



## **Welcome to the Summer Newsletter.**

Here we are going into summer and the weather still doesn't really know what it's doing. I have been trying to get out into the garden when I can, to start getting it ready for the nice weather. I have some tomatoes and a pepper plant growing for my salads and I have also converted 2 pallets into planters. See the pictures below. By growing your own fruit and vegetables, in whatever space you have, means you know what is going onto them before eating. There is nothing nicer, I think, than picking homegrown tomatoes and peppers to go onto your salad.

Getting outside doing some gardening, walking the dog or just walking in some nearby country side is

good for everyone's health and wellbeing.

I hope those that have been sitting exams are happy that they are now over or almost over. I hope that you get the results you want for the next step on your educational journeys.

We have had lots going on over the past few months, most of which you can read about in the newsletter below.

Don't forget to book your place and room if required for the WS family conference and information day on 21st September. Last day to book is 28th August.

Remember, if you have anything that you would like to see included in future newsletters, then please send it to the office, details at the bottom of this newsletter. Likewise, if you have any questions or concerns you can contact [Tracy](#), [Phillippa](#) or [Georgina](#) about these.

Take care

Tracy



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Wolfram Syndrome UK values your involvement with the newsletters, so please remember to share anything that you would like to see included in future newsletters as well as telling us what you have been doing. These can be sent to us at [admin@wolframsyndrome.co.uk](mailto:admin@wolframsyndrome.co.uk).

An audio version of this newsletter is posted onto our website and Social Media pages or if you would prefer the audio version or a large print printed version mailed to you, then please let us know.

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## Contents

- News and Updates
- News You Can Use
- Support Co-ordinators Updates
- WS Clinics
- Fundraising News
- Ways to Support WSUK
- Your News

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## News and Updates

### WS Conference



This year's conference is to be held at the Mercure Daventry Court Hotel, Daventry on Saturday 21st September 2024, so please save the date in your dairy.

There is a slight increase to room costs, I'm afraid, but it is minimal, Booking forms to reserve your place and room if required can be found on the [website](#)

and have been sent out. Please start reserving your conference place and room(s) if required now. The last date for booking is Wednesday 28th August. After this date rooms can't be guaranteed if you are wanting to stay.

A draft programme has been added to the website, but there may be some changes to be made.

Once again there will be a social event happening on the Friday evening for those that are staying. Phillipa will be happy for you to join in with what she has planned if you wish. Details about this will be added to the website nearer the time.

**Take part in Wolfram Research -  
Research Opportunity: Be a Participant in  
Our Exciting Eye Study (ORION)**

We are looking for participants to take part in our observational study of Wolfram Syndrome. The **Outcomes Research in Inherited Optic Neuropathy (ORION)** study is taking place in Cambridge led by the team of Professor Patrick Yu Wai Man. The aim of ORION is to better understand how the disease progresses in Wolfram Syndrome, in particular, how the eye is affected over time.

As a part of this study, we will measure various aspects of your vision, including how well you can read letters on a chart (visual acuity), colour vision, visual fields and contrast. We will also take some high-resolution scans of the back of your eye (retina and optic nerve) to measure its thickness (optical coherence tomography).

We are one of the few centres in the world to have access to an advanced camera known as the Ocumet Beacon, which uses a bright blue light to take a picture of the back of the eye. This will tell us how well the mitochondria in the eye are working. Mitochondria are the tiny batteries within a cell that produce energy needed for it to work properly. There is good evidence that mitochondria are affected in Wolfram syndrome.

As part of this study, we will also record the movement of your eyes using a camera to give us a better understanding of how some brain areas might be affected in Wolfram Syndrome.

