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Newsletter Summer 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 Summer newsletter. With the long winter hopefully well behind us now we can get lots of sunnier and hotter weather to help everyone's moods brighten up! With the lighter evenings it gives us all more opportunities to get out and explore the countryside, seaside or other areas around us.

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

GDPR

On 25th May the new GDPR (General Data Protection Regulations) comes into force. After this date WSUK will be unable to send you the quarterly newsletter or other information about trials, clinic, fundraisers etc. unless you have given us your written consent. Forms asking you to re-consent us storing your details and to allow us to continue communicating with you have been sent out by post and email. A separate form has been sent out from the platform we use for mass communication as well.

If you haven't done so already then please send us back your forms and confirm acceptance on the additional online request asap, otherwise this could be our



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:

July 27th
September 28th
November 23rd

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

last communication with each other. If you need a replacement consent form then please let me know as soon as possible.

Thank you

UK Clinical Trial Updates



Here is the latest update from Prof Barrett

Dear friends and colleagues,

I wanted to update you about the TREATWOLFRAM clinical trial. Rebecca Storey, our clinical trials coordinator, has done a fantastic job in writing all the regulatory documents. These include things like patient information sheets, consent forms, ethics submission, clinical trial... to read the rest click [here](#)

371 6890.

Adult Clinic Survey

A survey has been sent out and also posted on social media. If you haven't yet completed it, please do so. If you haven't received the link then click [here](#). WSUK are hoping we can help improve the adult service but we need your responses so we can present them to the team.

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

16th/17th July
1st/2nd Oct

As soon as there any further updates on the TreatWolfram drug trial they will be put on the website and emailed out to everyone.

7th Annual Conference

The date for this year's conference is 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 have rooms on offer at a **subsidised rate**, for you to book for the Friday and also for the

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.

BioMarkers Research Update

In the last newsletter I mentioned the grant funding that Prof Barrett had received for research into Bio Markers. Here is the update on this:

**1st teleconference meeting report
24 April 2018**

Report written by:

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 by going to the Hotel's [website](#).

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

Virginie Picard
(Association du syndrome de Wolfram)

Report validated by: Prof. Timothy Barrett, project coordinator.

The first update teleconference meeting on Biomarker project led by professor Tim Barrett took place on Tuesday 24 April, six months after the official beginning of the project.

Representatives of the three funding organizations were present: Stephanie Gebel (The Snow Foundation), Nolwen Le Floch & Virginie Picard (Association du syndrome de Wolfram) and Lode Carnel (Eye Hope Foundation).

The project coordinator, professor Timothy



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 a decision on the winner.

International WS Conference - Paris

Barrett, presented the progress of the project, with the kind assistance of two members of his consortium: Dr. Dewi Astuti and Dr. Anita Slade (University of Birmingham).

As an introduction, Professor Barrett recalled... to read the rest click here



USA

Updates

Some of you may be interested in reading about Dr Fumi Urano's trial update. This can be found on our website from [here](#). You can also read more on The Snow Foundation website. He is the lead researcher in the USA. He is one of many doctors & scientists working

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

Hopefully there will be some information from these teams that can be shared with you in the next newsletter.

Findacure Conference

On 27th February, a day when plenty of snow fell in

together from around the world. To read his updates click [here](#).

An achievement for Jennifer Lynch

For many attending a concert, going to the theatre or any large event is nothing to write home about. Not the case for Jennifer Lynch. She started losing her vision at about the age of 4.. stopped being invited to friends houses as parents were scared of her medical issues and is very sound sensitive. Over the last 6 years she has become very restrictive of what she does and spends a lot of time in her room.

For her 16th birthday last year we gave

the South, I had the pleasure of 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 WS and asked to showcase how we worked as an organisation. I had many people come up to me after to discuss my presentation further. Findacure kindly sent me a copy of my presentation. It is a slides and audio presentation and you can watch/listen to it [here](#).

