



Welcome to our Autumn e-newsletter.

This quarters newsletter contains news updates, information about our upcoming conference, 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

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.

News

UK Clinical Trial Update



Dear friends and colleagues, a brief update on the TREATWOLFRAM clinical trial.

I am pleased to say that we have now recruited over 10 participants- thank you to everyone who has taken part so far. Our first participants have reached their 6 month follow-up. I am very grateful that families are completing all their assessments. The information being collected will be incredibly helpful for the whole worldwide Wolfram community.

Our clinical trials pharmacy at St Guy's and St Thomas's hospital is packaging up the next batch of medicines to deliver to the Birmingham Children's hospital and Queen Elizabeth Hospitals sites. We anticipate the adult site opening during the next 6 weeks.

For those people who are already participating, I need to request that you **always** bring all your medicine pots and unused supplies of medicines

when you come for a study visit. This is really important for the integrity of the trial; and to check that people are taking the medicine. If we have to report that people are not bringing back their empty and unused medicine containers, the trial will be criticised when we report the findings. Secondly, may I ask that when participants come for repeat vision tests, please **always** bring along your prescription glasses. This is because we are measuring best corrected vision, corrected with glasses.

I look forward to meeting some of you at the WSUK conference in September, and discussing the trial with you in more detail then

Sincerely

Tim

8th Annual Conference

There is still a bit of time left to book your place!
Rooms are starting to run out!

Conference is Saturday 28th September at Whittlebury Hall Hotel once again, 9.00am - 5.30pm. Draft programme for the day can be found [here](#).

For those staying over on the Friday night we have arranged a quiz. We also plan to socialise in

Bentley's Lounge rather than the bar if possible as it is much quieter and has more space.

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!** At the time of writing there are only a few rooms left available for the Friday night. The dinner menu has been emailed out and some of you have already sent me your choices. If you require the menu to be resent then please let me know. I need these as well by **6th September**

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



First USA Families Conference

On 12th and 13th July Tracy Lynch visited the WS clinic at Washington University Hospital in St Louis, Missouri on the Friday and then the inaugural Families conference organised by The Snow

Foundation.

Prof Barrett gave a Skype presentation on the TREATWolfram Sodium Valproate trial in the morning and Tracy took part in a Parent Panel, along with 3 other parents, answering questions from other families in the afternoon. It was great to meet up with other families that have been in contact with the WSUK and Tracy via email or Facebook.

Counselling on offer....

Sheila Kelly, who some of you may have met at the Wolfram Syndrome Annual Conference, is a qualified counsellor and has kindly offered some free counselling to families or adults living with Wolfram Syndrome.

Sheila has experience of Wolfram Syndrome as she has two sisters with the condition. She is a Person-Centred Counsellor and a registered member of BACP (British Association of Counselling & Psychotherapy).

Sheila qualified at Warwick University in 2002 and has since worked in both the UK and Spain.

Sheila lives in North Warwickshire so can offer face to face counselling or counselling via telephone or Skype for people that aren't local.

If you are interested in finding out more, please contact Sheila directly on 07717 892927 or email her at sheilapk@hotmail.com (and please mention that you have read this article)

BGC Charity Day

Last year we were lucky enough to be chosen as one of the UK charities to benefit from this annual event. In memory of friends and colleagues who lost their lives in the 9/11 attack of the World Trade Centre, the global finance company donate all profits from their trading on that day from their 3 global offices in London, New York and Hong Kong.

We received our share of this donation, £5000, just as the last newsletter was sent out. We would like to thank BGC for this donation.

Do you work for or know someone that works for a large company? Would they be happy to choose us as their charity for a year or just for a one off event? Please let me know.

Clinical Trial Search Website Warning

I have been asked to make you aware of a website

that searches for current Clinical Trials. The site is called www.antidote.me.

The Senior Trial Co-Ordinator of our TREATWolfram trial had it brought to her attention by the parents of a child with Type 1 Diabetes who were searching for trials for diabetes and were shown details of just one trial, TREATWolfram, after just answering 5 elements:

Condition:

City:

Age:

Sex:

Distance people are willing to travel (up to 20 miles, 100 miles or any).

This website should be used with caution as data that you provide is used for 3rd party data collection which is how they get their main income. The other thing is that the terms and conditions allows the company to share the data collected with any 3rd party in the world.

If you go on to any website like this then you should use extreme caution, especially if you are divulging personal details. Make sure you read all terms and conditions before submitting any details.

Bus and Train Assistance

Are you aware of the Helping Hand Scheme?

Get extra assistance on buses with this new multi-operator card scheme.

Helping Hand is a free card scheme for passengers who may need extra assistance on buses, or require the driver to be made aware of something discreetly without having to verbally communicate it.

Cards, for example, can let the driver know if a passenger needs to be told when a stop is reached, if they need the driver to wait until they are seated or if they require a priority seat. It is possible to create a bespoke card if none of the existing cards fit your needs.

You can apply for a Disabled Person's Bus Pass online and you can also get a companion pass, which gives free travel to that person travelling with you if you need assistance. Look on your local council or bus service website for information about your area.

Many Rail companies also have Travel Assistance Cards that work in the same way as the Helping Hand Scheme, such as showing you need help in making sure you are on the correct platform.

If you prefer to travel by train then you can apply for

a Disabled Person's Railcard which gives a third of the cost of the rail fare. To apply for this then click [here](#). Some rail companies may also have an app that can be downloaded to your phone. They give a journey planner and platform information.

