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Welcome to our Spring e-newsletter and apologies that it is slightly late in being sent out.

We are all aware of the current situation in the UK, as well as around the world. Prof Barrett has provided us with some information which can be found on the 'Latest News' page on our website and will keep us updated in the future I'm sure.

I would like to welcome our new members that

have connected with us over the last few months. I hope you find some helpful information and advice in the newsletter, on the website and through our Facebook page. Our families are willing to help where they can.

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

WSUK values your involvement with the newsletters, so please remember to share with 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](mailto: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.

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## News

### WSUK website

Over the last few months there have been several updates to the site with the conference presentations added, new events and clinic dates etc.



### Sad News

It is with great sadness that I have to let you know that Gemma Balmforth passed away suddenly on 8th January 2020. Her funeral was held on 4th February. Donations were requested by the family to WSUK instead of flowers along with the request for everyone to wear red, Gemma's favourite colour.

The total raised was £723.00. We thank her family for supporting us in this way at this very difficult time. I know many have been in touch with her mum, Sara and also Rebecca, Gemma's

twin sister.

We send them all our love at this moment in time.

## Zebrafish Research Model Update

Dr Patrick Yu Wai Man, a Consultant Ophthalmologist and researcher, is using a zebrafish model to research the effect of WS on the eye. Read a brief update on his work [here](#).

## UK Clinical Trial Update



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

## **USA Update**

An update from Dr Fumi Urano about his work with WS Research can be found on the WSUK website by clicking [here](#).

## **European Reference Networks (ERNs) for rare diseases**

What is an ERN -

ERN will facilitate the sharing of knowledge, experience, medical research, teaching, training and resources. They use relevant communication and eHealth tools to enable the mobility of expertise across borders, rather than the movement of patients that travel to access care and expertise that does not exist in their country. ERN will also reduce inequalities of treatment amongst different diseases and countries within Europe. In addition to overcoming disease-specific challenges, ERN will help to realise economies of scale and the efficient use of resources for healthcare provision across the EU. You can read more about them [here](#) .

We and all the other Rare Disease groups need to start lobbying Government to ensure that the UK will still be a part of the ERN group when the Brexit transition period ends on 31st December. [Genetic Alliance UK](#) have information on their website about this and how we can all help to protect the ERN, click [here](#) for more information and how you can get involved. Think about contacting your local MP or Baroness Blackwood about this now as well.

## **WS Conference**

Saturday 26th September 2020 at Whittebury Hall.

For this year, 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 last year for rooms, dinner and conference day rate.

We will be asking you to pay your part of the room cost directly to us in advance instead of to the hotel when you check out. Some of you have already booked and paid, thank you. 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 non attendance last 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



publication was enclosed within every copy of the Guardian newspaper and the content is available [online](#). The campaign featured exclusive content from key thought leaders and industry voices in the run up to rare disease day 2020.

## **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 are:

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

Thursday 2nd July. Thornbury Leisure Centre. Bristol.

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

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

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

## **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](#).

Click [here](#) to access the January edition.

## **Carer's Wellbeing project**

WSUK has recently launched a new pilot project to help improve the wellbeing and reduce the isolation of WS parent carers. This pilot is being funded through a grant from the National Lottery Community Fund.

## **Current status – recruiting parent carers**

Parent carers are currently being recruited into the pilot project (up to max 20). Each parent carer will identify a specific activity that will help to improve their health and physical/emotional wellbeing. Parent carers who have just joined the project are interested in a range of different wellbeing activities such as spa treatments, gym membership, driving lessons and a training course to develop new skills to help their future employment.

WSUK will purchase the wellbeing activity for each carer (up to a max £300). Each carer will be asked to provide feedback on how the activity has helped to improve their wellbeing.

## **Plans for the future**

Once the pilot has been successfully completed, WSUK plans to apply for further funding, incorporating participant feedback, to extend the project in the future for more WS carers.

## **Interested?**

For more information or to register your interest in participating, please contact the WSUK office [admin@wolframsyndrome.co.uk](mailto:admin@wolframsyndrome.co.uk) or 01903 211358.

Thanks to all the players of the National Lottery.



## **Holiday Homes Trust**

Offer affordable holidays throughout England. All of their units accommodate wheelchair access. You can see where they have caravans by clicking [here](#) for a map.

Their affordable holidays are on a self-catering basis. They have caravans in a number of popular UK resorts and welcome families or individuals who are disadvantaged, whether through disability, income or other

circumstances. They are a small charity that specialises in providing quality, fully-accessible caravan accommodation for families and individuals that need a fun and relaxing break.