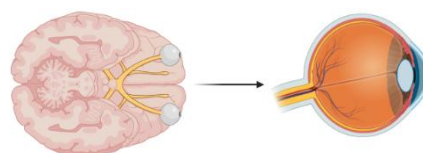
**We are keen to recruit individuals in the United Kingdom with:**

- **a genetic diagnosis of Wolfram syndrome**
- **aged 16 years or older**

As a participant in this study, your travel expenses will be reimbursed and the visit can be arranged at a time that is convenient for you. If you are interested in getting involved in this study or have any questions, please contact us using the details below:  
Email: [riddhima.gautam@nhs.net](mailto:riddhima.gautam@nhs.net)  
Phone Number: 01223 586716 (Monday to Friday, 9am-5pm)



CAMBRIDGE  
CLINICAL VISION  
LABORATORY



## **Wolfram Syndrome Global Virtual Conference**

On 13th April we held a virtual global research and trial update as it was felt that this would be helpful for the global community to hear some of the research and trials currently being worked on around the globe.

The presentations were recorded and are now available to view on the WSUK website on the [conference page](#) under the relevant heading, along with the questions and answers that were asked live and answered afterwards.

We are waiting for approval to allow one presentation to be released as unpublished data was shown.

A presentation is also now available from our 2020 conference as the data has now been published.

The plan is that we will hold a virtual research update, again with The Snow Foundation, a few months after each International Researchers Symposium. This will allow us to ensure that we bring you any new research news as well as any trial updates.



## UK Clinical Trial Updates



No information has been received at the time of this newsletter being sent out. A separate newsletter update with Research news will be sent out separately.



## **USA Trials and Research Updates**

No information has been received at the time of this newsletter being sent out. A separate newsletter update with Research news will be sent out separately.

## **WSUK Research Funding**

WSUK has made the first grant payment to a research project approved by our Scientific Advisory Board (SAB) back in February. We are assisting a project being run at the University of Birmingham with Dr Sovan Sarkar and Dr Malgorzata Zatyka for **Development of autophagy and NAD enhancers for Wolfram syndrome.**

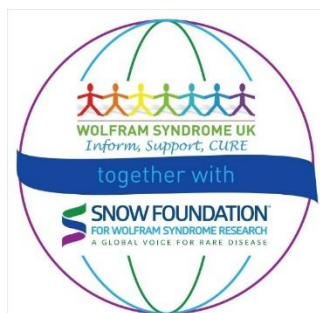
An additional smaller grant has been awarded to Prof Lies de Groef and Prof Catherine Verfaillie from KU Leuven University in Brussels for their work looking at **Therapeutic efficacy of base editing (BE) in a novel Wolfram syndrome (WS) mouse model.** We will be co-funding this with The Snow Foundation. All the legal paperwork is currently being processed before the payment is made to them.

An update we can share with you has been requested from the team at Birmingham University. This will be shared once we receive it. We hope to

be able to share some information about the other project in the Autumn newsletter.

We will be putting out another small grant funding call very soon to all WS researchers around the world..

We will also be co-funding a larger international research project with Snow Foundation in USA, more about this in a future newsletter. Our SAB have discussed the project and made their recommendations, so we now just need to do the required paperwork ahead of paying the funds across.



## **Goodbye**

At the end of May we said goodbye to Dr Denise Williams, Clinical Genetics Consultant, as she has decided to retire from her clinical role.

She will be continuing to work for the National Disease Registration Service for four hours a week. Arrangements are being made for one (or

possibly two) of her colleagues to take on the Wolfram syndrome clinics.

Denise plans to use some of her time with NDRS to look at the Wolfram data that has been collected over the years, so she will be continuing to work in the background.

Denise hopes to be at the WS conference in September so you will have a chance to say goodbye personally then. Denise will be missed by everyone who attends the clinics as she has helped many families and individuals with understanding the genetics around their condition and for family members.

Denise, thank you on behalf of all the WS community.

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## **News You Can Use**

### **International Patient Registry**

Have you wondered how to get involved in Wolfram Syndrome research but did not know how? Here's your chance...check out the Wolfram Syndrome Global Patient Registry at [wsglobalregistry.iamrare.org](http://wsglobalregistry.iamrare.org).

Wolfram Syndrome Global  
Patient Registry

Welcome to the Wolfram Syndrome Global Registry

[Learn more »](#)



## New Patient Passport

Patient organisations have been working with CamRare over the past couple of years to develop a Patient Passport for those affected by Rare Disease. The work has now been completed and our WS branded Patient Passport is now available.