Genetic Disorders UK

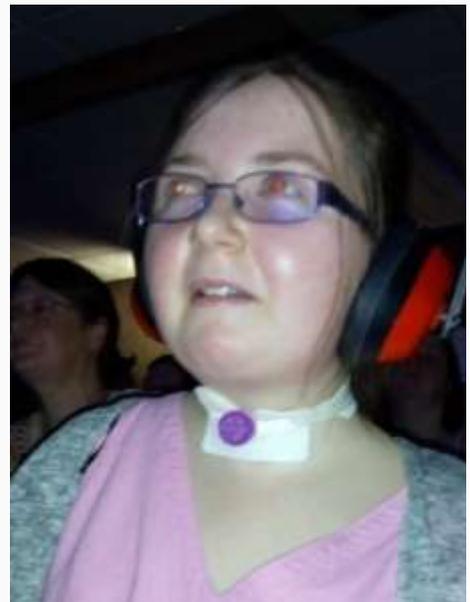
her tickets to see Gary Barlow in his live tour in Brighton. We spent time talking to her about it to prepare her of what to expect.

On 14th May we took one of friends her with us to watch Gary with a little apprehension of how she would cope. Jennifer was amazing!! She sat mesmerized as Gary performed a wonderful mixture of his solo hits as well as Take That hits. Towards the end of the night she even got up to clap along and dance, in her own way, to well known hits.

This was a massive step forward for Jennifer. Now to think of the next challenge for her.

On March 9th, I attended the 3rd GDUK leadership symposium. This was a day filled with presentations and a gaining and sharing of knowledge from other organisations within the Rare Disease community. At the pre conference dinner we heard from actress Samantha Renke (wheelchair going over the bride's foot Malteaser advert) talking about her condition and how she didn't let it stand in her way of becoming a secondary school teacher before becoming an actress.

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



Medical Exemption Certificates

Once a child has let full time education at 16/17/18 or 19 they will need to apply for a Medical Exemption Certificate to enable them to still receive free NHS prescriptions. These are only available to people with certain medical conditions.

A medical exemption certificate:

SUPPORTED BY



Good Luck!!

Good luck to all of our young adults and younger as they start to take their exams. Whether it is SAT's, GCSE's, B'TEC's or A Levels, just do what you can. We all know that you will do your best and we will be proud of you whatever grades you achieve!

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'. This book is now on sale. At the time of writing the price is to be confirmed. Please email, phone or message if you would like a copy. Keri will be bringing them to conference so if you

- entitles you to free NHS prescriptions only
- doesn't cover dental treatment or help with other health costs
- should be shown when you collect a prescription
- is valid for five years (or until your 60th birthday, whichever is sooner)

It's your responsibility to check the expiry date, and if you claim free prescriptions after your certificate expires, you could have to pay a penalty charge of up to £100.

You can apply for a medical exemption certificate if you have

want to wait you can get a copy then.

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.

Waitrose Collection

Naomi Bennett has been collecting, in the snow, at her local Waitrose once again with a shaker and handing out leaflets. She and her guide dog are well known locally so many residents already know about WS. Naomi and Crusoe managed to raise £230 despite the weather. Keep up the fantastic work!!!

Barber shop's Personal

one of the following medical conditions:

- a permanent fistula (for example, caecostomy, colostomy, laryngostomy or ileostomy) which needs continuous surgical dressing or an appliance
- a form of hypoadrenalism (for example, Addison's Disease) for which specific substitution therapy is essential
- diabetes insipidus and other forms of hypopituitarism
- diabetes mellitus, except where treatment is by diet alone
- hypoparathyroidism
- myasthenia

Best

Local barber shop, Sweeney Todd's, in Durrington; whose owner was also the winner of the Stephen Bassett achievement award last year has just beaten their previous highest collection total. Their collection shaker has just been counted with a total of **£207.04**. The amount raised isn't just from customers putting in loose change but also staff putting in some of their tips each month. Well done & thank you guys!!



