WOLFRAM SYNDROME UK
Inform, Support, CURE

Welcome to the Autumn newsletter.

Hello everyone,

Firstly, a huge congratulations to all our WS young adults who have achieved the grades needed to move on to college or university. The WSUK team wishes you the very best as you embark on this exciting new chapter - especially if you're heading off to live in Halls of Residence for the first time!

I hope you all managed to enjoy the summer and stay cool during the heat. While I personally love the sunshine, I do look forward to the change of seasons - the crisp autumn air, the earthy scents, and those cosy evenings when we can light the log fire again.

Autumn is always a busy time for us, with key events like our face-to-face conference, as well as two virtual conferences this year. You can find more information about these in the newsletter.

The summer months were packed with fundraising activities, and we're excited to announce a new fundraising challenge coming up. We'd love for as many of you as possible to take part - especially since it ties in with Global WS Awareness Day. Full details are further down in the newsletter.

If you'd like to contribute content for future newsletters, feel free to send it to the office; and, as always, if you have any questions or concerns, reach out to Tracy, Phillippa, Georgina, or Olivia.

Take care

Tracy

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.

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.

Contents

News and Updates

Annual Conference – Saturday 20th September 2025

There is still time to book your place(s) for this year's WSUK Annual Conference, taking place on **Saturday 20th September** at our usual venue in **Daventry**. Rooms aren't guaranteed, so please check with Tracy before making your payment.

The booking form and programme, are available on our website. If you would like to attend either of the planned first aid courses, please let Tracy know asap as there are only 12 spaces on each course.

What’s Happening at the Conference?

- **Craft Activities for Children:** A volunteer will be running a small craft and games session throughout the day for children attending the event. **Please note** that this is not an official crèche, and parents remain responsible for their children throughout the day.
- **Sports Taster Sessions:** The **Royal National College, Hereford** will be offering **taster sessions of various sports**, so everyone will have the chance to try something new.
- **Basic First Aid course:** This proved popular when we ran it 2 years ago. You receive a certificate and handbook afterwards. With only twelve places per session, you will need to book your place quickly.

Book Your Place Now!

If you plan to attend, please book your place and accommodation **now** as dietary requirements and dinner choices need to be with the hotel very soon.

For full details about the conference, including the programme, visit our website.

We look forward to seeing many of you in September for another fantastic event!

📅 Upcoming WSUK & Snow Foundation Online Conferences

We're pleased to announce two virtual global conferences featuring research presentations:

- **25 October** (afternoon, BST)
- **15 November** (afternoon, GMT)

As with previous online events, you'll need to register for each session that you wish to attend. Full details will be emailed out and added to our website after 6th October.

We hope you'll be able to join us.

WOLFRAM SYNDROME UK
Inform, Support, CURE
together with
SNOW FOUNDATION
FOR WOLFRAM SYNDROME RESEARCH
A GLOBAL VOICE FOR RARE DISEASE

WS Global Awareness Day (WSGAD)

🎉 WS Global Awareness Day – 1st October 🎉

Let’s raise awareness and funds for WSUK - every little bit helps!

Whether it’s a coffee morning with cakes and a raffle, joining an organised event, or hosting your own quiz night, getting involved doesn’t have to be complicated.

📣 We’re aiming to launch the new WS Clinical Guidelines in time for the day - perfect for sharing on websites, email, and social media.

🏃‍♀️ Olivia, one of our FSCs, has organised a challenge event - see below for details!

📰 Media or press coverage would be fantastic if you can arrange it.

💬 Let us know what you do and how it goes - we’d love to celebrate your efforts!

To help promote the day you can purchase a WSGAD t- shirt from our promotional [site here]

🚶‍♀️ Walk a Week for Wolfram – Starts 1st October

Join us this October for our brand-new fundraising challenge, launching on Wolfram Syndrome Global Awareness Day.

We’re inviting all our families to get involved - walk solo, with friends, or as a team. You’ve got the whole month to complete a week’s worth of walking, at any pace, any distance. No pressure, just participation!