We're delighted to join the growing global network of patient groups partnering with @CamRareDisease to bring their 'This Is Me' **#RarePatientPassport** to our community! The tools to communicate your **#RareCondition** to new people!

Sign up for yours here:

<https://forms.gle/ggp9afsaH8p8Ezd46> or scan the QR code below



## **DrDoctor Patient Portal at Birmingham Children's Hospital**

BCH now uses DrDoctor – a patient portal – to communicate with those they care for and their families about appointments. This means once your appointment has been booked, you will receive a booking confirmation via text message so you can add it to your calendar. You will then get handy reminder texts when your appointment date is coming up and you will receive an official letter electronically (via email or a message link) with further details about the clinic and any instructions you need to follow.

For more information go to our website [here](#).

Please note, the WS clinics will still be communicated from the Rare Diabetes Unit at BCH and Georgina, the FSC, rather than through the

DrDoctor portal.

## **PIP Update**

The Prime Minister announced plans in April to reform PIP alongside other benefit changes for disabled people. One of these was plans to reform [Personal Independence Payment \(PIP\)](#).

Personal Independence Payment (PIP) is a benefit to help with the extra costs of disability for adults aged 16 to pension age. It replaces Disability Living Allowance (DLA) for children when they turn 16.

Contact have an article on their website to give you full information about the reform. Click [here](#) to go to their page.

## **Universal Credit to expand to half a million more**

Managed migration is the process where claimants on existing means tested benefits and tax credits – known as the legacy benefits – are told these benefits are ending and are asked to claim Universal Credit instead.

Up until recently managed migration only applied to people getting tax credits and no other legacy benefits.

The Department of Work and Pensions [is now sending managed migration notices to claimants on other benefits.](#)

### **Worried what managed migration means for you?**

If you are confused or worried about what managed migration will mean for your family, Contact have lots of [information that can help on their website.](#)

## **Phab**

Phab provides safe and fun places for people to feel independent, meet new friends and gain confidence, together.

The national 100+ Phab Clubs are as varied as the people who attend them. They are shaped by the wants and needs of the club members but with a shared commitment to inclusion and accessibility. Held in accessible locations, supported by volunteers, Phab Clubs are places where disabled and non-disabled people of all ages come together with friends and family for all kinds of activities and events.

The Phab Adventure Residentials provide an inclusive and exciting experience away from home to promote confidence, social connections and build personal growth and sense of accomplishment and fun through a range of outdoor activities such as canoeing, rock climbing, caving, archery, sailing and much more.

The Phab Adventures are held at inclusive outdoor centres ensuring that everyone can participate. As well as a large amount of adaptive equipment and accessible accommodation, there is a positive environment where barriers are removed, and everyone belongs.

Each year children, young people, adults and families from around the country join us for an opportunity to learn new skills, make new friends and have a huge amount of fun.

Whilst away, support is received from the Project Leaders and a team of dedicated and enthusiastic volunteers who ensure everyone is safe, happy and having a Phab Adventure!

To learn more about the activity clubs or the



residential breaks got to the Phab website [here](#).

## **Growing fruit and vegetables in small spaces**

Ideas for smaller gardens, balconies and windowsills and to help with a healthy diet for all.

Limited outdoor space doesn't mean you can't benefit from delicious homegrown fruit and vegetables. Especially when prices are still high in the shops for lots of fresh produce. Growing your own means you also not what has gone your food. Nothing quite beats making a cocktail in the kitchen using fresh mint, or the satisfaction of adding some homegrown tomatoes to a side salad.

Don't worry if you only have a small garden, balcony, patio, or even a windowsill to play with. You might even be surprised how little room you need to help fruit and veg come to life.

Even if you only have a small space available that doesn't mean you can't grow loads of your own food. It's just a matter of being clever with the space you have and picking the right varieties.

Whether you want to start your own herb garden or get growing delicious vegetables, below are three

rules to follow on how you can make your smaller outdoor space work for you.

