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Welcome to our Autumn Newsletter.

We have been seeing many changes over the last few months with sporting venues allowing in spectators, music festivals and so much more. Vaccination remains a priority especially as we start to move towards the colder winter months.

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

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Updates from Dr Ben Wright and Prof Tim Barrett

These will be updated to the WSUK website shortly

USA Trials and Research Updates

The latest research updates from Dr Fumi Urano at Washington University, St Louis, USA can be found on our website. Click [here](#) to read it.



Gene Therapy to get a treatment for Wolfram Syndrome

The Spanish WS Association are proud to announce that, together with researchers from the Autonomous University of Barcelona (UAB), they have started the first gene therapy project for Wolfram Syndrome.

2 years ago, they joined a small group of families with a clear goal: to fight for a cure for this ultra-rare disease.

During this time they have collaborated with researchers from around the world to advance along this path.

Now they are taking one more step and with this project they are at the forefront of the fight against this disease. This research will last 2 years and may benefit all those affected by Wolfram Syndrome in the world.

Learn more about the project at
[Tratamiento Síndrome de Wolfram con Terapia](#)

[Génica \(afasw.com\)](http://afasw.com)



Therapeutic Advances in Rare Disease

A paper was published during August by the team at Cambridge University Hospital looking at new pathophysiological insights and therapeutic strategies. This paper has been added to the WSUK website but can also be found [here](#).

First NIHR Moorfields Eye Charity partnership fellowship awarded

Dr Patrick Yu Wai Man has been awarded funding for his Advanced Fellowship to evaluate patient outcomes and therapies for inherited diseases that damage the optic nerve. This research programme does not include Wolfram

syndrome, but it might bring parallel benefits. To read in full click [here](#).



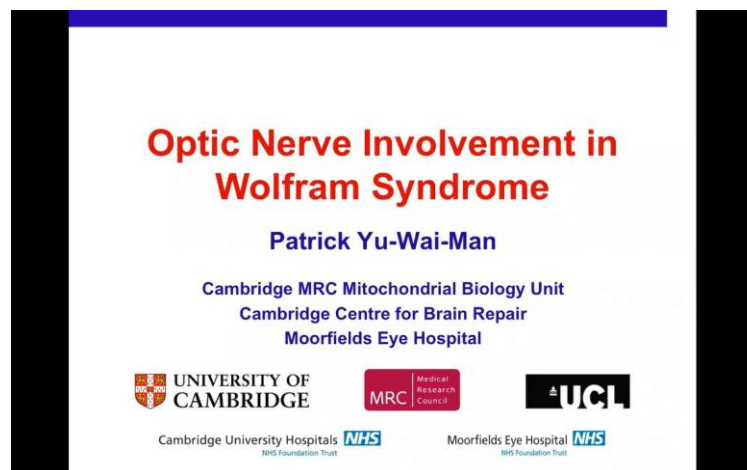
WS Conference

In July, our Board of Trustees made the decision to move the face to face conference to a virtual event. This was a difficult decision as we know how many of you wanted to be able to meet up, but with new cases increasing at that time it was felt to be in everyone's best interests to go virtual again for both dates.

The programmes, with links for registering for each presentation, for both events have been emailed out to everyone but you will also find them on our website [here](#). Both events are open to all our global community, affected individuals

as well as medical professionals. We hope that many of you will join us live, or you will be able to watch the presentations from our website once uploaded.

Each presentation has its own registration link so you can decide which one(s) you would like to watch without having to sit through them all. Just make sure you register for each one you would like to join.



Wolfram Syndrome Global Awareness Day

1st October will be the first ever WS Global Awareness Day. Along with some of the other WS organisations around the world we are

hoping to raise awareness amongst Ophthalmologists, Endocrinologists and Diabetes teams about Wolfram Syndrome. We are also aiming to raise public awareness by asking some of our communities to share their stories with their local media, to organise fundraising events on or around this date and also join us in a social media relay. This will be happening across the globe in all countries where each group has contacts.

If anyone feels they would like to contact their local newspaper, radio station etc. then please let the WSUK [office](#) know and we can send you a press release you can adapt and use to send to them.

As you can see a logo has been produced along with a separate website where specialists, doctors, public can go for more information.



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, especially after the last 18 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!

New Member to the WSUK Team

From 6th September we have a new member of staff joining our team, Mel Knowles. She will be working 14 hours a week over 4 days in an Adult Support role. As she settles into her role we will

send out more details about how she may be able to assist you.

Here are a few words from Mel introducing herself:

“I feel extremely privileged to be joining the wonderful team at WSUK and have already been made to feel so welcome by everyone. Coming from a background in healthcare and wellbeing support I feel excited at this opportunity, and am very much looking forward to working with and supporting the WS community. I look forward to meeting you all virtually over the coming months.”

News You Can Use

Gene People Partnership Network

Gene People Genetic Counsellor-led Helpline
0800 987 8985 / helpline@genepeople.org.uk

The Helpline runs Mon-Thurs 9-5 and is here to help with any condition and support any member of the family. The callers simply leave their name, number and the name of the condition they are calling about on a message and the team will call them back or they can email using the dedicated email address.

