



Newsletter Spring

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 Spring newsletter. I hope that not too many of you suffered with the coughs and colds over Christmas and the winter. With the lighter evenings hopefully we will start to get some brighter weather giving everyone the chance to recover from what feels like the wettest winter!!

This quarters newsletter includes updates from Prof Barrett and Dr Fumi Urano, information about Conference, 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

Static Caravan

The WSUK 3 bedroom static caravan is now available to book. Available dates can be found [here](#). It is located on a 5 star Haven holiday park in Pagham, West Sussex.

This is a beautiful part of the South Coast with plenty of places to visit. We hope that many of you will take up this opportunity. Dates are already going fast, but we do have some half term and Summer holiday dates still available. All prices are generously discounted from the Haven discounted prices. The season runs from 9th March to 2nd Nov 2018, so book early.

More details about the caravan, the park and the area can be found on the [website](#). Please call the office to enquire about availability or anything else - 01903 211358. WSUK members will also be allowed to use the Privilege Cards we have which will entitle you to discount in the restaurant, hire



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:

March 16th

May 25th

July 27th

September 28th

November 23rd

For more information please contact Debbie Gittins at

Debbie.Gittens2@uhb.nhs.uk tel: 0121 371 6890.

The dates for the Children's Clinics run from the Rare Disease Centre at Birmingham Children's Hospital

of sports equipment & in the shop. Please do make use of this fabulous facility.



7th Annual Conference

The date for this year's conference will be Saturday 6th October 2018 at Whittlebury Hall Hotel once again.

We already have a draft programme planned for the day 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 will have rooms on

are: (Dates may change)

30th April/1st May
16th/17th July
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 arrangements until you have heard from the hospital.

UK Clinical Trial Updates



At the end of last year

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, so book your place asap [forms](#) available now. There will be a **free** 3 course meal once again for those staying over on the Saturday night. For those staying the Friday night, food is available in the restaurant as well as from the Silverstone Bar. This year WSUK and WellChild will be paying £10 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.

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

Prof Barrett was awarded a grant by the newly formed International Rare Diseases Research Consortium (IRDiRC) for Biomarker research. His update about this is available on the WSUK website clinical trial page or can be accessed [here.](#)

As soon as there any updates on the TreatWolfram drug trial they will be put on the website and emailed out to everyone. A new update is to appear shortly as it has just been received, at the time of this newsletter being sent out. Click on the link above.



USA

Updates

Some of you may be



Findacure Conference

On 27th February I am giving a presentation at the Findacure Drug Repurposing for Rare Diseases Conference at The Royal College of Nursing, London.

The annual conference brings together patient groups, clinicians, researchers, and life science professionals, to discuss the latest developments in drug repurposing, and its role in the future of rare disease treatment.

I was asked to give a personal perspective as the parent of a child living with Wolfram Syndrome. This is the type of story that many of the audience

interested in reading Dr Fumi Urano's updates on The Snow Foundation website. 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](#).

Kidz to Adultz Exhibitions

These exhibitions are organised by Disabled Living UK. 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

will not normally get to hear. I was also asked to showcase how we worked as an organisation to drive research for a treatment for Wolfram, what it means to me as a parent and charity, and how we hope to be involved with the repurposing programme in the coming year.

Genetic Disorders UK

On March 9th, I will be in London again to attend the 3rd GDUK leadership symposium. This is a day filled with presentations and gaining of knowledge of other organisations that may be able to help us with future fundraising, information to assist you as well as raising our profile amongst the Rare Disease community.

We are part of the GDUK Partnership programme, which means that if a workplace or school signs up for Jeans 4 Genes day for the first time they can nominate us as their charity and we will get half of

them.

Dates for 2018 are:

Middle - Ricoh Arena, Coventry - 15/3/18

Wales and West - Leisure Centre, Bristol - July 2018

South - Farnborough International, Southampton - 17/5/18.

For full details and further information go to their website [here](#).

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](#)

the money they raise. This will continue every year until they no longer take part or choose another charity.



New Support Group in Georgia

In January we were contacted by the founder of a new support group, Wolfram Syndrome - Georgia. Matsatso, the founder of this group, is affected by WS herself. In Georgia Wolfram Syndrome is not on the list of rare genetic diseases and there is no statistical data of WS. The only data that is available is in the "Diabetic Child Protection Association", where there are 20 people with WS (official data).

She has met the chairman of the Committee on Health and Social Issues of the Parliament of Georgia and was



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: mydonate.bt.com/charities/wolfram syndromeuk. 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!

Monthly

asked why she needed WS to be in the list of rare genetic diseases since people with WS already received free medication for Diabetes Insipidus and Diabetes Mellitus. She explained to him that there are other things that are needed as there are so many other parts to WS. Things like help with hearing aids and glasses.

At the moment there is no specialist clinic for WS affected patients to be seen or to discuss any issues, as is the case in so many countries because of its rarity. Matsatso is hoping this can be changed.

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.

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.

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



Give as you Live®

6th Annual Charity Golf Day

Our annual charity golf day is back and is once again being kindly sponsored by Penfold Verrall. This year it is taking place on Friday 27th July at Mannings Heath Golf Club, Near Horsham, West Sussex. Over the last 5 years this event has raised almost £30,000. This money has been used to help purchase the charity caravan, towards conference and will be used to support those that will be taking part in the clinical trial starting this year.

We already have 9 teams confirmed to play along with some fantastic prizes already donated.

Thank you so far to 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

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 shopping. It's that simple. Click [here](#) to start raising funds for WSUK now.



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

for 2 and to Whittlebury Hall Hotel, Northamptonshire for a 1 night spa break for 2 people. More to follow in the next newsletter.

London to Brighton Bike Ride

Iain Lynch and 3 friends have signed up to take part in their first ever long distance bike ride, in September this year. Training has not yet started but will do as they get to the end of their University courses. 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.

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)

March

Patrick Bezzina
Shiffa Ahmed
Victor Carnel
Katie Gibson
Krystal O'Farrell
Mike van Brenk

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 run 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.

Looking for a new challenge or experience

Are you looking to try a new experience that will challenge you and take you out of your comfort zone? Do you fancy learning a new skill? How about sailing? The Jubilee Sailing Trust could be the answer. The JST sailing charity established for 40 years exists

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



to promote social inclusion, challenge prejudices about disability and break down barriers between people of different ages, abilities, backgrounds and cultures through the medium of Tall Ship sailing.

If this appeals to you have a look at their website [here](#). They also have a [short film](#) which brings their work to life and has just been short listed for the UK Charity film awards.



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