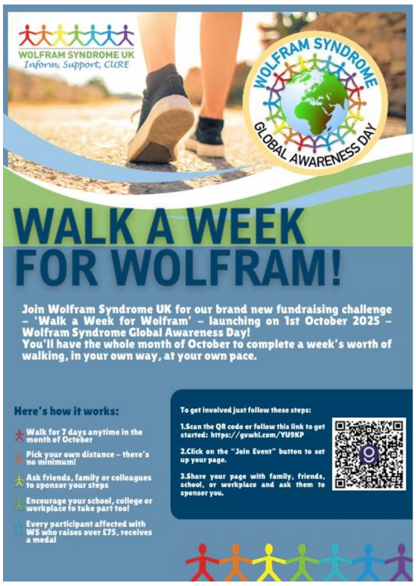
💻 To take part:

1. Follow this link: https://gvwhl.com/YU9KP
2. Click “Join Event” to set up your fundraising page
3. Share it with friends, family, colleagues - anyone keen to support your walk

🏅 A little thank you:

WS affected individuals who raise over £75 will receive a medal to mark their amazing effort!

Let’s get moving this October - raising awareness, funds, and hope for everyone affected by WS.



WALK A WEEK FOR WOLFRAM!

Join Wolfram Syndrome UK for our brand new fundraising challenge – ‘Walk a Week for Wolfram’ – launching on 1st October 2025 – Wolfram Syndrome Global Awareness Day!
You’ll have the whole month of October to complete a week’s worth of walking, in your own way, at your own pace.

Here’s how it works:

- Walk for 7 days anytime in the month of October
- Pick your own distance – there’s no minimum!
- Ask friends, family or colleagues to sponsor your steps
- Encourage your school, college or workplace to take part too!
- Every participant affected with WS who raises over £75, receives a medal

To get involved just follow these steps:

1.Scan the QR code or follow this link to get started: https://gvwhl.com/YU9KP

2.Click on the “Join Event” button to set up your page.

3.Share your page with family, friends, school, or workplace and ask them to sponsor you.

WSUK Funded Research Projects

WSUK have contributed funds to three research projects over the last 18 months, one in Birmingham, UK, one in Belgium and one in Montpelier, France. Lay summary updates from these projects can be found on the WSUK website. Dr Sovan Sarkar, from Birmingham University, one of the researchers we have funded will be speaking at our conference in September about some of his research.

Other Research Updates

TREATWolfram Trial Update

TREATWOLFRAM

On June 23rd, we shared the initial results of the TREATWolfram Trial via email. We know the outcome wasn't what any of us had hoped for, and we understand how disappointing that news was. At the time, the research team still had more analysis to complete, which they expected to take around six weeks.

You can now read the full trial report on the WSUK website here:

Looking ahead, Professor Barrett will be speaking at this year's WSUK Conference, where he'll talk about the findings and what the next steps might look like for the trial and the Wolfram community. His talk will be recorded and shared on the conference page afterwards for anyone who can't attend in person.

He'll also be presenting at the Global Virtual Conference on November 15th. Like the WSUK event, all talks will be recorded and made available on the website a few weeks after the event.

USA Trials and Research Updates

Dear Friends,

I hope you had a wonderful summer with your family. Each week, I have the privilege of seeing patients with Wolfram syndrome in our clinic, and every day I stay connected with you through phone calls, Zoom, and email. Many of you travel long distances from across the country and even abroad to come to St. Louis. I know how challenging this can be, and I truly appreciate the effort you and your families make. I also want you to know that we are making steady progress, and I'd like to share some of these updates with you today.

Wolfram Syndrome Workshop in Paris

I had the privilege of attending and co-organizing the 10th International Wolfram Syndrome Workshop, held in Paris on June 13–14, 2025. This landmark event brought together clinicians, scientists, and advocates from around the globe to share the latest research and clinical.... read more here.

News You Can Use

International Patient Registry

Get Involved in Wolfram Syndrome Research

Ever wondered how you could help advance research into Wolfram Syndrome but weren’t sure where to start? Here's the opportunity.

Take a look at the **Wolfram Syndrome Global Patient Registry** at wsglobalregistry.iamrare.org.

