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Welcome to our Winter e-newsletter.

This quarters newsletter contains news updates, information about conference, fundraising events, how you can get involved and more.

Please remember to send me 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 version will be posted on to Facebook as well. If you would prefer the audio version to be emailed to you then please let me know.

Wishing you all a very Merry Christmas and a Happy New Year!

News

New WSUK website

At the end of conference, we launched our new look website. It has a fresh new colour scheme and is easier to navigate. Colours have been chosen with VI members in mind. There are new pages with information as well as a translator button at the bottom of the page.

Please let us know what you think of the new site and if there are any languages missing that you think should be on there. Web address is still the same www.wolframsyndrome.co.uk. If you have any problems accessing the site then please let us know.

Zebrafish Research Model Update

Last year WSUK made a donation to Dr Patrick Yu Wai Man who is using a zebrafish model to research the effect of WS on the eye. Read the update on his work [here](#).

UK Clinical Trial Update



To read the latest update on the TreatWolfram trial click [here](#)

PROMSWiSe Project

Those of you that are affected by WS will have received information about the PROMSWiSe Research project, either via email or post. This project is linked to the TREATWolfram trial but isn't just for those on the trial. No medication is involved in this project.

Some of you have already responded and Dr Slade, who is running the project, and WSUK thank you for this.

Others are yet to respond. If you could either return your completed invitation forms to the WSUK office or directly to Dr Slade it would be appreciated. If you don't wish to take part, then please let the WSUK office know and that way we won't keep sending you reminders about this. A certain number of participants are required and that number has almost been met.

If you would like to take part but have lost the paperwork please let the office know and we can resend them to you.

A Cost of Illness Study Report

A report has recently been published in the Orphanet Journal for Rare Diseases, which evaluates the burden of Wolfram Syndrome in the United Kingdom. Professor Barrett and Dr Richard Thompson, from Findacure, were both involved in this study along with 4 other medical professionals. To read the report click [here](#).

VICTA

In October VICTA launched their new Parent Portal. The aim for this Portal is to be a one stop information hub for all parents and carers raising a child who is blind or

partially sighted. WSUK are listed on the portal under eye conditions. Click [here](#) to go to the site.

Just Can't Wait!

One item I thought would be of interest comes from the Bladder and Bowel Community, b&b. They have produced a card and an app that tells someone when you show it that you have a medical condition and need to use a toilet quickly. Some places such as pubs or restaurants only allow on site customers to use the facilities. Now if you show this card or app to retailers, restauraters, publicans or hoteliers they should quickly understand your urgent needs and direct you towards the nearest available toilet. It is hoped that with this means of communication it will provide people with bladder or bowel problems the confidence to participate in more of the social activities they have avoided in the past.

Whilst researching for information for this newsletter I received a e-newsletter from the MoneySaving Expert website with top tips to help people with disabilities as one of the topics.

All you have to do is fill in a form and a few questions online and a card will be sent out to you.

For more information click [here](#) or call Freephone 0800 031 5406.



Also have a look at the MSE [website](#) as you might find other helpful information and advice here

WS Conference

Save the date Saturday 26th September 2020 at
Whittebury Hall.

For 2020, the decision has been made by the Trustees to slightly change the way your room bookings and payments are made for conference, following the costs we had to pay for people not attending this year for rooms, dinner and conference day rate.

We will be asking for you to pay your part of the room cost directly to us in advance instead of to the hotel when you check out. This way you can also spread the cost prior to conference. You will still be required to pay for any food and drink you purchase when you check out. If you cancel in the 3 weeks before the conference, so **after** our cut-off date then the money you have paid won't be refunded as we still have to pay for the room, your delegate fee and the meal if were staying on the Saturday; as the food is ordered as soon as I email our final numbers to the hotel. If you cancel before the cut-off date then you will receive a full refund!

This isn't a decision we have made lightly but we had to pay £739 for nonattendance this year. This could have been used elsewhere by WSUK and Jody at WellChild. Please remember conference is paid for from fundraising and donations!

WSUK members still get a better deal than some other Rare Disease patient groups for conference. Others charge family members, medical professionals etc. to attend the actual conference as well as having to pay higher room costs for each night they stay.

Further details and the booking form will be put on the website as well as future newsletters and social media pages.

Below is an infographic of this year's actual costs for putting on conference.



Video presentations from 2019 can be found on the [WSUK](http://www.wsuk.org) website and the Wolfram Syndrome UK [YouTube](https://www.youtube.com/channel/UC...) channel.



Stephen Bassett Achievement Award

The Stephen Bassett Achievement Award is given in memory every year to any person within the WS community. The winner is chosen by the WSUK Trustees from the nominations sent in by you.

