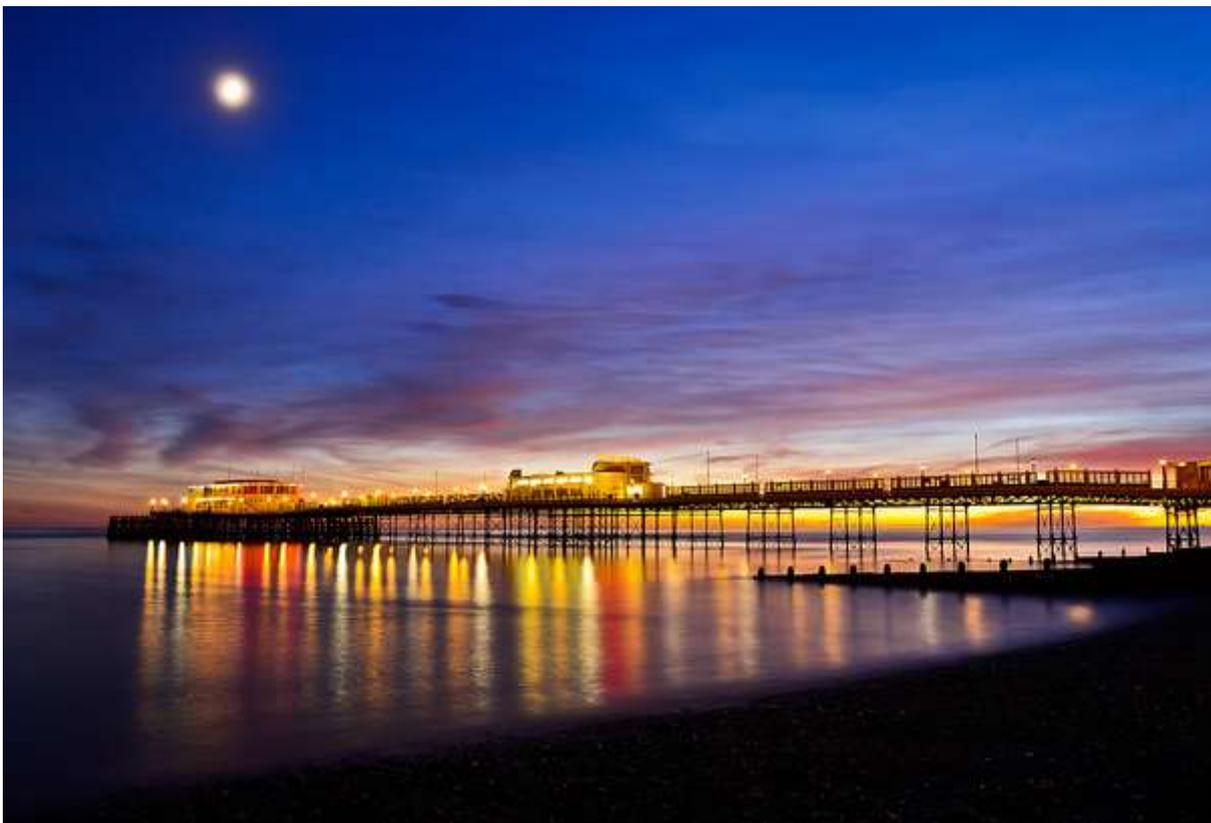


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**Welcome to our Summer newsletter.**

**This quarters newsletter contains news updates, information about conference, past and upcoming 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](mailto:admin@wolframsyndrome.co.uk)**



## **News**

### **UK Clinical Trial Updates**



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

### **8th Annual Conference**

**Conference is Saturday 28th September at Whittlebury Hall Hotel once again, 9.00am - 5.30pm (TBC). 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!

