



Newsletter Winter 2018. What's been happening and forthcoming dates/events that may be of interest to you all. Contact me if you have a story that I can include in future newsletters.



WOLFRAM SYNDROME UK
Inform, Support, CURE



Welcome to our Winter newsletter and the last one of 2018. What an amazing year we have had! Lots of fundraising has taken place with some amazing totals reached.

This quarter's newsletter includes links to updates from Prof Barrett and Dr Fumi Urano, information

about Conference, lots of fantastic fundraisers that have taken place, ways to get involved with fundraising, some as simple as just by shopping online, upcoming fundraiser events 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 any stories, news, fundraiser dates that you would like to see included in future newsletters. These can be sent to me at admin@wolframsyndrome.co.uk

WSUK would like to wish you all a very Merry Christmas and a happy and healthy 2019!

News

UK Clinical Trial Updates



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

7th Annual Conference



Clinic Dates 2019

Adult Wolfram clinics are run from the Centre for Rare Diseases in the Heritage Building at The Queen Elizabeth Hospital, Birmingham and are taking place on the following days:

January 18th
March 29th
May 24th
July 19th

Conference took place on Saturday 6th October 2018 at Whittlebury Hall Hotel and was well attended. We had a Psychology doctor come over from St Louis, USA to hold workshops for us.

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



SAVE THE DATE - next year's conference is a week earlier on Saturday 28th September, so put the date in your diary now.

Stephen Bassett Achievement Award

This year the Stephen

September 27th
November 29th

All dates are currently provisional

For more information please contact either [Andrea Mitchell](#) , or [Tracy](#) at WSUK.

The dates for the Children's Clinics run from Waterfall House, the Rare Disease Centre at Birmingham Children's Hospital are:

7th & 8th January
4th & 5th March
3rd & 4th June
7th & 8th October

All dates are currently provisional

If you would like to be referred for a clinic, or have a child you would like to attend, please contact [Jody](#)

Bassett Achievement Award went to James Smith. This is a posthumous award and was given to his mum Kim at this year's conference dinner. James was one of the first 2 people with WS that Paul and I met after Jennifer's diagnosis and starting up WSUK. His words, thanking us for what we were doing & making him feel that he was no longer alone have stuck with both of us. James was inspiration to everyone that met him. He was always joking around & telling weird jokes that you just had to laugh at. He never took himself too seriously. He readily took part in holding a workshop at conference a few years ago. He got involved with VI rowing & cricket over the last few years, even writing a piece for the newsletter about it. He used to post almost daily, sometimes more, on Facebook about what he

(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.



USA Updates

Some of you may be interested in reading about Dr Fumi Urano's trial updates. These can be found on The Snow Foundation website as well as ours. He is the lead researcher in the USA. He is one of many doctors & scientists working together from around the world. To read his updates click [here](#).

Social/Activity Break proposal

was doing or how he was feeling and receiving plenty of comments from those posts.

It was an honour to know James and he will be greatly missed by us all.

Fundraising Stars

As many of you know WSUK like to show our thanks and some recognition to our fantastic fundraisers each year, by awarding them a star medal saying "WSUK Fundraising Star" and the year.

This year our stars are:

Naomi Bennett
Keri Chambers
Colin and Rosy Gray
Rob Mcilvrde
Sophie Lynch and 2 friends
Shane Roberts
Julie Fox and The Nutcrackers
Sun Tang
Iain Lynch
Marie Keenan

At a recent meeting a proposal was put forward to the Trustees about WSUK providing 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.

Emma Greenwood
The Bezzina Family.

Our fundraiser of the year award was given to Colin and Rosy Gray for raising over £4500. The award was presented to them by the Chambers family.

New Rare Disease Centre for Children opens

[Waterfall House](#) - the new Rare Disease Centre at Birmingham Children's Hospital opened this summer and is the UK's first rare diseases centre for children.

Birmingham Children's Hospital treats approximately 9,000 children and young people with more than 500 different rare diseases from across the UK and have 11 highly-specialised services - including Wolfram Syndrome. The Wolfram Children's Clinic has moved from the

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

Festive Days out for all

Here is a list of dates and places, with website links, to enjoy a festive day out in the lead up to Christmas:

[Dickensian Christmas Festival](#), Rochester, Kent. 1st & 2nd December.

[Christmas Market](#) and lights switch on, Chipping Campden, Gloucestershire. 2nd December.

[York Christmas Festival](#), N Yorkshire. 15th November - 23rd December.

[Christmas Lights in Mousehole](#), Cornwall. 5-11pm from 15th December- 4th January.

[Winter Festivals](#), Edinburgh,

Clinical Research Facility in the main building and will now be held on the ground floor of Waterfall House. Facilities include:

- Family area
- Play areas
- Kitchen
- Sensory room
- "Chillout" room
- Disabled toilets
- Braille and induction loop hearing
- Nine consulting rooms
- Research room
- Seminar room

Waterfall House is on Whittall Street, down the side of the main hospital building. The Royal Angus Car Park is directly opposite.

