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Newsletter Autumn 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.



Welcome to our Autumn newsletter. What an amazing summer we have had. At the time of writing I am looking at the lawn in my garden and all I see is burnt grass where as back in May it was an area of green grass and weeds. I know for those of you reading this with WS the heatwave makes life extremely difficult as you have to try to find ways to keep cool which isn't easy. Now it is time for some to get ready for back to school, the nights to start drawing in and getting ready for conference which is always a

great weekend.

This quarters 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

News

UK Clinical Trial Updates



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

7th Annual Conference



Clinic Dates 2018

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:

The date for this year's conference is Saturday 6th October 2018 at Whittlebury Hall Hotel once again. Please book now if you haven't already done so.

The programme for the day has been planned to include Prof Rajat Gupta giving a Neurology presentation and Philip Warford the Managing Director of Renaissance Legal, who is coming to give a presentation and some workshops regarding Wills, Trusts and other things legal. We have several companies and organisations confirmed to exhibit on the day as well.

As usual we have rooms on offer at a **subsidised rate**, for you to book for the Friday and also for the Saturday night. There is a slight increase in room costs for 2018. Rooms are first come, first served due to the limited amount we have reserved for us. The

September 28th
November 23rd

For more information please contact Debbie Gittins at Debbie.Gittens2@uhb.nhs.uk tel: 0121 371 6879.

The dates for the Children's Clinics run from the Rare Disease Centre at Birmingham Children's Hospital are: (Dates/location may change)

1st/2nd Oct

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

Places are by invitation only, so please **DO NOT** book or make any travel

last date to confirm your attendance and to request a room, if still available, is

Friday 7th

September, [forms](#) available now.

There will be a **free** 3 course meal once again for those staying over on the Saturday night, all menu choices need to be returned by **Friday 7th September**, the menu has been sent out to those who have already confirmed attendance. For those staying the Friday night, food is available in the restaurant as well as from the Silverstone Bar. This year both WSUK and WellChild will be paying £10 total per person towards the cost of meals for those staying on Friday night as well.

Guests staying over will have the use of the Spa facilities which includes, pool, gym and relaxation rooms; **but will have to pay for their own treatments.** These will need to be booked and paid for in advance by you by going to the Hotel's [website](#).

arrangements until you have heard from the hospital.



In Memory

Back in May the sad news was received about the passing of James Smith, who was a very dear friend to many of us. He was an absolute pleasure to know, with a love of life and a wicked sense of humour. WSUK sent a rose bush called 'Sweet Memories' on behalf of everyone in our community to his mum, Kim, and the family. This way they can see the rose grow and bloom each year in his memory.

A collection was held after the funeral and 2 Facebook donation campaigns were also run raising funds in his memory. The

Video presentations from 2017 can be found on the [WSUK website](#).



Stephen Bassett Achievement Award

We are coming to the time of year for deciding who will win the Stephen Bassett Achievement Award. This is announced and presented at conference. We would like you to start thinking about who you think deserves this award. It doesn't have to be a WS affected person, it could be a parent, a fundraiser, a doctor but it does have to be someone who has dealings with the WS community in some way. Start thinking and send your nominations in now, or by **7th September**. The Trustees will then make

total raised from those is £1396.41. Family and friends also have plans for further fundraising in the near future.

In honour of James' memory I am including the article he wrote for our Spring newsletter in 2017.

My Sporting life

Hi my name is James Smith, I am 30 years old and I have just completed my second season of Visually Impaired cricket. I absolutely love being part of it because it's fun and very sociable. I play for the Durham Viper Jets cricket team. We play in a domestic league with three other teams. It is not just local teams we play in the North and East of England but against other teams

a decision on the winner.

International WS Conference - Paris

In June I attended the 7th International WS conference, held in Paris, along with some of the professionals you know - Prof Tim Barrett, Dr Patrick Yu Wai Man and Dr Fumi Urano. It was a day and a half of full on presentations from doctors and researchers from all around the world. We heard from doctors in Israel, USA, Estonia, Japan and many other countries in Europe. There were also representatives from other WS organisations, some recently formed, this was a great chance for us to share knowledge and information between ourselves.

Genetic Disorders UK

Did you know we are part of

as well.

It is adapted very well for visually impaired people. We use a bigger ball, which is a size 3 football with ball bearings in it so we can hear it and larger stumps. The rules change depending on your site classification; if you are totally blind, have little sight or better sight.

Personally I prefer batting. I am not the greatest of bowlers and when I field I am used more by the boundary. No one judges you if you make a mistake, others just help you and it is really fun. I would so look into it if there was a team near you.

I also take part in rowing with some of

the GDUK Partnership programme, which means that if a workplace or school signs up for 'Jeans for Genes Day' for the first time they can nominate us as their charity and we will get half of the money they raise. This will continue every year until they no longer take part or choose another charity.

Jeans for Genes Day is Friday 21st September, so not long to register. Why not ask your school or workplace to sign up now. Their page can be accessed [here](#)



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

my friends. One of my friends Julie Fox, who has WS as well, takes part and got the team set up. We are not competitive, we just do it for a bit of fun and a laugh. Everything I do seems to help me and I just have fun and enjoy life.

