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Welcome to our Autumn newsletter.

We have been keeping in touch with many of you during this very different summer via email, telephone and Zoom. We've had informal Zoom chats with you which we plan to continue and is just the chance to chat about anything and Question and Answer sessions with our professionals with questions submitted by you.

The more formal ones have been recorded and added to our [Covid-19](#) news/information page on our website. Information is being added as we receive it about related issues, so it is worth checking back regularly.

This newsletter doesn't have much fundraising

content due to the restrictions of the last few months but does tell you how YOU can fundraise for us whilst shopping from home and more.

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 news of what you have been doing. These can be sent to us at [admin@wolframsyndrome.co.uk](mailto:admin@wolframsyndrome.co.uk)

An audio version is posted on to Facebook/Twitter as well as the website. If you would prefer the audio version to be emailed to you then please let me know.

## News

### UK Clinical Trial Update



Due to the current situation there has been a temporary halt to recruitment for both the children's

and adult's trials. As soon as we have any updates these will be emailed out and put on the website/social media etc.

## **Zoom check in's with WS Community**

We have been holding regular check in's with our community via the Zoom platform, both formal and informal chats.

We've held monthly ones with the medical teams in Birmingham and guest speakers with questions submitted by you beforehand. These have been recorded and then uploaded onto our [YouTube](#) channel as well as the [Covid-19](#) news page on our website for those unable to join on the day or to watch back again.

We have also had some informal chats with group of you. These are the chance to chat, ask questions between families or to connect with someone from outside your household. We plan to continue with these fortnightly for the rest of the year at least.

Please do join in with these if you can, even if it is just to submit a question on that month's topic. If you have problems connecting using the link sent out, then please let us know and we will endeavour to help you get connected.

## **Hidden Disability Shop**

The Hidden Disability shop has sunflower lanyards, face covering exempt cards and other sunflower items that can be purchased [here](#).

## **WS Conference**

As you will now be aware from email communications, Conference this year has now been moved to a virtual conference.

We have 2 dates for workshops and presentations.

We will be holding a Urology presentation on the 19th September at 2.00pm (BST). You will need to register for this and the link will then be sent to you.

On 26th September we will be holding workshops to include Ophthalmology and Speech and Language in the morning. You will need to register in advance as numbers will be restricted for these sessions.

In the afternoon we will hold the presentations which will include a presentation about drug research from Estonia; a TREATWolfram trial update and an Ophthalmology presentation about Optic Nerve involvement in WS. Register for the presentations you would like to watch and the relevant links will be sent.

Each presentation will be recorded, so for all presentations the audience will be muted and you

will only see the speakers on screen. Any questions will need to be put in 'Chat' or 'Q&A' during the session. The questions will then be asked at the end by the hosts. Any questions that we don't have time for will be asked of the presenters after and emailed back to the person who asked as well as put on the website with the video.

The full programme with links to the registration can be found on the website by clicking [here](#).

As this is a new way of doing this please bear with us for any issues that may arise.

Next year's date is Saturday 25th September 2021 at Whittlebury Hall.

Zoom video presentations from this year's conference will be posted onto the [WSUK](#) website and the Wolfram Syndrome UK [YouTube](#) channel once they are ready.



**Kidz to Adults Exhibitions**

The largest FREE UK events supporting children and young adults up to 25 years of age with disabilities and additional needs, their families, carers and the professionals who support them.

Due to Covid all the dates for this year have been cancelled. Dates and locations for 2021 as well as other information can be found on the Disabled Living website [here](#).

### **Carer's Wellbeing Project Update**

20 of our parent carers are taking part in this pilot project. This means recruitment for new carers is currently closed.

Each carer will be able to participate in their chosen wellbeing activity, which will be purchased by WSUK (up to £300 per carer).

Some of our carers have already started their wellbeing activities – including spa and beauty treatments and complimentary therapies. Others are waiting for further easing of restrictions or until they feel ready/safe to start.

If you are carer and would be interested in participating in this project in the future (subject to funding), please contact the [office](#) or call 01903 211358.

This pilot project is being funded through a grant from the National Lottery Community Fund. Thank

you to all the players of the National Lottery from everyone at WSUK.



## **WSUK Breaking Down Barriers Project Update**

WSUK is conducting a project with Black Asian Minority Ethnic (BAME) families affected by WS called “Breaking Down Barriers”.