Wolfram Syndrome Global Patient Registry

Welcome to the Wolfram Syndrome Global Registry

Parents and siblings who are carriers can also submit their details and answer relevant questions. All of this information will be incredibly valuable for researchers in the future.

Thank you for taking the time to contribute - your support makes a real difference!

First Barbie Doll with Type 1 Diabetes (T1D) Launched

Mattel has now launched its first Barbie doll with type 1 diabetes, the latest addition to a range it says has been designed “to enable more children to see themselves reflected and encourage doll play that extends beyond a child’s lived experience”.

The new Barbie has been designed in partnership with the global type 1 diabetes not-for-profit Breakthrough T1D. The doll wears a continuous glucose monitor (CGM) on her arm to help manage her condition, and to keep it in place she uses (Barbie pink) heart-shaped medical tape. Barbie also carries a mobile phone with a CGM app to help track her blood sugar levels throughout the day. To read the full article click here.

✨ VICTA Grant Scheme – Now Open!

The **2025 VICTA Grant Scheme** is now accepting applications until **19th September 2025** to support blind and severely sight impaired (SSI) young people aged **8 to 29** in the UK.

🛠️ What’s Covered?

- VICTA-assigned laptop
- Assigned software
- Laptop + software bundle
- Independent living aids (e.g. white canes, talking hobs)

Note: Equipment is for **home use only**, not for school, college, or work.
Contribution: Successful applicants contribute **at least 20%**.

📅 Deadline: Friday 19 September 2025

Apply and find full details at VICTA.org.uk/grants
📧 grants@victa.org.uk | 📞 01908 240 831

My Medical Support

WSUK are pleased to announce our new partnership with **My Medical Support**!

This innovative platform helps individuals and families living with Wolfram Syndrome store and share vital medical information - securely and instantly - in an emergency, anywhere around the world.

As part of this partnership:
✓ You'll get **10% off any subscription - code WOLFRAM10**
✓ **15% of your subscription** will be donated directly back to Wolfram Syndrome UK
That means better safety for you, and ongoing support for our work.

Why It Matters

Living with Wolfram Syndrome means managing a wide range of health needs – from diabetes and vision loss to neurological complications.

With **My Medical Support**, you can keep all essential health details – including conditions, medications, and emergency contacts – in one secure place, ready for medical professionals in any emergency.

We’re proud to offer our community **a practical tool that protects your health and supports our mission.**

👉 Learn more and sign up:
https://www.mymedicalsupport.co.uk/?partner=wolfram-syndrome

You can also find out more along with a short video on the WSUK website

Bonus:

As part of our collaboration with **Cambridge Rare Disease Network**, you’ll also get access to the **only digital version of the Rare Patient Passport** - an essential tool to communicate your rare disease journey clearly and quickly in emergencies.

MY MEDICAL
SUPPORT

CamRARE Passport

RARE
patient
passport

THIS IS
me

camRARE

....have worked with families & clinicians to create a fillable, personalised **health & care passport** to help communicate your key medical & care information in an emergency, away from home or when meeting new people.

GET
YOUR
PASSPORT

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IN PARTNERSHIP WITH

The QR code in the poster will go to the CamRARE web page with the updated application form on, or you can use the weblink here - https://www.camrarедisease.org/patient-passport/

🌟 Stephen Bassett Achievement Award – Nominations Open

Celebrate someone special in the **Wolfram Syndrome (WS) community** by nominating them for the **Stephen Bassett Achievement Award** — recognising personal achievements, resilience, and everyday acts of kindness.

🕊 Honouring Stephen's Legacy

Created in memory of Stephen Bassett, whose impact on WS research continues to inspire, this award celebrates those making a difference in their communities and lives.

📅 Deadline: 7 November 2025

The winner will be announced in our **Winter newsletter**.

Nominate someone who inspires you today!

Help Shape the Future of Rare Condition Research

The Manchester Rare Conditions Centre, in partnership with the NIHR Manchester Biomedical Research Centre, is expanding its patient and carer network - and we'd love your help spreading the word.

