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Welcome to our Summer newsletter in these strange times for all of us. We have been keeping in touch with many of you during 'lockdown' via email, telephone and Zoom chats. We have had a couple of informal Zoom chats with you which is just the chance to chat and a couple of more formal ones with our medical professionals and questions that have been submitted by you. These more formal ones have been recorded and added to our

[Covid-19](#) news/information page on our website.

Even though restrictions are being slowly lifted to allow for some to return to work and exercise more, whilst still practicing social distancing; we must still all ensure we take the same precautions as at the start of 'lockdown' to prevent the spread of this infection. Here at the WSUK office we are remaining self-isolated/shielding until the end of June at least, regardless.

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.

WSUK 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 me at admin@wolframsyndrome.co.uk

An mp3 and WAV version are 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.

ERN (European Reference Network) Eureka Registry

Early in April an email was sent out asking for any WS person that developed Covid-19 to get in touch with us at the request of Prof Barrett. This was so he could include figures into his weekly submissions to the ERN and also to get some idea of how patients with rare disease are being affected and how well they coped.

Please let us know in the office, admin@wolframsyndrome.co.uk, and we will pass the information on to Prof Barrett straight away.

Zoom check in's with WS Community

Since the beginning of April we have been holding regular check ins with our community via the Zoom platform.

We have held 2 formal ones with the medical teams in Birmingham 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 ones which are chance to chat, ask questions between families or just the chance to connect with someone from outside your household.

Please do join in with these if you can. If you have problems connecting using the link that gets sent out, then please let us know and we will endeavour to help you get connected.

New WSUK Trustee

We are pleased to announce the appointment of new Trustee, Abby Gardner, following the resignation of Darren Lynch and Michael

Chandler at the beginning of the year. Abby will represent those affected by Wolfram Syndrome as well as bringing a younger voice to the team.

WS Conference

At the time of writing this newsletter we are still living with restrictions to our way of life though some of these are starting to be eased slightly, but we still have no idea about what the coming months will hold and any future changes. No decision has yet been made about conference; at the moment it is still booked for happening on Saturday 26th September 2020 at Whittebury Hall.

We will keep you all updated via the website, Social Media and email. We are looking at alternative ways of running it so we don't have to fully cancel it. If we are unable to attend the hotel this year then those that have already

Kidz to Adultz 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.

Dates and locations for 2020/21 are:

WALES and WEST - Thursday 2nd July - The International Convention Centre (ICC), Newport.

SCOTLAND - Thursday 10th September. [Royal Highland Centre](#), Lowland Hall, Ingliston, Edinburgh
EH28 8NB

SOUTH - Wednesday 30th September
- Farnborough International Exhibition and Conference Centre. Farnborough

NORTH - Thursday 12th November - EventCity,
Barton Dock Road, Manchester, M17 8AS.

MIDDLE - Thursday 18th March 2021 - Ricoh
Arena, Coventry

More details can be found on the Disabled
Living website [here](#). Check for updates if you
are thinking of attending as these dates are
likely to change.

Carer's Wellbeing Project Update

To date, **13 of our parent carers** are taking
part in this project and a further **3-4** are in
active discussions with us about joining.

Each carer will be able to participate in their
chosen wellbeing activity,.. read more [here](#)...

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, we are inviting members of our BAME WS community read more [here](#)....

Medical Exemption Certificates

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

Following the advice given to us to wear masks when out in public where it is difficult to social distance, WSUK have purchased a triple layer, reusable face mask for each of our known UK affected community members and 1 other person in the household where relevant. It is therefore essential that we have the correct postal address for you. If you have moved recently and not told us please do so as soon as possible.

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](#)

As soon as we have the masks they will be sent out to our UK members.

Fundraising and Upcoming Events

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.

Poetry Book

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

The poetry book is £3.00 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.



Fundraiser by the Bukhari family

Late last summer the Bukhari family in Manchester held a fundraiser event at their family owned restaurant, Ashiana, to celebrate trading for 25 years for 2 charities, us being one of them. Money continued to come in to them in the way of tips etc.

As they aren't currently open, the family have now transferred the money raised for us into the charity bank account. The total raised was £680.00! A certificate of appreciation has been sent to them for displaying once they re-open to thank all their customers for raising so much.



London Marathon

Roseanna Marshall, a relative of one of our members, has secured a place in the 2020 London Marathon, which she was due to run in the week she celebrated her 30th birthday, the date has now changed to 4th October. She is running for WSUK and SANDS, both are causes close to her heart.

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

2.6 Challenge

As so many mass participation fundraising events have had to be cancelled this year, the organisers of these events including the London Marathon came together and created the 2.6 Challenge. This was launched on 3rd April to the public with the aim to get as many people and charities

involved in doing a fundraising event on 26th April, what should have been Marathon day for many, revolved around the numbers 2 and 6 or to just make a donation to charity.