They believe that holidays are for everyone. You can stay in some of the country's best holiday parks close to beautiful countryside and enjoyable beaches. All their caravans have great facilities to make sure you and your family have a wonderful time. For more details and prices for this year go to their website [here](#). They are also listed on the Recreation page on the WSUK website.



**Holiday Homes Trust**  
Affordable family holidays

**Apply for an Orbit Braille Reader  
20 through the VICTA/RNIB grant scheme**

**VICTA is currently working in partnership with RNIB on a product grant programme focused on supporting independent study using technology.**

If you are registered blind or partially sighted and a UK resident you could be eligible for an Orbit Reader 20 for Braille users (age criteria 8-29 years).

The Orbit Reader 20 is a compact and revolutionary refreshable braille display offering easy book reading and note-taking, it is portable and features 20 refreshable eight-dot braille cells.

**[You can find out more about the product on the RNIB website here](#)**

Successful applicants will be asked to pay **£40** toward the cost of the Orbit Reader – these are one-off charges to cover VICTA's administration costs.

All applications are independently reviewed by VICTA Trustees and outcomes will be notified in writing. No outcomes will be given over the telephone.

To find out more and to apply for this scheme, please follow the link below.

If you have any queries please get in touch at **[grants@victa.org.uk](mailto:grants@victa.org.uk)**. or to find out more about their grants programme click **[here](#)**.

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## **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](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 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.



## Rare Disease Day

Rare Disease Day is an annual event held on the last day of February. This year being a leap year it was on 29th February, a rare day in itself.

CEO, Tracy Lynch, spent a week giving Assemblies to the students at The Angmering School in West Sussex talking about Rare Disease Day and Wolfram Syndrome.

They had a separate presentation during their Tutor Group sessions at the start of the day to

encourage them to get involved by campaigning to Government to help raise further awareness for all Rare Disease groups and the issues that affect us.

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

## **Race2Amsterdam**

Over the weekend 14th - 16th February teams of students from Edinburgh University took part in their RAG's first Carbon Neutral Charity hitchhike race from Edinburgh to Amsterdam. Two students chose to raise funds for WSUK setting a target of £500.00. At the time of writing the total raised including Gift Aid was **£738.75!**

Despite the weather thrown at the UK by Storm Dennis that weekend the race went ahead with our fundraisers arriving in Amsterdam about 5.30am on the Sunday morning, cold and tired.

Read their account of their journey [here](#).

Thank you Leon and Rohan for choosing to support our charity and the work we do.

## **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.

## **WSUK Annual Golf Day**

Our 8th Annual Charity Golf Day is being sponsored by Penfold Verrall, who continue to support us with our fundraising efforts, thank you to them for this. This is taking place at the end of July at

Mannings Heath Golf Club, Horsham.

We currently have 13 teams signed up to play and 8 holes sponsored.

We already have some great prizes donated for our raffle and auction, so far we have:

A grandstand voucher for 2 from [Royal Windsor Racecourse](#)

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](#)

Hospitality for 20 for British Superbike Championship at Brands Hatch.



Afternoon Tea  
Experiences  
Across  
London



[b-bakery.com](http://b-bakery.com)  
020 3026 1188  
[info@b-bakery.com](mailto: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.

## **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.

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## 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:

March 27<sup>th</sup> - **CANCELLED**

May 22<sup>nd</sup>

July 17<sup>th</sup>

September 25<sup>th</sup> (day before Conference)

November 27<sup>th</sup>

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.

The adult centre is now open for recruitment, so invitations to attend will be sent out shortly.

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:

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 to the new Mr and Mrs Bennett.**

On Wednesday 19th February Jared and Amy Duong, from USA, got married. Read Jared's words about this [here](#).

We wish them much happiness in their married life together.

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, so please remember to send them 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](mailto: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.

**Update on Give as you Live** - Amazon seems to no longer be making donations on purchases made through 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. 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 (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)

Belated birthday wishes to George Jones who was missed off the February list in the last newsletter.

#### March

Patrick Bezzina

Federica D'Elia

Victor Carnel

Raquel Gebel

Mike van Brenk

#### April

Haidar Hussain  
Sadiya Shazhad  
Anne Henshaw  
Eeshan Garg

**May**

Naomi Bennett  
Jason Greenwell  
Charlotte Hurt  
Ciara Steuart  
Doug Lynch  
Maria Saliba  
Sterling Rodda  
Cecilia Marino  
Selina Wong





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