This year the award was given to Abby Gardner. She has overcome issues regarding her mental health and her eyesight getting worse whilst changing university after her first year and getting a 2.1 at the end of her 2nd at a new university. Dealing with the transition from one setting to another as well as living independently can be daunting for anyone but when living with a condition like WS it makes this much harder. We believe her to be a great role model as she isn't letting WS stop her from

achieving her dreams.



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 so far are:

Wednesday 4th March. Ricoh Arena, Coventry

Thursday 7th May. Farnborough International Exhibition and Conference Centre, Farnborough.

Thursday 2nd July. Thornbury Leisure Centre. Bristol.

More details can be found on the Disabled Living website

[here](#)

Rare Revolution

A first of its kind, digital magazine giving a voice to those affected by RARE conditions and the charities that represent and support them. You can sign up to receive their free quarterly magazine straight to your inbox by going to their website [here](#).

Grant Funding News

We are pleased to announce that Gina our Grant's funding co-ordinator has successfully secured funding for WSUK for a couple of pilot projects which will both be starting in the next few months. Watch your in-boxes, social media pages and the newsletter for more about them as they start to happen.



Fundraising and Upcoming Events

Upcoming and past 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.

Charity Christmas cards and Poetry Book

Our Charity Christmas cards are now available for sale as well as the Poetry Book created using poems sent in by some of our members.

Cards come in a pack of 10 of just 1 design for £3.25 a pack, less expensive than some other charity cards in the shops. Postage and packaging is extra. 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. Images of all the designs can be found on the website and on our Facebook/Twitter pages.



Rare Disease Day

Rare Disease Day is an annual event held on the last day of February, next year being a leap year it is 29th February.

We would like to ask you to get involved now! Ask your child's school, or your school/college, ask your work place or ask a friend or family member to ask

their place of work if they would hold an event for us on Rare Disease Day or the day before as 29th is a Saturday.

We already have a school local to us that will be holding an odd sock and wacky hair day as well as a cake sale, with our CEO going in all through the week giving a presentation to all year groups during their assemblies. They are also planning on holding discussions and hopefully some other things like quizzes during their Tutor Group sessions at the start of the day to help raise further awareness about WS and other rare diseases.

You could organise a dress down day, odd sock, cake sale or other fundraising idea to raise funds. If you organise something then please let me know and we can include it in the newsletter along with any photos you might have.

For further information about Rare Disease Day or to get ideas go to their website [here](#).

London Marathon

Roseanna Marshall, a relative of one of our members, has secured a place in the 2020 London Marathon which she is running in the week she celebrates her 30th birthday. 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.

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 it's 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.

Challenges for WSUK

Do you know anyone that is running a marathon, full or half, a 10K race, a bike race or any other extreme challenge? Ask them if they would be prepared to do it for WSUK? Are you or anyone you know up for the challenge? Let us know. We will help promote what they or you are doing in the newsletter and via Social Media. We will help where we can with local media as well.

We are registered with [Doitforcharity](#) if you want to take part in an organised event. Click the link above for more details of what they offer.



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.



Clinic Dates 2020

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

January 24th

March 27th

May 22nd

July 17th

September 25th (day before Conference)

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. Please also ensure contact details are kept up to date.

Recruitment clinics for the TREATWolfram Trial will be held separately to the above dates.

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:

13th and 14th January
2nd and 3rd March
1st and 2nd June
5th and 6th October

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.

WS Members Section

Congratulations!

For those of you who knew the late Stephen Bassett and his wife Kelly, we would just like to share this news.

Kelly Bassett and her fiance Richard welcomed their baby son to the world on 15th November weighing 6lb

6oz. Although we lost Stephen 4 years ago Kelly is still part of our WS community and we wish her and her new family much love at this happy time.

More news/stories from our members can be found on the WSUK website - [Your Stories](#) page. This page will be updated as we get the stories in.

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. You could sell cakes to work colleagues, have a dress down day in the office, organise a small raffle, or have a karaoke night in your local pub. [read more](#)

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



WSUK is registered with Virgin moneygiving, so if you are considering taking part in

a sponsored event you can create your own fundraising page to get online sponsorship (Click on image). This is also for anyone that would like to make an [online donation](#). We are also registered with [Wonderful.org](#) and [Total Giving](#).

If you would also like paper sponsorship forms then email us at the charity office and we will email you a form to print off as many times as you like:

admin@wolframsyndrome.co.uk

Don't forget to ask people to Gift Aid their donation!



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.

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

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 (a form is 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)

December

Abby Gardner

January

Amber Troth

Chris Toouli

February

Amy Hawkins



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website*

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