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

Scotland. 16th November - 5th January.

[Traditional Festive market](#), Bakewell, Derbyshire. 24th & 25th November.

[Christmas at the Bishop's Palace](#), Wells, Somerset. 9th - 23rd December.

Why not get involved in fundraising for WSUK?

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](#)



If you are considering taking part in a sponsored event you can now create your

Behind The Fence'. Both books are on sale for £6.00 each. Please email, phone or message if you would like a copy.

Fundraising Project Idea

In the last 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

own fundraising page to get online sponsorship. WSUK has signed up to BT's mydonate 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

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



Give as you Live®

Make your shopping count!

selected poems.

There is no rush but a deadline will be 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.

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.

Dragon Boat Festival

Want to help us raise more – just by shopping online? Well now you can via Give as you Live. Shop with your favourite stores and they'll donate a percentage of your purchase to us and it won't cost you a penny extra. Simply join, install and start shopping. It's that simple. Click [here](#) to start raising funds for WSUK now.

You can also shop through GoRaise and raise funds whilst you shop at no extra cost. Go to their website [here](#), sign up and start raising funds for us.

The logo for GoRaise, with 'Go' in teal and 'Raise' in pink.

If you use eBay, were you aware that you can raise funds for your favourite charity

The Bennett family had a stall again at the annual Dragon Boat Festival held at Bewl Water Reservoir in Kent. They had a sweet tombola and leaflets to hand out. They raised **£275!** Well done everyone

50th Anniversary Bike Ride - Update

Colin and Rosy Gray celebrated their golden wedding anniversary by inviting family and friends to join them on a 50 mile bike ride around Normanton on Soar. They arranged 3 different routes of varying lengths to suit everyone taking part including children. They then finished off the day with an anniversary party where they asked for donations to WSUK rather than presents. In the last newsletter I reported that their total including Gift Aid stood at £3887.50 and was

whenever you sell or buy on the site. For more information about how this works click [here](#).



The majority of people use Amazon when shopping nowadays. You can either raise funds for us by using the Give as You Live portal or go direct to Amazon Smile using this [link](#), which we are now registered with.

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.

Ask 3 friends or family members if they would

still rising! Their page has now closed with a final total of **£4531.25**!! Thank you and well done from all of us!!



London to Brighton Bike Ride

Iain Lynch, Marie Keenan and Emma Greenwood took part in their first ever long distance bike ride, on September 22nd from London to Brighton. The weather was warm and sunny which made the challenge of Ditchling Beacon, a very steep and windy road up the South Downs slightly harder to contend with in the last few miles of their ride. They all managed to complete the

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.

Several families have already encouraged others to donate regularly, so why don't you?

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.

challenge with one person ending up in hospital for some stitches on her ankle following a bit of a tumble off her bike. Between them they have raised £1000.00 including Gift Aid

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.



Collect stamps to raise money for WSUK

A great way of raising money for WSUK is to collect postage stamps.

WSUK will receive a cheque at the end of each month based on the weight of the stamps received. Any postage incurred in sending stamps will be refunded to WSUK. (Please make sure you send in a decent quantity each time).

You can ask friends, family and work to collect stamps and postage labels for you. The more stamps we send in the more money we will receive. Christmas and birthdays are a good time for lots of stamps. To read more about this and where

A Night of 80's Hits

Our final WSUK organised event of 2018 is happening Saturday 15th December at St Paul's, Worthing. Our popular live 80's night is back. What better way to start the festive season and to finish off the year!!

Once again we have Synthony 101 providing the music along with a group called The Gangsters.

Tickets are now sold out with over a month still to go before the event.

A Night of 80's hits
presented by:
Club Wolfram
featuring
THE GANGSTERS
SYNTHONY 101
Saturday 15th Dec 2018
Evening compered by: Richard Reynolds
at St. Pauls Worthing
bar available
Official Sponsors
SWEENEY TODD'S
All proceeds to local Worthing Charity
Doors open at 7.30 pm
Tickets £15
Tickets available direct from
Sweeney Todds @ Tesco's Durrington
St. Pauls Worthing
www.wolframsyndrome.co.uk
01903 211358

to send them click [here.](#)

Birthdays (worldwide)

December

Zeshan Hussain
Lydia Hayden
Alice Hayden
Abby Gardner
Romina Cambedda
Lauren Gibilisco

January

Gavin Allman
Chris Toouli
Amber Troth
Georgina Carolan
Daniel Mulhern

February

Junaid Rahman
Amy Hawkins



follow on [Twitter@WolframSyndUK](#) | [friend on Facebook](#) <http://tinyurl.com/p7hbhe5> | [forward to a friend](#)

Copyright © 2018 Wolfram Syndrome UK. All rights reserved. Registered Charity No 1152445. Registered in England & Wales. **Our mailing address is: 9 Church Way, Worthing, West Sussex, BN13 1HD. Telepho 01903 211358**



[unsubscribe from this list](#) | [update subscription preferences](#)