We're looking for new members to join our We R Rare Patient, Carer and Family Steering Group, which brings together people from across **Manchester** and **Northwest England** to drive meaningful change.

Why Lived Experience Matters

People with lived experience of rare conditions help shape our research, services, and support. Their insights ensure our work is truly patient-led. Over the past 18 months, our Steering Group members have:

- Shaped research, services, and support for those living with rare conditions
- Provided strategic input to both the Manchester Rare Conditions Centre and the Manchester Biomedical Research Centre
- Influenced groundbreaking research into rare conditions
- Raised awareness of the daily challenges faced by individuals and families

There are further details on the poster below and you can email them Our email: mrcc@mft.nhs.uk.

The closing date is Sunday 28th September.

Manchester Rare Conditions Centre

Your Voice Matters

Help Shape the Future of Health Care and Research for Rare Conditions

Join the We R Rare Patient, Carer and Family Steering Group!

- Do you have personal lived experience of rare conditions?
- Are you based in Manchester or the North-West?
- Want to make a difference in healthcare and research for rare conditions?

Whether you're a patient, carer, or family member, your insight can drive meaningful change and **make a difference to the rare condition community**.

Join our We R Rare Steering Group and you, with our existing members, will

- Shape groundbreaking research that reflect real-world needs
- Advise on service design to improve support for patients and families
- Raise awareness of the challenges people with rare conditions face every day

Together, we're building a future where rare voices lead the way!

We are looking for new members to join, with a particular focus on men as well as individuals from diverse backgrounds, to ensure we better represent the full spectrum of lived experiences.

Interested in getting involved?
Visit the website and complete the expression of interest form by
Sunday 28th September 2025!

Get involved and make a difference!

Join We R Rare!

Visit www.mrcc.org.uk/engagement-advocacy/we-r-rare for more information and to get involved today!

Support Co-ordinator's Updates

Family Support Co-ordinators

Hello Everyone,

Welcome to the first joint update from both Olivia and Georgina!

2025 FSC Feedback Survey

A call to all our families –
Please take a few minutes to complete our 2025 FSC feedback survey using the link below:
https://www.smartsurvey.co.uk/s/3PTNYP/
Your input is really important as it helps us to understand how we have impacted your family and where we can improve. The survey is anonymous, so we will not know who has responded.

Please provide your response before **30th September** so your feedback can be included in our annual contract report for BCH.

VICTA Grant

The **VICTA grant** scheme supports children and young people who are registered blind or severely sight impaired, helping them access VI-friendly equipment and technology. The application deadline is **19th September**. For more information, please visit our website or the **'News You Can Use'** section of this newsletter. We encourage you to consider if this grant might be relevant to your family.

Walk a Week for Wolfram

We're excited that **Walk a Week for Wolfram;** our brand-new fundraising campaign is launching on **1st October** – **Wolfram Syndrome Global Awareness Day**.

We encourage all our families to take part! You have the whole month of October to complete **a week's worth of walking** with your friends, family or by yourself. You choose how far you walk, so everyone can join in. We would love to hear how you get on; photos are definitely welcome!

To get started:

1. **Follow this link:** https://gvwhl.com/YU9KP
2. Click **"Join Event"** to set up your fundraising page.
3. Share your page with family, friends, co-workers, and anyone who would like to sponsor your challenge.

As a special thank you, **WS affected individuals who raise over £75 will receive a medal**!

WS annual conference

Olivia is looking forward to attending her first WS annual conference, which promises to be an exciting event with our inaugural youth panel, British Blind Sport taster sessions running all day, and first aid sessions. Olivia hopes to see many of our families there!

Georgina will unfortunately be missing conference this year, as she will be in Milan celebrating her daughter's 20th birthday.

As we approach the final quarter of 2025, there is still much to look forward to including: our final MDT clinic at BCH, two virtual clinics, a transition clinic at QEH for those moving into adult services, and the WS conference. We remain committed to supporting our families, fostering connections, and sharing valuable information.