As part of this project, 17 members of our BAME WS community have shared with us their experiences of living with WS, their interactions with WSUK and how we can better support our BAME families in the future. To each of you who have taken part, thank you so much for sharing your feedback, which is really valuable for our future activities.

You will see more on this project later in the year, including a new Breaking Down Barriers page on our website.

If you are part of our BAME WS community and would like to share your experiences and feedback, please get in touch via email to the [office](#) or call 01903 211358. We would love to hear from you whether you are WS affected, sibling, parent, or wider family member.



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



## **Medical Exemption Certificates**

A reminder, if you are 16 or over and no longer in full time education, you need to apply for a Medical Exemption Certificate so you can get your prescriptions for free.

Click [here](#) for the link for the website page that has all the information about this certificate and if you can apply.

On the ‘How to apply’ drop down it does say that you need to request a form from your doctor to apply.

## **Face Masks**

On 13th July, we sent out washable facemasks to our UK affected members and for 1 other person



in the household where relevant. This was well timed as the Government then announced that the wearing of facemasks would become mandatory in shops from 24th July. Thank you to those of you have contacted us and sent us photos, to say how much you like the masks.

We have some more in stock now which we are selling for £15 each with postage extra. All profits go straight back to the charity. Thank you for supporting us this way.

Here is some guidance around Face Masks from Prof Barrett:

It is likely that wearing masks in public spaces helps reduce transmission of Covid19. Read more [here...](#)