What to expect when your child moves into adult diabetes care

As your child grows up, they'll move from paediatric care into adult care. This is what lots of medical professionals call transition.

Everyone with [Type 1 diabetes](#) will have a medical team around them that will help them manage their diabetes as best they can.

Moving clinics can be a nervous time for both you and your child. You'll both have to get used to a new team, a new system and as a parent or carer, you'll have to get used to your child having more control when it comes to their diabetes management. Click [here](#) to read the full article on the Diabetes UK website.



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.

Maltese Wedding Donations

Work colleagues of one of our Maltese families recently got married and asked for donations to be made to WSUK. This is growing tradition in Malta where couples ask for donations instead of wedding souvenirs. The amount received from their wedding is £259.67. Our thanks have been sent to the happy couple.



7th Annual Charity Golf Day

Our 7th annual charity golf day was held on Friday 26th July at Mannings Heath Golf Club and Wine Estate, once again sponsored by Penfold Verrall Ltd. We received some fantastic raffle and auction prizes donated by some of the companies taking part, such as a BMW M4 master experience for one at Brands Hatch, Hospitality for 10 people at the Madjeski stadium for a London Irish rugby match, 4 T20 tickets for a Sussex Sharks cricket match at the Sussex County ground, 2 x 3 month memberships at the East Sussex Glider Club.

After an early thunderstorm with a very heavy downpour, we had 19 teams go out and play with a BBQ after along with the raffle, auction, prize giving and forfeits. The day raised a total of **£14,550**, so far. Thank you to WSUK Trustee and owner of Penfold Verrall, Darren Lynch, for once again arranging and sponsoring the day.

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.

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](#).

Last date is

North - 14th Nov, 9.30-4.30

Event City, Barton Dock Rd, Manchester.



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:

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. 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:

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 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

One of our 11 year old members recently got through to round 2 of the 500 word short story competition run by BBC Radio 2. She is allowing me to share her entry with you all.

Beyond the Barricade- by Evie West

Being deaf has never stopped me, in fact, it has made me even more determined to prove that we are all unique, it doesn't matter what we look like or where we come from; we are all human, and that will never change....

"Shannon, Shannon, wake up" Trinity grinned, giving me a gentle shake.

"What?" I groaned, opening a sleepy eye.

"You need to go backstage, they're calling you on" she replied, ushering me towards the door.

"What if they judge me?" I ask, fingering the cochlear implant fastened to the side of my head.

"They won't," Trinity smiled "You need to go out there and show them that deaf people are not weak characters, in fact deaf people are probably some of

the most mentally strong people on Earth.....”

Taking a deep breath, I toss my hair behind me, fondle the silver sequins glimmering on my sky-blue dance leotard and amble upon the stage. In my head, my dream of performing at the British Dance Championships soars above the sky, urging me on, urging me to be bigger, stronger and better than ever before.

I am who I'm meant to be.

This is me...

This is my moment in the spotlight.

For me, deafness has never been a barrier...

Launching into a hip-hop sequence, I channel all my power and energy into the dance. I lose myself in the dance, letting flow through me, taking over my thoughts and emotions of the past years, since I was diagnosed with hearing loss... First, I do a roundoff back handspring into a tuck layout, ere hurling myself into a lyrical piece, gracefully leaping across the stage. Then the beat drops....

The crowd are loving every minute, they don't care that I'm deaf, that I'm not like them.

That's all I ever wanted, to not be judged.

I finish with a front ariel, before posing dramatically, with a huge grin on my face. A huge uproar from the audience lasts for ages before the clapping eventually dies down. The lights dim and I walk off stage...

Sinking into Mum's arms, tears streaming down my face, I feel so proud of myself, I've done it, I've shown the world that deafness doesn't hold people back, that you can still achieve your dreams.

“Shannon, they're calling you back on for the awards, you've made it into the top ten!” Trinity races in, shouting.

Top ten in Britain, this is more than anything I ever

expected, way beyond...

“Shannon Banks, first place”

What? I'm in a daydream, this isn't real, is it?

Impossible! I walk up to collect my medal and trophy, for the first time ever, I am the best.

Deafness didn't stop me.

I wrote this story to have a meaning, not just a meaning, but a true meaning. To prove that, no matter what disability you may have, we all deserve to have a place on this earth. Every one of us shouldn't care what we look like, its who we are that matters. This story is based upon true experience of being deaf myself, of all the hospital appointments I've ever had to encounter, of all the times, I've had to be brave and not let it hold me back; so to all deaf people out there, I wanted to say...

Never let it hold you back.

Deafness is not a barrier

Thank you Evie for allowing us to share your short story.

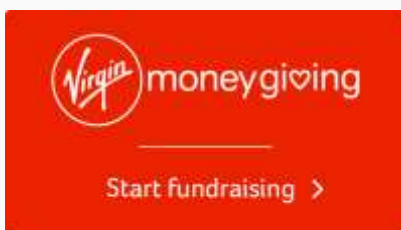
Evie also recently won an 'Oscar' at her school for a poem she wrote which is being included in a collection of poems we are producing to sell to help raise funds for the work of WSUK.



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 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](#); 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)

September

Matsatso Khachapuridze

Gavin O'Farrell

Melissa Hulse

October

November

Ellie Eagles

Asal Fallah Damavandi

Aaron Gough

Clare Caws

Georgina Fleming

Jennifer Lynch

Mariam Al-Takriti



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