Best Wishes,
Georgina and Olivia

Email: georginaking@wolframsyndrome.co.uk
Mobile: 07592 629813

Email: oliviaedwards@wolframsyndrome.co.uk

Mobile: 07756 778454

Family Support Co-ordinator Page – https://wolframsyndrome.co.uk/family-support-coordinator/

Adult Support Co-ordinator

Well, here we are in the middle of August - it’s certainly been rather warm recently and my allotment is looking rather parched; but I have come back from my annual leave to an excess of courgettes, tomatoes, beans, squashes, raspberries and plums.

The last few months have been a bit stressful for me as I lost my dad in July and had to make all the arrangements and sort things out, so apologies if you have been trying to reach me. Please feel free to reach out via phone, email or WhatsApp if you need some help, advice or support.

A call to our adult community –
Please take a few minutes to complete our 2025 ASC feedback survey using the link below:

https://www.smartsurvey.co.uk/s/PLWEUY/

Your feedback is very important as it helps us to understand your thoughts on the support that I provide and where I can improve going forward. The survey is anonymous, so I will not know who has responded. If you need support around filling it in, please do get in touch and one of our team will assist you.

Our adult population is continuing to grow, and we currently have people waiting for their WS clinic appointment, so please be patient. The clinic team is doing their best to ensure people are seen.

I always feel humbled and motivated at the same time when I hear good news stories from the community. Two exciting stories recently, hearing of the birth of baby Violet- how exciting for the family, and how inspiring to hear about a WS adult becoming a mum and getting to enjoy family life. The other one was to hear fabulous A level results from one of my young adults, meaning they can go on to study law at their chosen university.

I am still involved in the bigger rare disease space, making sure that WS gets heard and talked about. I have a few meetings coming up where discussions will be about the new framework for rare diseases (NHS England and others) as well as the NHS 10-year plan and what that means for us, as a community.

I won’t be able to attend the WSUK conference this year as I am getting married. I will miss seeing you all, but I know Tracy has put together a brilliant programme. It is always such a good time for meeting others in the community, to chat informally and to hear new research information. If you are interested in attending on the 19th-21st September, do please get in touch asap.

Phillippa
Tel: 07752193635
Email: phillippafarrant@wolframsyndrome.co.uk

WS Clinics

WS clinics are typically **face-to-face**, but if you’re unable to travel to Birmingham, a **virtual appointment** can be arranged upon request.

Adult Clinic

Adult clinics are held at the **Centre for Rare Diseases** in the **Heritage Building** at **The Queen Elizabeth Hospital, Birmingham**.

If you can no longer attend your scheduled appointment, **please let the clinic team, Phillippa (our Adult Support Coordinator), or Tracy know** as soon as possible, so that your place can be offered to someone else. There's usually someone ready to take an available appointment.

Due to hospital policy, clinic appointments can only be rescheduled **once** per patient, as the WS community has grown. **Failure to attend** will result in **discharge from the service**.

2025 Clinic dates

26th September - Transition
28th November

Please make sure your contact details are kept **up to date** with both the hospital and the **Wolfram Syndrome UK office**

Children's Clinic

The Children’s Clinic is held at **Waterfall House**, the Rare Disease Centre at **Birmingham Children’s Hospital**.

If you are unable to attend, **please inform Georgina or Olivia (Family Support Coordinators), Tracy, or the hospital** as soon as possible—even if you have a **virtual appointment**. This allows your place to be offered to someone else.

Attendance at both clinics (virtual or face-to-face) is by invitation only.

2025 Clinic Dates

26th September - Transition at QEH
6th - 7th October
5th and 13th November (both Virtual clinics)

Please **DO NOT** book travel or make arrangements **until you have received confirmation** of your clinic invite and hospital instructions regarding whether your appointment is face-to-face or virtual.

Keeping **your contact details updated** with both the hospital and **WSUK** is essential.

Further Information

Visit our website for:

- A **‘**Who’s Who at the WS Clinic**’** page, introducing the team
- The Family Support Coordinators page with updates from **Georgina and Olivia**
- **Maps** of The Queen Elizabeth Hospital and a floor plan of Waterfall House for new visitors

For full details, check out the WSUK website.