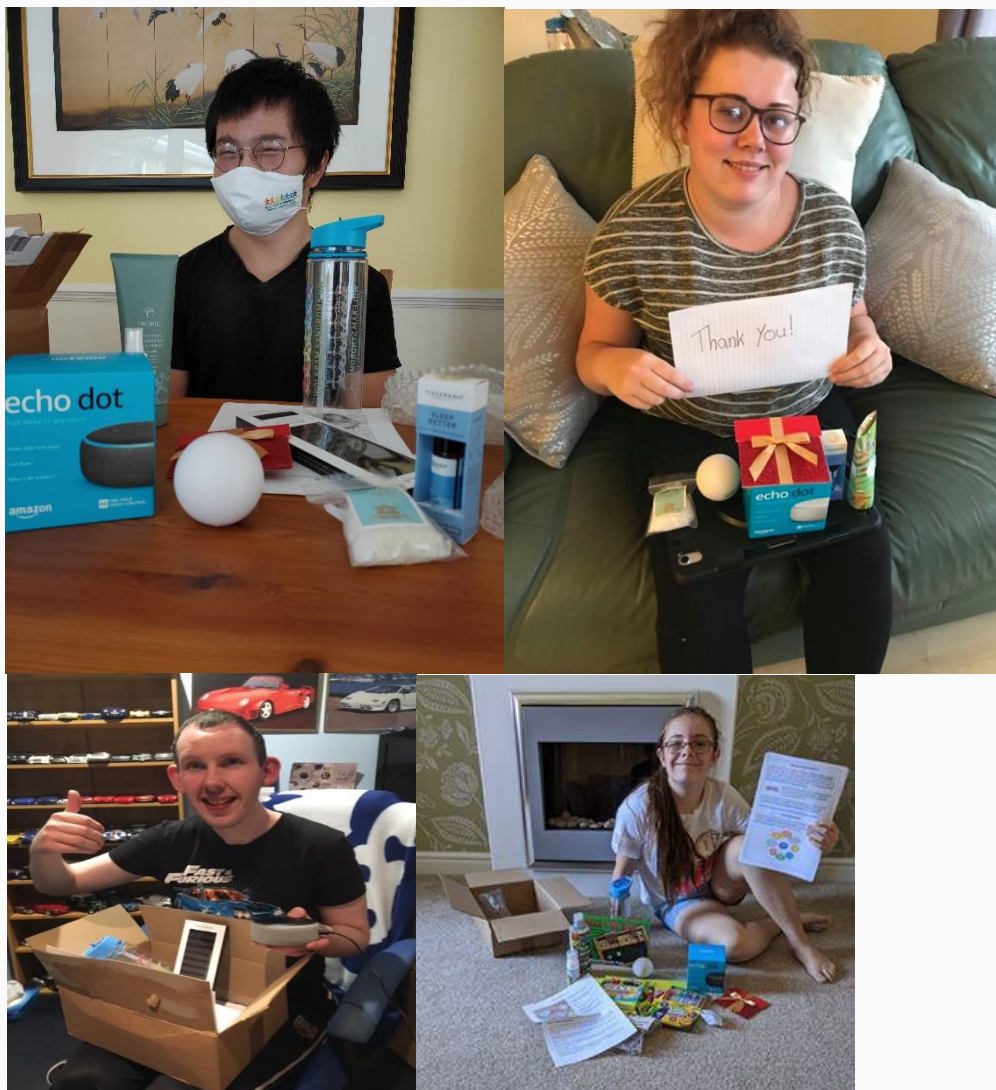
### **Wellbeing Boxes**

At the end of July all UK affected members (that we have details for) were sent out a 'Wellbeing Box'. This was made possible with funding from the National Lottery Community Fund and HM Government's Coronavirus Community Support fund to help us support our community.

These arrived with great surprise by you all as no one was expecting these, especially after receiving the facemasks.

Many of you contacted us straight away to express your surprise and thanks. All the comments we

received were positive and will be fed back in our 'End of Grant Report' that has to be done. Thank you to all of those who also shared photos of you with your boxes. It was fantastic to see so many happy faces!



## **Distance Aware Badges**

Those of you who follow social media may already know about the Distance Aware logo. This is an initiative started by NHS Wales and The Bevan Trust. It is now being shared and used around the whole of the UK.

We have produced some badges which some of you

will have already received, the rest are on their way. They are a simple design with a double ended arrow, a polite way of please distance. This badge is for use by anyone with concerns about social distancing.

If you know anyone who would like one or if you want more then, just contact the office. All we ask is for a donation towards the cost and postage. There are 5 colours but we can't guarantee colours sent out.

On the website there is some more information about this along with links to pdf posters you can print off for home, school, work etc. There are 3 messages in each of the 5 colours.



Post a picture with your badge on social media using #DistanceAware.

## **New - Genetic Alliance UK partnership with the MedicAlert Foundation**

GAUK are proud to announce their new partnership with The MedicAlert Foundation, the UK's only charity providing medical ID services. This partnership will allow those with genetic, rare and undiagnosed conditions to save 10% on The MedicAlert Foundation's service, while also raising valuable funds for Genetic Alliance UK.

MedicAlert protects those with underlying medical conditions, keeping them safe in emergencies, by ensuring that care decisions can be made based on their needs. As a MedicAlert member, your record will detail your conditions, allergies, medications, history, implants and emergency contacts, as well as scanned documents such as health management plans, advance decisions and reports. Your record will..... read more [here](#).

To learn more about MedicAlert go to their website [here](#).

## **Fundraising and Upcoming Events**

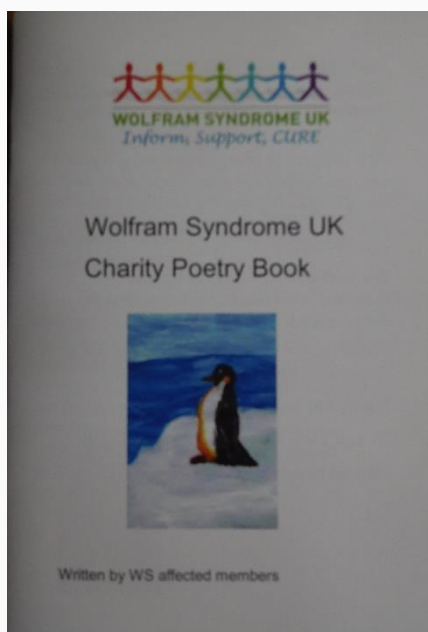
Upcoming events can be found listed on the events page of the Wolfram Syndrome website [www.wolframsyndrome.co.uk](http://www.wolframsyndrome.co.uk)

Remember to keep checking the website for upcoming events, any recent news articles & links.

## Poetry Book

Our Charity Poetry Book is available to buy. It has been created using poems sent in by some of our members.

The poetry book is £2.50 with £1.00 p&p. All the profits go straight into the charity account. You can purchase from the shop page on the [WSUK website](#) or by contacting the office.



## Hair today.....

The friend of one of our families decided to take

on a challenge for us slightly different to something she would normal do. This is what she had to say -

"Usually I'd take on a physical challenge and jump off a very high bridge or swim up the river or walk a very long way. But three months after having the virus I'm still not quite up to par. So I've gone for something a bit more obvious with a bit more pow(!) factor. I'm going to, or rather my friend and top hairdresser Hayley Simpson is going to shave my head.