## **How to grow fruit and vegetables in small spaces:**

### **Be creative with containers**

There are certain varieties of fruit and vegetables that are specifically suited to growing in containers. They tend to be shorter in stature and don't require support such as staking. Their smaller size tends to mean that they're happier with a bit more root restriction that they get when grown in a container. Don't let their small size fool you, these plants are still really productive and strong.

### **Think vertically**

If you're limited with square footage, consider going up instead. Thinking vertically is a layout and growing tactic that is often overlooked in our gardens – not to mention the fact that it can add so much character to an outdoor space.



Don't just look at the floor space you have available, think about growing vertically. Using trellises and arches to grow space hungry crops like squashes and climbers can be a great space saver. If you're using containers you can still make the most of arches by placing the containers nearby and creating a beautiful edible canopy within your space. Hanging baskets and bags can be used for tomatoes and strawberries as well.

Windowsills are often forgotten about once we've finished propagating but don't forget these are great growing spaces – particularly south-facing ones.

With your indoor sills bursting with micro tomatoes and herbs and outdoor window boxes full of dwarf beans and edible flowers, these can be truly productive spaces of your home.

### **Smaller space vegetable varieties**

There are a whole range of seeds that are specially designed for containers and small-space growing –

and even some edible houseplants that you can grow in your house. Garden centres and Nurseries usually sell a range of “grow your own” seedlings/plants as well.

### **Recommended small space vegetable varieties:**

- Dwarf Beans such as Oscar Broad bean and Red Swan, a beautiful pink French bean that will only get around knee high.
- Tom Thumb Pea – produces loads of peas on a pocket size plant.
- Vilma Micro Tomato – happy on a sunny windowsill and can even grow your tomatoes through winter under a grow light.
- Lettuce, such as Copacabana and Arcade, make great cut and come again salad leaves.
- Purple Ball Basil – a nice compact deep purple basil that can be grown on a windowsill.
- Tumbling Tom tomatoes
- Watercress

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## **Support Co-ordinator's Updates**

### **Family Support Co-ordinator**

Hi everyone,

As we head into June, and of course summer, which is long awaited this year, we will be starting to implement a virtual clinic, for 2024 only at this stage. For those of you that remember the Covid19 days, virtual clinics were in place instead of the face-to-face clinics. However, these virtual clinics in June are in addition to the face-to-face clinics that Birmingham Children's Hospital provide. WSUK will of course, provide a feedback questionnaire for these clinics to measure the families' thoughts and feelings on them.

As part of my continued team effort to support WSUK, at times I attend the community catch up sessions held by Tracy Lynch. On one of these sessions, I spoke of my extreme day tripping ventures, and the adult community shared with me that they wanted to hear more! Check out my article on travelling later on in the newsletter in the 'Your Stories' section.

I send multiple emails to families, and as we head into the second half of the year, I send them to families so they can comment on my feedback evaluation and invites to the annual conference, please if you haven't already done so, mark my emails as "safe sender" or "not junk" as a lot of the

time, the emails do land in people's junk folder. It would be great to communicate more with some of you.

Have you seen our inspirational people page on the website? There are many people featured on there, the latest Saif, from the WS community has not long received his black belt in Ju-Jitsu. Well-done Saif!

As the school summer holidays are approaching, I have been contacting families to meet with them over this period, if you feel you would like a visit from myself, please do not hesitate to get in touch.

Best wishes,

Georgina

Tel - 07592 629813

[Georginaking@wolframsyndrome.co.uk](mailto:Georginaking@wolframsyndrome.co.uk)

[Family Support Co-ordinator Page](#)

### **Adult Support Co-ordinator**

The days are getting longer and at last the sun has begun to shine (at times!). It makes us all feel a bit more cheerful when we see the sun.

Life at WSUK is keeping me busy, supporting adults in the community with a variety of issues such as housing, social care referrals, and clinic appointments, alongside helping some access their local services, which we of course all know is not very easy at times. Don't forget to reach out to me if you need some help. (my contact details are below) and I will do my best to help or signpost to someone who can.