Sponsored Walk

In memory of James, Julie Fox along with some of friends of hers and James from Blind Life in Durham are going to be walking 21 miles along a recognised route from Whitby to Scarborough on 25th September. The total raised will be included in the next newsletter.



Behind The Fence'. This book is now on sale. Both books are on sale for £6.00 each. Please email, phone or message if you would like a copy. Keri will be bringing them to conference so if you want to wait, you can get a copy then.

New Fundraising Project Idea

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.

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](#).



Congratulations!

Congratulations to Gavin and Natalie Allman who got married on 18th June. Gavin's Guide dog Marvel was ring bearer for the day.

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.

Mini Triathlon for WSUK

On Saturday 12th May, in a very cold Dorney lake, in the deep depths of Berkshire,



Cards and Calendars

Christmas may be a few months away but it will be here sooner than we think. We have our charity Christmas cards available again, £3.25 a pack of 10, along with an A3 calendar for 2019, £10 each. The calendar has been produced using artwork by Jennifer Lynch during art therapy. All of

Sun Tang, who has a niece with WS, undertook his first grueling mini triathlon - this entailed a 400m swim - 20k bike - 5k run. And he completed it without collapsing and coming last.... well nearly :). Sun would like to thank all those who supported him and helped to raise £500 for Wolfram Syndrome UK.

these are available by calling the office or if you are attending conference. We have already sold some calendars and had some reserved for collection. Postage and packing charges will be extra.



Why not get involved

in fundraising for WSUK?

You could sell cakes to work colleagues,



Worthing 10K run

On Sunday 3rd June we had 2 family members of Trustees Paul and Darren Lynch and a couple of friends all run the Worthing 10K for the first time, all for WSUK.

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 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

First is Darren's eldest daughter Sophie. She convinced 2 friends to run with her, running not only to raise funds but to prove to themselves that they can take on a challenge like this with little training. They raised £821.25 including Gift Aid, beating their £300 target.

Secondly, Rob who is married to Paul and Darren's cousin also did his first distance run to help raise funds and awareness. He managed to pass his target of £250 and raised £285.

Well done and thank you to them all.

6th Annual Charity Golf Day

Our annual charity golf day, once again kindly sponsored by Penfold Verrall took place on Friday 27th July at Mannings Heath Golf Club, Near Horsham, West Sussex. Over the last 5 years

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!

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

this event has raised almost £30,000.

We had 19 teams take part in the day with several golf competitions running. The day's winning team were **Northern Commercials**. The trophy was presented at dinner where there was also a raffle and auction with some fantastic prizes donated.

Thank you to the following companies for donations of prizes to the auction and the raffle - Northern Commercials for their donation of hospitality for 20 at the Touring Car Championships final in September at Brands Hatch, to the Spread Eagle Hotel, Midhurst, West Sussex for a voucher for afternoon tea for 2, to Whittlebury Hall Hotel, Northamptonshire for a 1 night spa break for 2 people, to Piltdown Golf Club, Stoke by Nayland Golf Club and Kingswood Golf Club for vouchers for a 4 ball of golf at each, Penfold

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 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

Verrall for the donation of their corporate box with hospitality for the 22nd September game, R.H.Amar for a food hamper, Hitachi, SMT Volvo and 2 x 3 month full memberships for the East Sussex Gliding Club.

The day raised a total of **£15,219.00!!!** Our best fundraiser, beating last year by over **£6000!** The date for next year has already been booked.

Here is the winning team



50th Anniversary Bike Ride

Colin and Rosy Gray celebrated their golden wedding anniversary by raising funds for WSUK.

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 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.

They are family friends of the Chambers family so know all about WS through Keri and her brother Alex who sadly passed away a couple of years ago. Colin & Rosy invited family and friends to join them on their 50 mile bike ride on 4th August around the area of 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. They initially set a target of £1000, which they then increased to £2000 and increased again to £3000. Their total including Gift Aid currently stands at £3887.50 and still rising! The link to their fundraising page is [here](#). Thank you so much to them for supporting us.

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.



Collect stamps to raise money for WSUK

A great way of raising money for WSUK is to collect



London to Brighton Bike Ride

Iain Lynch and 3 friends are about to take part in their first ever long distance bike ride, on September 22nd. They have the delights of Ditchling Beacon to look forward to, which is a very steep and windy road up the South Downs. Rather than me!! Their online donation pages are:

Iain and Luke 's

<https://mydonate.bt.com/fundraisers/iainandluke>

Marie and Emma's

<https://mydonate.bt.com/fundraisers/marieandemma>

Please feel free to share their pages to friends and family.

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 to send them click [here](#).

Birthdays (that I know about, UK and overseas)

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.

SAVE THE DATE!!

Plans are already under way for the final WSUK organised event of 2018. Saturday 15th December at St Paul's, Worthing will be our popular

September

Matsatso
Khachapuridze
Gavin O'Farrell
Melissa Hulse

October

November

Asal Damavandi
Aaron Gough
Clare Caws
Georgina Fleming
Jennifer Lynch

Happy birthday to
you all!



live 80's night. 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 £15 each and can be purchased from the WSUK office.



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

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