafts which were lots of fun. I have made a lot of new friends, gained important life skills and I really love life here.

Crown Green Bowling

by Clare Caws

When I caught indoor bowling on TV I fancied having a go and marvelled at how they got the curve of the ball right to reach the Jack.

When a man with a guide dog, who I barely knew, said he was getting interested people together for Crown Green Bowling, I thought I would give it a go. Luckily a few people who attended had bowling experience for those of us with no idea!

I learnt how the balls...um I mean woods are weighted on one side to make it curve towards the Jack. Although the greens appear completely flat they have areas which have gradients away from the centre of the 'Crown' which we have to get used to and learn how to use the weight in the woods with the variation in gradient on the green (this is where the name 'crown green' comes from).

Now I and my guide dog Maggie meet several other people and dogs, who wait patiently, while we play the gentle game, sometimes holding competitions and planning trips! Our helpers are fantastic, standing in their hi-vis jackets marking where the jack is that we need to aim for, and preparing tea and coffee refreshments during the 2-hour session.



Birthdays (UK and worldwide)



June

Andrew
Michele
Jared
Norbert
Briana

Sophia
Shane
Andrea
Luke
Anton
Aya



July
Arkevon
Julie
Devanshi
Anniya



August

Helen
Ali
Nelson
Felix
Keri
Taybah
Morgan
Rebecca
Evie

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

Our mailing address is:

Wolfram Syndrome UK
9 Church Way
Worthing, West Sussex BN13 1HD
United Kingdom