We had a few donations and 2 fundraisers, both done with in the Government guidelines.

One was Jennifer Lynch, who has WS. She cycled on the exercise bike for 26 minutes and raised **£434.75** inc. Gift Aid.

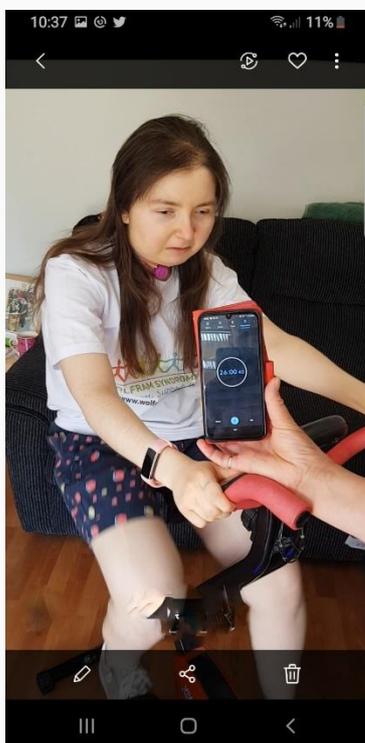
The other was Jennifer's PA and her 5 year old daughter. They ran and rode a bike up and down their road 26 times. They raised a total of £735.00 inc. Gift Aid. We contacted the young lady's school to inform them of what she was doing and received this reply from them -

It was so lovely to receive your email and to hear about S taking part in the 2.6

challenge. She certainly is a credit to our school and we are incredibly proud of her achievements towards such a worthy charity.

It was lovely to receive such positive news at this difficult time, and we will be sharing this with our staff and parents.

Jennifer also received positive comments from the Head and staff from her school.



In a recent update from the organisers of the 2.6 challenge over £10 million has been raised.

WSUK Annual Golf Day

Unfortunately due to the Corona Virus we have 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 have donated prizes for our auction. We won't be wasting them as we will be auctioning them off to the golfers who would have played on the day to raise some funds still. Sadly, some of the events we had vouchers for will have been cancelled due to the virus.

A Bungee Jump from [Buyagift](#)
£50 experience voucher from [Experience Days](#)

Afternoon tea for 2 at [Brigit's Bakery](#) in
Covent Garden

Weekday tour for 2 at [Silent Pool Gin Distillers](#)



Afternoon Tea
Experiences
Across
London



b-bakery.com
020 3026 1188
info@b-bakery.com



SILENT POOL
DISTILLERS

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

We have been very fortunate as a charity during these tough times to receive 2 large donations. One came from Danesfold Shoot which was just under £700 and the other from friends of one of our families, who are also now becoming regular supporters for us. They kindly made a donation of £800 and also Gift Aided it to take it up to £1000.00!

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 are currently to be confirmed as we have no idea how things will work over the next few months. Our WS Teams are looking at other ways to hold the clinics for you whether as a virtual clinic or telephone call.

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

July 17th (TBC)
September 25th (TBC)
November 27th (TBC)

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.

Please also ensure contact details are kept up to date.

For more information please contact [Tracy](#) at WSUK.

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 (TBC)

If you would like to be referred for a clinic, or have a child you would like to attend, please contact [Jody](#) (Children's clinic/transition) or [Tracy](#) (both clinics).

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 the Jody or Tracy know so that, that place can be offered to someone else.

Activities for increasing happiness

During uncertain times it is common to feel unhappy or suffer from low mood. Although this can be very difficult, it is possible to increase your happiness and improve your mood. There are many ways to do this, inside and outside of your home.

The three most popular happiness practices that currently exist are mindfulness, kindness and gratitude.

Below are lists of activities that are a part of these practices that may help you to feel happier and more relaxed. Read the full article [here](#).....

There are also some VI accessible exercise links on the [Covid news](#) page on the website.

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, especially whilst many shops are only selling online.

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.

Update on Give as you Live - Amazon is no longer linked with this portal. Don't worry though if you are an avid Amazon shopper you

can still raise funds for us by using Amazon Smile, the same service and cost as usual. Here is the [link](#) to change your account or you can wait for the little pop up to appear, could be a while for that.

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)

June

Andrew Tolmie

Jared Bennett

Norbert Azzopardi

Shane Roberts

Andrea Millership

Luke Gough
Anton Todorov

July

Arkevon Grandberrry
Julie Fox
Devanshi Chauhan
Anniya Parveen

August

Helen Gripaios
Nelson Rodda
Felix Rodda
Keri Chambers
Morgan Carlier
Rebecca Balmforth
Evie West



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