



**Welcome to our Spring newsletter. I'm sat writing this looking out at my garden with the sun shining down on all the new life appearing, giving hope to what is in store for the rest of the year. Which is similar to how we are all feeling now that the TREATWolfram Trial has started.**

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

I'm looking forward to hearing about all your fundraising and other stories that we can share, so please remember to send me anything that you would like to see included in future newsletters.

These can be sent to me at

[admin@wolframsyndrome.co.uk](mailto:admin@wolframsyndrome.co.uk)



Happy Easter to everyone!

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## News

### UK Clinical Trial Updates



Here is the latest [update](#) from Prof Barrett, click the link to read.

## 8th Annual Conference

Conference is Saturday 28th September at Whittlebury Hall Hotel once again, 9.00am - 5.30pm (TBC).

Bookings can be made by emailing the [booking form](#) to the WSUK office. More information can be found [here](#). Last date to make your booking is 6th September!

Video presentations from 2018 can be found on the WSUK website and the Wolfram Syndrome UK [YouTube](#) channel.



## Social/Activity Break proposal

This was mentioned in the last newsletter and a separate email will be sent out about this as well. WSUK will look to provide some funds towards a group activity break either

**just for those affected or their families as well. We are looking at breaks organised by groups like The Calvert Trust, Jubilee Sailing Trust and others. These breaks would provide the opportunity to take part in activities during the day and then to socialise in the evening.**

**We would like an idea of interest in such a chance before we commit. A deposit would be required to commit to the holiday. Further details are to be finalised once we know how many individuals and families would be interested in something like this.**

**We are also looking into other social activities for our members and will be in touch about this in the near future.**

**[Email](#) the office if you would be interested.**



**Many of you will have already heard the sad news about Katie Gibson who unfortunately passed away on New Year's Eve with her**

family around her. A Christmas Rose plant and card were sent on behalf of everyone in the WS community to her family; this will continue to grow in memory of Katie. Her ashes are being interred on her birthday next month.

Our love and prayers are sent to her family.



## Are you looking for work

**B B C**

**EMPLOYABLE ME IS BACK!**

This time we are looking to help job seekers with a wide range of disabilities and conditions.

Do you have a disability or condition and struggle to find work?

Are you overqualified and not fulfilling your potential in your current position?

Do you need help to uncover your talents?

If this sounds like you or someone you know, EMPLOYABLE ME, wants to hear from you.

E: [employableme@optomen.com](mailto:employableme@optomen.com)  
T: 0203 227 59 35

 

**optomen**

Description of photo above

**From BBC - Employable me is Back!**

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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.**

## A Night of 80's Hits

This was the last fundraising event for 2018 held. Despite the terrible weather everyone that came along had a fantastic night of live 80's music. We raised a total of **£4700.60** after costs.



## 3rd Brighton Marathon

21 year old Marcus Lynch is running his 3rd marathon in aid of Wolfram Syndrome UK after a year off. Training is underway and his fundraising page is now live. If you or anyone you know would like to sponsor him his sponsor page can be found on BT Mydonate or [here](#).



## 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.



## 80's Summer Wolf-Jam

Our popular live 80's music night is back! To celebrate summer this is happening Saturday 29th June at St Paul's, Worthing.

**Doors open at 7.30pm. Tickets £20 each (£1.00 p&p if purchased over the phone). If you are in the area & fancy a night out then get our ticket and come along.**

80's Summer Wolf-Jam  
presented by:  
**Club Wolfram**  
featuring:  
**SYNTHONY 101**   
**Saturday 29th June 2019**  
Evening compered by: Richard Reynolds  
at St. Pauls Worthing  
bar available  
Official Sponsors  
   
All proceeds to local Worthing Charity  
 Doors open at: **7.30 pm**  
Tickets **£20**  
Tickets available direct from  
Sweeney Todds @ Tesco's Durrington  
St. Pauls Worthing  
Wolfram Syndrome UK Office 01903 211358  
[www.wolframsyndrome.co.uk](http://www.wolframsyndrome.co.uk)

## **Fundraising Project Idea**

In a previous e-newsletter I announced our new fundraising project to include all members of WSUK. I would like to ask everyone affected by WS, that would like to, to take part in our next project. I would like to create a book with a collection of poems from you all. This would be a great way for everyone to be involved in raising funds. I'm sure there are many creative minds out there.