Fundraising News

Upcoming Events & News

For details on upcoming events, visit the **events page** on the **Wolfram Syndrome UK** website: www.wolframsyndrome.co.uk.

Remember to check back regularly for updates, recent news articles, and useful links.

FJN Charity Football

The 6-a-side football tournament organised by **FJN Solutions** took place on **27th June in Horsham**, bringing together 12 teams of players and supporters for a fantastic day of games.

With the sun shining it was a lively and enjoyable tournament raising a total of **£1199.20.** This year there was also a team playing with some female players in the mix for the first time, which was great to see and making it inclusive to more individuals. The total raised this year by FJN and all those taking part was **£4605.06!!** Thank you to everyone involved in these events. We really appreciate all the hard work that goes into organising these matches.

A huge thank you to all involved for their generosity and enthusiasm - it was a great success!

Annual Charity Golf Day

This popular annual event returned for its 12th year on Friday 18th July.

The day was another incredible success! The day was filled with sunshine, swinging clubs, sizzling BBQ, and serious generosity. Together, we raised an amazing **£23,120 -** an incredible achievement!

Huge congratulations to Northern Commercials Team 1 for their first-ever win! 🎉

We were delighted to hold the event once again at the beautiful Mannings Heath Golf Club. The mix of good-hearted competition and fundraising brilliance made the day really special.

Thank you to everyone who participated, supported, and contributed to making this event such a memorable success. Special thanks go to our two event sponsors Penfold Verrall and Northern Commercials. We'd like to thank some of the hole sponsors who didn't have teams playing as well - Golding Barn Estate, Small Dole; RPS Contractors; Thompsons; BTR Brakes; Day Aggregates; G&S Tyres; Landmark Contractors Southern Ltd; The Parsonage, Tarring and Tyrone International. We couldn’t have done it without any of you!

The date for 2026 is already being planned.

Golf Day round 2

On 2nd August the grandfather of one of our younger community members put on a golf day for the Bewdley Pines Golf Club, where he is Captain. At the time of this newsletter coming out we were still waiting on a total. This will be reported in the December newsletter. We thank everyone for all their hard work and support.

Big Half Marathon

On 7th September, Emma Brooks, aunt to Amy Hawkins one of our late community members, is running the Big Half in London with a close friend. They have set up a fundraising page with GoFundMe - Miles for Amy If you would like to support them you can use the link here. So far Emma has raised **£325.00**. Thank you.

Stories like these show just how much can be achieved with determination, support, and a strong community behind you. Whether it’s fundraising, taking on new challenges, or simply raising awareness, there’s always an opportunity to make a difference.

Let’s keep celebrating the incredible things our WSUK community accomplishes - who knows what inspiring achievements will come next!

The only limitations are those imposed on you by others and by yourself!

Continued Support!

A Huge Thank You to Our Supporters!

We’re incredibly grateful to all the members of the WSUK community, as well as their friends and families, who donate regularly through monthly standing orders and direct debits.

Your generosity allows us to keep doing what we do - thank you!

Could You Help Too?

Would you consider making a monthly donation to WSUK? Even £2 a month - less than the price of a posh coffee - can make a real difference. If you're interested, just get in touch with Tracy in the office for bank details.

By donating this way, your full contribution goes straight to WSUK, without any processing fees from online fundraising platforms.

Why not set yourself a little challenge? Ask three friends or family members if they'd like to do the same - it's an easy way to make an even bigger impact!

Fundraising & Gift Aid

There are plenty of ways to get involved in fundraising, and you can find all the platforms we're registered with on the WSUK website.

If you're donating, don't forget to Gift Aid! It's a simple way to increase your donation at no extra cost to you. All we need is a name and address, and there are Gift Aid forms on our website for single or multiple donations - just print the relevant one off and send it back to us.

Got an Event to Share?

Are you taking part in a fundraising event, or have something you'd like us to promote? Let the WSUK office know, and we'll share it on social media and in the newsletter.

Thank you again for your support—it truly makes a difference!

Ways to Donate to WSUK

Facebook Donations

Thank You for Your Support!