I wanted to show solidarity with my friend's daughter who is affected by Wolfram Syndrome. Usually a shaved or bald head draws some sort of attention, unwanted or not. This is what she faces every day with her dark glasses, ear defenders and long cane. She holds her head up and gets on with life."

On 12th July the lady in question, Jules Lang went ahead and had her head shaved. Jules had set a target of £1000 but has managed to raise with Gift Aid a total of **£4440.31!**

Jules also managed to get us a brief mention at her work the following week, when she was giving the travel news on BBC Radio 2's breakfast show with Zoe Ball. Zoe Ball compared her look to GI Jane.



Thank you for being brave to do this and raising such a fantastic total, Jules!

The link to her fundraising page is

<https://uk.virginmoneygiving.com/juleslang>



## **London Marathon**

Roseanna Marshall, a relative of one of our members, had secured a place in the 2020 London Marathon, which she was due to run in the week she celebrated her 30th birthday, the date was changed to 4th October but there have been further changes due to the continuation of restrictions. Runners will now be running 26 miles from home or anywhere in the world on a course of their choice. Runners are being allowed to defer their place to a future London marathon in



2021,2022 or 2023. Next year's date has already been moved to October instead of April.

Roseanna is running for WSUK and SANDS, both are causes close to her heart. We wish her well in this, especially as she won't have the usual crowds to cheer her on.

If you would like to support her then click [here](#) to go to her fundraising page.

## **WSUK Annual Golf Day**

Unfortunately due to the Corona Virus we had to cancel this year's event.

We would like to thank Penfold Verrall, who continue to support us with our fundraising efforts, for the planning they have done to this point and for agreeing to sponsor the new date for 2021

We thank the companies that donated prizes for our auction. We didn't waste them as we held a silent auction on the day to the golfers who would have played to raise some funds. With the auction and donations we raised **£3900.00**

## **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 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 have been very lucky to be thought of by several people 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.

## **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.



## **Clinic Dates 2020**

All clinic dates have currently been moved to a virtual clinic/telephone call format; but it is hoped that face to face clinics will return soon but with a slightly different format.

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

September 25th (Telemedclinic)

November 27th

If you are no longer able to attend the date you are invited to, **PLEASE** let the clinic team know so that someone else can be invited in your place.

**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:

5th and 6th 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 but will let it be known.

Places for both clinics are by invitation only, so please **DO NOT** book or make any travel arrangements until you have heard from the hospital. If you are unable to attend then **PLEASE** let Tracy or

the hospital know so that, the place can be offered to someone else.

## 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 for charity, try a virtual sing along, or have a virtual Big Night In and donate what you would have spent on going out to charity? Let us know if you do something different and we can include it in a future newsletter.

All the fundraising sites we are registered with can be found on our website.



## **Make your shopping count!**

Want to help us raise more just by shopping online? Well now you can .

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.

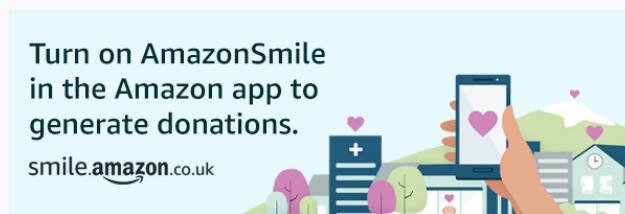
Links to register can be found [here](#); or you can click on the relevant image above to be taken straight through to the registration page. Install the reminder link so you will be asked if you want to raise a donation when you go straight to the retailer's website. Simple.

## **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.



## Monthly Donations

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.

Why don't you 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).



## **Facebook Donation Pages**

Did you know that you can now create donation pages using Facebook to raise funds for WSUK? We have had several people do this already using their birthday's as a way to fundraise instead of receiving presents. Click [here](#) to go to Facebook to create your page.

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

#### **September**

Matsatso Khachapuridze

Jordan Mandeville

Gavin O'Farrell

Melissa Hulse

#### **October**

#### **November**

Ellie Eagles

Finlay Stevens

Asal Damavandi  
Chloe Thorne  
Aaron Gough  
Clare Caws  
Georgina Fleming  
Asif Butt  
Jennifer Lynch  
Mariam Al-Takriti



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