The Helpline gives free, independent support and information. It does not refer, order tests or prescribe. Callers often want to know what tests to discuss with their clinician, what things mean in the information they've been given and what the ramifications are.

Anyone with any genetic condition, and their family members can get in touch. It is not limited to immediate family members, and those in the wider support network, such as teachers, nurses and social care workers can call. Importantly,

there is no time limit to the calls: the caller takes the time they need.

So, if you have some questions for a registered genetic counsellor, do give them a call: 0800 987 8985.



Disability Grants

Your Guide to Grants for the Disabled

Do you have a Disability?

Are you a parent or carer of a Disabled child or adult?

If so, use this [website](#) to save time finding Disability Grants.

Charities and Trusts provide funding towards the high cost of disability equipment, holidays,

housing, days out.....in fact anything above and beyond the normal costs of everyday living.

Searching for extra funds takes time - in between work, hospital appointments, caring, therapies.....

And the hundred and one other things we all have to juggle every day!

That's why Disability Grants is here to help YOU, your family or anyone you're supporting with a disability.

Discover what's available nationally and in your local area by searching the individual sections.



Inclusive Gym Membership - UK

GLL is a not-for-profit charitable social enterprise committed to delivering a better quality of fitness

and leisure, libraries and performing arts facilities for everyone. They're committed to providing access to quality community facilities - and more - at a price everyone can afford. They already manage over 258 facilities, and they're adding more all the time operating under their 'Better' brand.

They aim to get more people, more active, more often. They promote healthy and active lifestyles, giving communities access to facilities that help improve their health and happiness through participation in activities. It could be gyms, libraries, playgrounds or world-class venues such as those on the Olympic Park.

They will ENGAGE and welcome new participants, introducing them to activities that reflect their needs.

They will SUPPORT our communities to make lifestyle changes through targeted programmes.

They will ADAPT their approach and offers to ensure everyone can participate in their services.

They will SUSTAIN participation by offering varied programmes, facilities and memberships.

Choose accessibility for everyone

They believe activity is for everyone and that's why they offer a range of memberships to suit your requirements. Their Inclusive membership gives people who are registered as disabled access to their local gyms, swimming pools and fitness classes. You can also use the facilities at over 200 centres across the UK.

Bring it to Better, where you'll find a welcoming environment to discuss your personal requirements with their friendly fully-trained staff.

To find out more go to their website [here](#).



News from Humanware

Humanware have an exciting reading machine Hark Reader, which turns text into speech immediately.

Hark Reader is available from £1495 and includes a FREE Battery and FREE Carry Case.
*(Offer available until 30th October 2021)

The wonder of the new Hark Reader is how fast and accurately it will turn printed text into speech with a choice of regional human sounding voices. Ready to use out of the box, simply turn Hark Reader on, place a document on the surface and Hark Reader will instantly start

reading.

No wi-fi needed, no buttons to press, no fuss, just sit back and enjoy reading. Place your letter, book, magazine, newspaper article, medicine box, food packaging, or any printed text on the surface of Hark Reader and within just one or two seconds it will be read aloud. Choose from a selection of naturally sounding voices from around the UK.

To stop reading, simply remove the document from the surface and place your next item on the top.

Hark Reader can be used visiting family and friends or even further afield on holiday. With the optional battery pack Hark Reader can be used anywhere, its' sleek, lightweight compact folding design means it can be easily stored or moved. An optional keypad gives the facility to navigate forwards and backwards through a document by para-graph, sentence, word or character.

For more information please visit [Humanware](#) or call Freephone 0800 587 2589 to book an in-person demonstration.

If you would prefer a virtual on-line demonstration, visit [HarkReader Demonstration](#) and book a convenient time and date.



Face Masks

Do you know someone who would like one of our facemasks or would you like another ready for the winter season? Although at the time of writing facemasks are no longer mandatory, it is likely we will be advised to wear masks again when out in public during the winter to help reduce the risk of infections.

We have some stocks of our washable face masks left, which we are now selling for £7.50 each, with postage starting at £1.00 for up to 3 masks.

These masks are lightweight with a fluid repellent outer layer and an antimicrobial inner layer. They have 2 round the head adjustable elastics which you could change to over the ears if you preferred with some adjustment.

All profits go straight back to the charity.

Thank you for supporting us this way.



Contact the [office](#) to place your order.

Useful items you might like

1. A new deodorant has been launched called Sure Inclusive. It is a new design that anyone can use. It has a braille label with instructions, an easy grip shape and a larger roll on applicator.
2. For those of you who struggle with the heat, when we get it, there is a wearable neck fan you can purchase that is designed to be worn like

headphones. They're battery operated using a USB charger too. These can be purchased for £12.99 from [Amazon](#). There are others available on the site. Don't forget to purchase using Amazon Smile and you can raise funds for WSUK for free at the same time.

3. Also available from [Amazon Smile](#) is the Geemarc extra large keyboard. The keys are bright yellow with extra large black bold print to help people with a vision impairment. Price currently £24.71.