Your poem can be about anything, in any style. You can send in one poem or more. We

will then sort through them and produce a small book that everyone could then sell with the selected poems in.

A deadline has been set of 30th June 2019, to allow for time for editing and printing. This will mean that they will definitely be ready for people to buy at next year's conference on 28th September 2019.

I look forward to reading your creative works.

## **Kidz to Adultz Exhibitions**

**'Kidz to Adultz' events are organised by Disabled Living. Disabled Living has an enviable reputation of organising the very prestigious Kidz to Adultz event since 2001 and now hold five of the largest FREE UK exhibitions totally dedicated to children and young adults up to 25 years with disabilities and additional needs, their parents, carers and all the professionals who support and work with them. Read more [here](#).**

Dates for this year are:

**Middle** - 21st March, 9.30-4.30

Rioch Arena, Coventry.

**South** - 16th May, 9.30-4.30

Farnborough International Exhibition and  
Conference Centre, Farnborough.

**Wales and West** - 4th July, 9.30-4.30

Thornbury Leisure Centre, Bristol.

**Scotland** - TBA

**North** - 14th Nov, 9.30-4.30

Event City, Barton Dock Rd, Manchester.

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## Clinic Dates 2019

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 29th

May 24th

July 19th

September 27th

November 29th

**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.**

The clinics up to September should also be the recruitment for the TREATWolfram Trial.

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:**

4th and 5th March  
3rd and 4th June  
15th and 16th July  
7th and 8th 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 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 hospital know so that, that place can be offered to someone else.**

### **Living Behind the Fence**

**Following on from her autobiography 'Living in a Box'; Keri Chambers has now written a biographical memoir about her late brother Alex called 'Living Behind The Fence'. Both**

**books are on sale for £6.00 each. Please email, phone or message if you would like a copy.**



## **My Life - Shane Roberts**

As most of you know, I have a 7 year old guide dog named Toby...just like a shire horse really and well trained!!! Talking of trains, we spend half our year travelling! Went to Teignmouth last March, Blackpool last April, Hassocks last May, Liverpool last July, to Toby's puppy walkers in Devon last August, to conference last October, then Windermere November and Christmas...so a rail good year!!!

Off to Blackpool in April with a huge group of VIPs...but only know a few! Since Vista found me a Befriender, I've become travel man...thanks to a VIP I met through her! When away I/we do activities, go for a mystery walk or 2, eat, socialise...and I catch up on missed sleep! My friend orders the tickets and books rail assistance, so off I go!

As Del Boy says...He who dares wins...so dare I

do! So don't let anything hold you back...and you could always join me on a trip, if you are nervous!

Thank you Shane for this encouraging piece about your travels around the UK. If anyone has anything that they would like to share about activities they do, journeys they make to somewhere new or anything else then please send it to me to share in future newsletters.

## **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](#)**



**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. This is also for anyone that would like to make an [online donation](#). We are also registered with [Total Giving](#) and [Wonderful.org](#). All the sites we are registered with can be found on our website.

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 GoRaise. 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](#).**

## **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.**



**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 birthdays as a way to fundraise instead of receiving**

presents.

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

### **March**

**Raquel Gebel  
Patrick Bezzina  
Shiffa Ahmed  
Victor Carnel  
Krystal O'Farrell  
Federica D'Elia  
Mike van Brenk**

### **April**

**Sadiya Shazhad  
Anne Henshaw  
Nakhaash Hussain  
Eeshan Garg**

### **May**

**Doug Lynch  
Naomi Bennett  
Jason Greenwell**

**Sterling Rodda**  
**Charlotte Hurt**  
**Selina Wong**  
**Cecilia Marino**  
**Maria Saliba**



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