We're always incredibly grateful to WSUK members and their families who think of us on special occasions or when taking on fundraising challenges. Many choose to create **Facebook fundraiser pages**, turning their birthdays and events into opportunities to support WSUK.

A **huge thank you** to everyone who contributes in this way - it makes a real difference and helps us continue the work we do.

PayPal Giving Fund

Do you want to support Wolfram Syndrome UK without any fees being deducted?

PayPal Giving Fund is a great way to do just that! Unlike many other fundraising platforms—including standard PayPal—this option ensures that **every penny of your donation** goes directly to WSUK.

You can donate via PayPal Giving Fund using this link: paypal.com/gb/fundraiser/charity/76200.

Your generosity helps us continue the vital work we do—**thank you for your support!**

PayPal Giving Fund

You can also use this **QR code** to make a donation to WSUK - a quick and simple way to support the vital work we do.

Please feel free to **share it with friends and family** to help spread the word. Every donation, big or small, makes a real difference.

Other Ways to Support WSUK

PayPal - Give at Checkout

Did you know you can donate to WSUK while shopping with PayPal? Just **set us as your favourite charity**, then click to **donate £1 at checkout** whenever you make a purchase -it's a simple way to make a difference!

How to Set WSUK as Your Favourite Charity:

- **Quick Link Method:**
  - **Click here** → paypal.com/gb/fundraiser/charity/76200**.**
  - Select **Wolfram Syndrome UK** as your favourite charity.
  - Log in to PayPal and follow the steps to complete the setup.
- **Directly Through PayPal:**
  - Log in to **PayPal**.

- Click **“Set your favourite charity”** and search for **Wolfram Syndrome UK**.
- Select us as your favourite and confirm—it’s as easy as that!

Next time you shop, you’ll have the option to **donate £1 at checkout**, helping WSUK continue its vital work.

Every little bit helps—**thank you for your support!**

Raise Funds for WSUK While You Shop Online!

Give as you Live
Online


easyfundraising
feel good shopping

Raise free funds for us every time you shop online

Find out more

Want to support WSUK without spending a penny extra? Now you can—just by **shopping online!**

We’re registered with **Give as You Live** and **easyfundraising**, two fantastic platforms that let you **raise donations simply by shopping at your favourite stores**. Whether you’re booking holidays, renewing insurance, or just doing your usual shopping, a percentage of your purchase will be donated to WSUK - at no **extra** cost to you!

How It Works:

✓ **Sign up** using the links provided.

✓ **Shop as usual** through the platform.

✓ **At checkout**, the retailer **donates to WSUK -** sometimes just a few pence, other times up to **£40**!

Don’t Forget the Reminder Tool!

Install the **shopping reminder tool**, so whenever you visit a retailer’s website, you’ll get a prompt to raise a donation - no need to remember manually!

It’s quick, simple, and an easy way to support WSUK. Why not sign up today and start making a difference?

WSUK Shop & Fundraising Merchandise

Our **Charity Christmas cards** are now in stock to purchase. Each pack has 10 cards of one design. They cost £3.00 each with P&P starting from £2.95. As well as the cards we also have other products available for purchase - all helping to raise funds for WSUK! Go to the **WSUK shop** page for more information

WSUK Clothing & Accessories Website

We have a linked website dedicated to WSUK - branded clothing and accessories such as tea towels, bags, and mugs. You can find the link on our shop page.

📦 **Delivery is available to most countries** - just check the bottom of the website for full details. Plus, at the end of each month, there’s usually a **free UK P&P** offer!

Each sale supports WSUK, and while our range is currently minimal, you can choose from **three different logos**:

✓ **Wolfram Syndrome UK**

✓ **WS Global Awareness Day** (to help spread awareness every 1st October)

✓ **WSUK & Snow Foundation** joint logo (reflecting our close partnership in organising global virtual events and the International Researchers Symposiums).

Want to Help Raise Funds?

There are lots of ways to get involved in fundraising, and you'll find ideas on our FundRaising Inspiration page on the website, including raising funds from used stamps.

If you're arty or crafty and have something we could sell to raise funds, we'd love to hear from you! You could also consider selling your creations at craft fairs to help raise awareness and support WSUK.