Project Updates

Caregiver's WellBeing Project Update

This pilot project, funded by the National Lottery Community Fund, has made good progress

throughout the summer. Almost all of our 20 carer participants have been able to start or continue their wellbeing activities following the easing of restrictions, with 5 carers now fully completed.

As the pilot is heading towards completion, we have started planning for the next phase. Our goal is to apply for new grant funding that will enable us to launch a second phase of the project. Feedback provided by our current carer participants will form an important part of our new funding application. Thank you to all our carers who have shared very positive feedback so far – your contribution will provide important evidence for potential funders. If you are a participant who has not yet been able to give feedback, please get in touch with Marie (mariemcgee@wolframsyndrome.co.uk) or Tracy

(admin@wolframsyndrome.co.uk) to share your thoughts.

This autumn we will be sending all our WSUK carers a short Registration of Interest Form that will help us understand the number of carers who are potentially interested in being part of a second phase of this project.



Wolfram Syndrome UK Breaking Down Barriers Project Update

Our Year 2 Breaking Down Barriers (BDB) project has made good progress during the summer:

1) New BDB webpage –

The new [BDB webpage](#) is now available. This

new page provides updates and information from our project and broader work, which currently includes:

- links to helpful organisations for BAME communities
- short intro videos in English, Urdu and Arabic
- link to the dual language leaflet (English / Urdu) – Understanding WS

2) Video clips of your experiences.... –

to read the full update click [here](#)



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.



Brighton Marathon

On Sunday 12th September, Lewis Gardner brother to Abby a WS affected adult and WSUK

Trustee, will be running the Brighton Marathon for us. He has set a target of £500 and at the time of writing he was half way to reaching this.

His fundraising page can be found [here](#).



Charity Golf Day

Following on from having to cancel our Annual Charity Golf Day last year and a double booking for this year, This popular event has been booked for 1st October.

Penfold Verrall will very kindly be sponsoring this event once again with a lot of the teams that have played previously ready to sign up. This is always a great day for all that take part whilst raising funds and awareness for us at the same

time.



80's music night

Another popular event is our 80's night. This is back again and being held on 30th October with 80's tribute band, Synthony 101, providing the music supported by Disco Kings.



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:

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:

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.

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, as we are still waiting for pictures and information from some of the clinicians but it will be hopefully very shortly.

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.

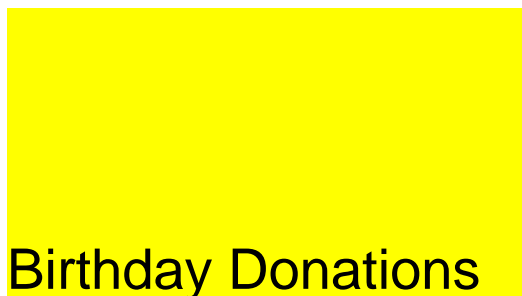
Payroll Giving donations are deducted before tax so each £1.00 you give will only cost you 80p, and if you're a higher rate tax payer it will only cost you 60p.

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 (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?

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 charity?

If you are working from home why not donate the cost of one day's commute to us each month.

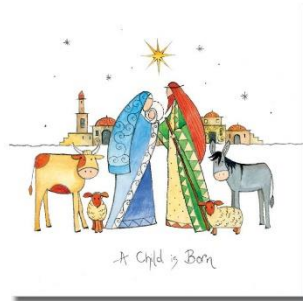
We appreciate that times are hard for everyone but whatever you can do to help fundraise will be greatly appreciated by us all.

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 our [website](#).

Website Shop

We have various items available for purchase on our website shop including our ever popular Christmas Cards with 7 new designs. 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 retailers website, so you don't need to worry about forgetting. Simple!

To date we have had almost £1000.00 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.

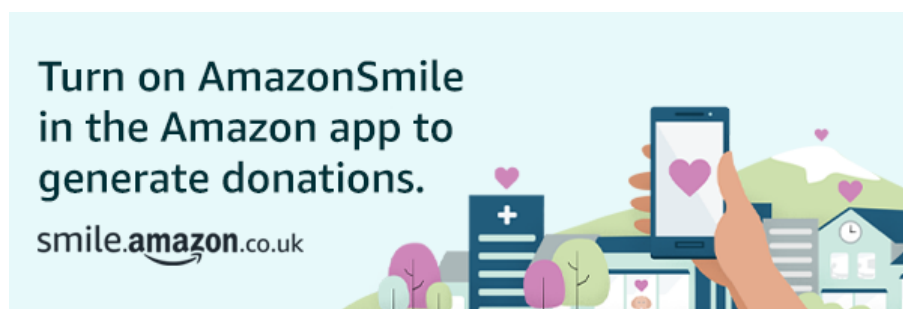
1. Open the Amazon Shopping app on your

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

Birthdays (UK and worldwide)



September

Gavin O'F

Melissa

Jordan

Leila (Matsatso)

Cory

Ellie



October



November

Aaron

Finlay

Asal

Clare

River

Mariam

Ellie

Asif

Luqman

Chloe

Eddie

Alessandra

Zoe

Nihan

Jennifer

Happy birthday to you all!!



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