This leads me onto the new project that I am starting, which will centre around adult support - what it means to you as a community, how we can try to better connect our adult community and how to offer more targeted support. So, on this note, keep an eye out for a short survey that I will be sending out soon, to help me get a feel for what's needed. There is no obligation to participate, but the more responses that I receive, the more it becomes your community and not simply led by me and what I think is needed.

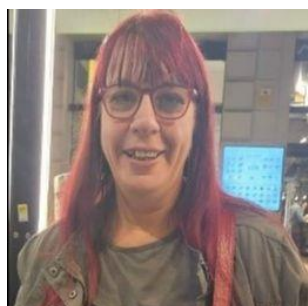
I will see some of you in the clinics over the next few months, as well as catching up with some of you at this year's annual conference in September. If you arrive on the Friday before conference, I will be hosting another social event for those who want to take part. This may well involve some more bingo and another quiz (less complicated this year!!) – but I'm always open to your ideas. Over the course of

the Saturday, I will be available to talk on a 1:1 basis in a separate room if you feel that you need some support on any topic. Come and find me! Or if you like to plan, we can book a time in advance.

I hope you all have a good summer and enjoy some relaxation. As some of you know I am in a band so I will be touring around a bit in my caravan, playing at a few festivals so I am also hoping for good weather!

Best wishes

Phillippa



Tel: 07752193635

E: [phillippafarrant@wolframsyndrome.co.uk](mailto:phillippafarrant@wolframsyndrome.co.uk)

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**WS Clinics**

**Clinic Dates 2024**

WS clinics are generally face-2-face, but if requested can be done virtually if there are reasons why you



can't travel to Birmingham.

Adult clinics are run from the Centre for Rare Diseases in the Heritage Building at The Queen Elizabeth Hospital, Birmingham on the following dates:

**28th June - (clinic full)**

**27th September**

**22nd November**



If you are no longer able to attend the date you are invited to, **PLEASE** let the clinic team, [Tracy](#) or [Phillippa](#), our Adult Support Co-ordinator, know so that someone else can be invited in your place. There is always someone ready to take a slot if you can't.

Due to hospital policy, a clinic appointment can only be changed once for a patient as there is now a larger WS community than previously. **Failure to attend will mean you will be discharged from the service.**

**Please ensure contact details are kept up to date with both the hospital, whichever one you attend, and the Wolfram Syndrome UK office!**

The dates for the Children's Clinics, run from Waterfall House, the Rare Disease Centre at Birmingham Children's Hospital are:

**10th and 11th June (clinic full)  
7th and 8th October**



If you are unable to attend **PLEASE** let [Georgina](#), Family Support Co-ordinator, [Tracy](#) or the hospital know asap, so that the place can be offered to someone else, even if you are having a virtual clinic appointment. There will always be someone ready to take up that slot if you can't.

**Places for both clinics whether virtual or face to face are by invitation only.**

Please **DO NOT** book or make any travel arrangements until you have received confirmation of your clinic invite and have heard from the hospital as to whether you need to attend in person or will be

having a virtual clinic appointment.

Birmingham Children's Hospital fully launched their DrDoctor Notification system in January 2024.

Please read about this further up in the newsletter.

Some of our families are receiving email or text notifications that they are on a waiting list for a WS clinic, which is causing a bit of confusion.

**If you have been told you are attending a clinic already, please ignore the reminders as they are auto generated.**

We have a '[Who's who at the WS Clinic](#)' page on the website, as well as a [Family Support Co-ordinator's](#) page with information from Georgina.

There is a map of the [Queen Elizabeth Hospital](#) site and a floorplan of [Waterfall House](#) for new visitors, on the clinics page of the WSUK [website](#).

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## **Fundraising News**

Upcoming 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.



## Charity Football

Regular supporters, FJN Solutions in Horsham, have once again organised two charity football matches.

April 19th will see them playing a regular football match and on 14th June there will be 12 teams taking part in a six-a-side tournament, just like last year.