Pub collection

Shane Roberts asked the pub in the village where he used to live if they would be kind enough to have one of the WSUK coin collection shakers on their bar. This has just been emptied and banked with the sum of

- gravis
- myxoedema (that is, hypothyroidism which needs thyroid hormone replacement)
- epilepsy which needs continuous anticonvulsive therapy
- a continuing physical disability which means you cannot go out without the help of another person
- cancer and are undergoing treatment for either:
 - cancer
 - the effects of cancer
 - the effects of cancer treatment

These are the only conditions that entitle you to a medical exemption

£105.30 inside. The shaker is on its way back to the pub to start again.

Do you have a friendly pub or barbers that you use a lot, that might put a collection shaker out on display. Ask them and I can arrange for shakers to be sent to you along with a letter of authorisation to allow you to collect it when full.

Worthing 10K run

We have 2 family members of Trustees Paul and Darren Lynch and a couple of friends all running the Worthing 10K for the first time, all for WSUK.

First is Darren's eldest daughter Sophie. She has 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. Sophie's fundraising page can be found [here](#).

certificate. If you're not sure about the name of your condition, speak to your doctor.

If you're entitled to a certificate because of your medical condition, your doctor will give you an application form.

You should expect to receive your certificate within 10 working days of your application being received. For further details about this then go to the website here

Do you know about the CEA Card?

The CEA Card is a national card scheme developed for UK cinemas by the UK Cinema Association (UKCA).

Secondly, Rob who is married to their cousin and is also doing his first distance run to help raise funds and awareness. His fundraising page can be accessed [here](#).

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. In the past this money has been used to help purchase the charity caravan, gone towards conference costs and this year will also be used to support those that will be taking part in the clinical trial starting later this year.

We currently have 19 teams confirmed to play along with some fantastic prizes already

The Card enables a disabled cinema guest to receive a complimentary ticket for someone to go with them when they visit a participating cinema.

The Card is also one way for cinemas to make sure they look after their disabled guests. If you require an adjustment to visit a cinema because of your disability, cinema staff should make them for you whether you have a CEA Card or not.

The Card is developed by UKCA's Disability Working Group, whose members include film exhibitors and distributors, and national disability charities such as Action on Hearing

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 for 2, to Whittlebury Hall Hotel, Northamptonshire for a 1 night spa break for 2 people, to Mannings Heath Golf Club for a 4 ball of golf and 2 x 3 month full memberships for the East Sussex Gliding Club.

50th Anniversary Bike Ride

Colin and Rosy Gray are celebrating their golden wedding anniversary by raising funds for WSUK. 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 have

Loss, the RNIB, Dimensions and Muscular Dystrophy UK.

More details can be got from their website 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

invited family and friends to join them on their 50 mile bike ride on 4th August around the area of Normanton on Soar. They have arranged 3 different routes of varying lengths to suit everyone taking part including children. They are then finishing of the day with an anniversary party where they are asking for donations to WSUK rather than presents. They have set a target of £1000, and at the time of writing this they were at £740. The link to their fundraising page is [here](#).

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 just started now they have finished 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

with them.

Dates for 2018 are:

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](#)

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.

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



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/wolframsyndromeuk](https://www.bt.com/charities/wolframsyndromeuk). 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

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 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.

donation!

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.

Several families have already encouraged others to donate regularly,

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 live 80's night. What better way to start the festive season and to finish of the year!! Further details will be posted on our Facebook page and in the next e-newsletter.



so why don't you?



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 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 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)

June

Jared Bennett
Shane Roberts
James Smith
Luke Gough
Andrea Millership
Andrew Tolmie

July

Julie Fox
Devanshi Chauhan
Arkevon Grandberry

August

Helen Gripaios
Keri Chambers
Nelson Rodda
Felix Rodda

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