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



## **Social/Activity Break proposal**

This has been mentioned previously. WSUK will look to provide 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.**

**We are also looking into other social activities for our members and will be in touch about this in the near future.**

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

### **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](mailto:sheilapk@hotmail.com) (and please mention that you have read this article)

## **Disabled Living Newsletter**

Some of you may already receive the monthly newsletters from Disabled Living but if not you can find the latest copies here or shared on our Facebook page:

[Disabled Living Newsletter May/June Transitional Years by Kidz to Adultz.](#)

## **Recent Questionnaires**

Thank you to everyone that took the time to complete the recent questionnaires that were sent out recently. Your answers will help us to provide evidence when applying for grant funding, to enable us to provide a better service to you our affected families and individuals.

There were also some helpful comments included. Your assistance in things like this is always appreciated.

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## **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](http://www.wolframsyndrome.co.uk)**

**Remember to keep checking the website for upcoming events, any recent news articles & links.**

## **3rd Brighton Marathon**

21 year old Marcus Lynch ran his 3rd marathon in aid of Wolfram Syndrome UK after a year off. Marcus managed to complete the marathon with a time of 4 hours and 21 minutes, a very respectable time considering

he had only done 6 training runs with the longest being 10 miles in distance. Currently he has raised £458.75 inc Gift Aid. His fundraising page is still live until 29th June. If you or anyone you know would like to sponsor him, his sponsor page can be found on BT Mydonate or [here](#).



## Cake Sale for WSUK

Jennifer Lynch organised a small cake sale the week before breaking up from college. With some assistance from her learning support assistants she baked cakes during her Key Skills classes to sell. She also sold some of our charity pens and wristbands raising a total of £123.32.



## **Waitrose Collection**

**Naomi Bennett has been collecting in her home town again for WSUK. She contacted her local Waitrose store to ask permission about collecting there again. This is her 3rd collection at the store. She raised £270.00 from shoppers donations. Well done and thank you Naomi.**

## **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. Rosie Gray, who celebrated her wedding anniversary last year by fundraising for WSUK with a sponsored bike ride, recently also had a big birthday where she asked for donations to WSUK instead of presents. We received the sum of £540, with Gift Aid to follow.

We have also benefitted from some Facebook followers setting up donation pages as well for their birthdays. The most recent payment made from Facebook was for £705.97.

A big thank you to everyone who supports us in this way.

## **Fundraising Project Idea**

There is still time to submit your creative writings. So far only 3 people have contributed. 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 selected poems in.

A deadline has been set of 30th June 2019, to allow time for editing and printing. This will mean that they will definitely be ready for people to buy at this year's conference on 28th September 2019.

I look forward to reading your creative works.

## **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](#).**

Dates for the rest of the year are:

**Wales and West** - 4th July, 9.30-4.30  
Thornbury Leisure Centre, Bristol.

**Scotland** - TBA

**North** - 14th Nov, 9.30-4.30  
Event City, Barton Dock Rd, Manchester.

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## **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:

July 19th  
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:**

3rd and 4th June  
15th and 16th July  
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 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 hospital know so that, that place can be offered to someone else.**

**My Life by Naomi Bennett**

I am in my final year of studying for my BA Hons

degree in Social Sciences with the Open University. I am currently studying Counselling and Forensic Psychology which is really interesting. This module and another module on politics have been my favourites. It has been hard work but on the whole I have enjoyed it.

When not studying, I keep myself busy with my volunteering. I do hand massages for the residents at 2 care homes and also visit Age UK every Friday to give the clients hand massages and have a chat. Three times a week, I help out with 2 mother and toddler groups. I also enjoy playing games, scrabble and cards, at my local library every Tuesday and in my spare time I enjoy meeting friends for coffee or lunch and reading my braille book at the library.

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



## 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](#)



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. This is also 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](mailto: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](#).

## **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.**



**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.**

# **Birthdays (UK and worldwide)**

## **June**

**Andrew Tolmie  
Jared Bennett  
Norbert Azzopardi  
Andrea Millership  
Shane Roberts  
Luke Gough  
Anton Todorov**

## **July**

**Julie Fox  
Devanshi Chauhan  
Anniya Parveen**

## **August**

**Helen Gripaios  
Nelson Rodda  
Sterling Rodda  
Keri Chambers  
Evie West**



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