FJN Solutions sponsored Horsham FC in this season's FA Cup, and have kindly donated one of the three signed and framed FA Cup shirts they were presented with to be raffled off to raise funds for us. This was raffled off at a home game against Lewes on 1st April and raised £900.00.

The charity match played on 19th April raised £1250 with a score of 5-7. The next event by FJN is the 6-a-side tournament on 14th June.



We would like to thank FJN for their continued support.

## **80 Mile Cycle on 80th Birthday**

Ongoing supporters, Colin and Rosy Gray, cycled 80 miles in April for Colin's 80th birthday for WSUK.

They are friends of one of our initial families and have supported us for over 5 years with cycling fundraisers, one of which was linked to their 60th wedding anniversary.

From the sponsored bike rides and Colin's 80th birthday party a total of **£4560** has been raised inc. Gift Aid!

Thank you to them for their continued support!



## Charity Golf Day

Our 11th annual charity golf day sponsored by Northern Commercials this year, is being held at Mannings Heath Golf Club and Wine Estate on 19th July.

We would like to thank Mid Sussex Golf Club who have donated a Four ball voucher as an auction lot for the day along with other auction prizes coming in.

This is a popular event with all teams that are invited to take part and a great day is had by everyone involved. The amount raised will be given in the Autumn newsletter.



**Continued Support!**

Thank you to those members of the WS community and their friends/families who donate regularly, through monthly standing orders/direct debits, to support the work that we do.

Would you consider making a monthly donation to us? If so, then please contact Tracy in the [office](#) for bank account details.

Why not set yourself a task of asking **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 the office know if we can Gift Aid your/their donation. We just need a name and address to do this (forms for [single](#) or [multiple](#) donations are on the website, these can be printed off and sent back to us).

Why not get involved with fundraising for WSUK?

**Let us know if you do something and we can include it in a future newsletter.**

All the fundraising sites we are registered with can be found on the WSUK [website](#).

**If you have any event that you would like to share**

or possibly promote please let us know in the WSUK office.

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## Ways to Donate to WSUK



### Facebook Donations

We continue to be thought of by WS members and their families when it comes to their birthdays or they are doing a fundraising event through creating [Facebook fundraiser pages](#).

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



### PayPal Giving Fund

PayPal Giving Fund is a way of donating to Wolfram Syndrome **without** any fees being **deducted** by the fundraising platform like many of the others do. The



link for this page is

[paypal.com/gb/fundraiser/charity/76200](https://paypal.com/gb/fundraiser/charity/76200)

PayPal Giving Fund



This QR code can also be used to make a donation to WSUK. Please feel free to share with friends and family.

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## Other Ways to Support WSUK

**PayPal - Give at Checkout**



Want to support WSUK when you shop online? Set us as your favourite charity, then click to donate £1 when you checkout with @PayPal for your purchases.

There are 2 ways to do this.

1. By using the link below, select us as your favourite charity and then log in to your account to complete

the process.

[paypal.com/gb/fundraiser/charity/76200](https://paypal.com/gb/fundraiser/charity/76200)

2. Log in to PayPal. Click " Set your favourite charity", type in our name Wolfram Syndrome UK. Confirm this is your favourite charity and we will appear on your homepage.

## Make your online shopping count!



Want to help us raise more just by shopping online? Well now you can! It's very easy to do.

We are registered with online shopping portals [Give as You Live](#) and [easyfundraising](#).

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. You can also raise funds when shopping for things like holidays and insurance.

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. Install the reminder link so you will be asked if you want to raise a donation when you go straight to the retailer's website, so you don't need to worry about forgetting. Simple!

Sometimes it may be a few pence, other times it can be up to £40 for a retailer donation. Help us by signing up today!

## **One-off Pieces of Art**

22-year-old, Jennifer Lynch, has been busy creating individual pieces of Art this year.

Jennifer has no vision remaining, but with some assistance using pouring/fluid paint she has been creating art on box canvases and canvas boards, which can be framed.

These pieces of art have been capturing attention and have been purchased by some of you at last year's conference and by others who have seen the artwork on Facebook.

The artwork has now been added to the [WSUK shop](#) page for you to look at and purchase if anyone

wishes. A lot of them are brighter in real life, photos don't really do them justice.

If you would like to purchase a piece of art then please contact the office for P&P to be calculated and to make payment. Jennifer has donated the cost of materials so 100% of the sale price goes to WSUK.



### **Blank Greetings Cards**

We have also just added some blank greetings cards to the shop page. There are 5 designs, copies of Jennifer's paintings. Cards are available individually for £1.50 with P&P of £1.00. Please contact the office if you would like to purchase any.



**WS clothing and accessories website**

WSUK has created a new website for WS branded clothing and some accessories such as tea towels, bags and mugs.

The products are made from organic cotton and printed in a renewable energy powered factory. When they are no longer wearable or wanted the items have instructions on how to send the product back to be re-milled and remade.

Delivery can be made to almost every country, just check the bottom of the website for delivery details and answers to any questions you may have.

WSUK will receive funds from the sale of each product. Currently we have a minimal range of products available. There are three logos to choose from - Wolfram Syndrome UK; WS Global Awareness Day for anyone that would like to help raise awareness every October 1st and the Wolfram Syndrome UK and Snow foundation joining together logo. The two organisations work closely together putting on the virtual global events and for the last two years the International Researchers Symposium.

Please send us any images of you wearing or using any of these products if you make a purchase. Go to the website [here](#) where you can also read a bit

about the company we are using. A link will also be found on our WSUK shop page on our website.



Information about ways to raise funds can be found on our website [Funding Inspiration](#) page

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## Your News

Please send in anything you would like to share with the WS community. The deadline for sending to be included in the Autumn newsletter is **23rd August**.

### Rory's story

Rory's story was shared by Genetic Alliance UK for their March Blog. Rory's mum Rachel has shared it with us [Rory's Story - Genetic Alliance](#).

### Extreme Day Tripping

As mentioned in my update, when taking part in the

community catch ups, I happened to mention that I had been part of a new community called EDT – Extreme Day Tripping! The purpose of this group is to try and travel as far as you can, or even just to a new place in just 1 day! Meaning, on the most part I am back in my own bed at home for lights out. This concept works really well for me, because up until recently I had 2 elderly dogs that I don't like leaving for long periods of time. Unfortunately, one of my beloved dogs passed away in February.

So far, since I started EDT, I have been to Alicante, Venice, Belfast and Stockholm, I have Copenhagen and Basel booked too! I want to talk to you about my experience of Alicante. We flew from Manchester airport, which is just 1hr 15min drive from us (at 3am) the flight out was 6.30am and the flight back was supposed to be 7.15pm but delayed to 9.30pm. The flight was 2.5hrs long.

What I noticed most about Alicante was how accessible and disability friendly it was. Everywhere was flat, or had lifts to take you to the non-accessible areas. The pier had a lift, and the castle – Santa Barbara which stands 166m high had a lift also. Along the promenade it was completely flat, and on the beach, there were wooden paths to give more accessibility.

I saw many people there with disabilities and in

wheelchairs, there was also a lot of dogs! More than any other European city I have visited recently; and I had the general feeling that different was accepted there. The buses were accessible, and the staff were friendly and helpful. The bus into Alicante centre is just 10mins and goes from outside the airport's arrivals hall, it cost just 3 euros to get into town. There is plenty of places to eat and drink along the promenade, all accessible, and if you want to venture into the city for shopping it is all flat with wide streets and lots of traffic lights to guide you.

Myself and my eldest son, 21yrs old, went in December 2023 and the temperature was a glorious 19 degrees reaching 23 degrees mid-afternoon! It was the perfect way to spend what would be a chilly winter day in the U.K! I will in future look out for any accessible routes and anything that may help our community in the future to travel.

Georgina King - Family Support Co-ordinator

## **Birthdays (UK and worldwide)**





Happy birthday to everyone that has a birthday to celebrate during June, July and August.

We hope that you all have a great day!



**Happy birthday to you all!!**