🎨 **Got something to share?** Send us pictures and details, and we'd love to feature them in a future newsletter!

Your News

Got something you'd like to share with the **WSUK community**? We'd love to hear from you!

Whether it's a **fundraising event, personal achievement, awareness campaign**, or anything else related to **WSUK**, send it in to be included in the **Autumn newsletter**.

📅 **Deadline for submissions: 26th November**

Let’s celebrate the amazing things happening within our community - **we can't wait to hear from you!**

Congratulations!

Abby Gardner, one of our dedicated WSUK Trustees and a member of the WS community, along with her partner Andrew Sullivan, welcomed their beautiful daughter Violet into the world on June 25th at 3:45 am. Violet weighed a healthy 7lb 1oz at birth.

Both mum and daughter are doing well and are looking forward to attending the WSUK conference this September.

Congratulations to Abby, Andrew, and Violet on this joyous occasion! 🎉

Clara Steuart Joins the London National Open Youth Orchestra Ensemble!

We are thrilled to share that Clara Steuart, a talented young WS adult, has been offered a place as a Saxophonist for the **London National Open Youth Orchestra Ensemble**! This is a dream come true for Clara, who was eagerly awaiting the news.

Clara will soon receive her rehearsal dates and musician's agreement, with her journey starting this September.

To celebrate her achievement, here's a link to a video of Clara playing ‘This is Me’ on the piano at Waterfall House: https://youtube.com/shorts/lQm888nUEv4?feature=share

We wish her the best as she embarks on this exciting new chapter! 🎉

In memory

In June, we sadly lost two known members of our community: Krystle O'Farrell, 37, from Aberdeen, and Patrick Bezzina, 23, from Malta. Patrick and his family were regular attendees at the WS clinics in Birmingham as well as the WS conferences. Both will be deeply missed.

Our heartfelt sympathies, on behalf of the entire WS community and the WSUK team, have been sent to both families.

In July, we also learned of the passing of three other members of our community: a 28-year-old young man in February, a 74-year-old lady in May (our oldest WS-affected person in the UK), and a 23-year-old in July.

The WS community and WSUK team extend their warmest sympathies to all at this time.

In loving memory of my guide dog Crusoe - by Naomi Bennett

Crusoe sadly passed away on the 7th February 2025. It was very sudden and unexpected and I miss him terribly.

I feel I was very lucky, blessed and fortunate to have had a guide dog like Crusoe. He was my first guide dog; my first match and I had him for nearly nine years. He was a lovely and hardworking dog. He was very conscientious, always wanted to do his best and he knew how to keep me safe.

Having Crusoe was wonderful as he helped me to get out independently and he really helped me to build up my confidence. It was like having my eyesight back psychologically and I was able to do the same as anyone else, like going to the shops, going for a walk, catching the bus and meeting friends and family for coffees and lunch etc. Through having Crusoe, I was able to do a number of different voluntary roles in the community and I have got to know more people and made new friends through him.

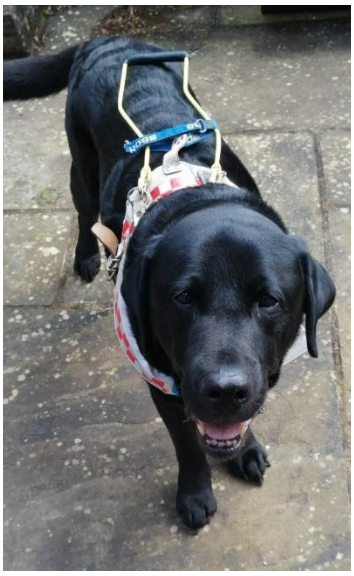
He was very loyal, lovely and a real softy. He loved to be made a

fuss of, loved to play with his toys (he had 58 in total and 3 toy boxes!) and he loved to have a brush. He was also very fond of a carrot or two! Even when he was sound asleep, he could hear when I was chopping carrots and would immediately appear at my side and looked at me with his big brown eyes hoping for a piece. How could I refuse?
Crusoe was a loving, caring and gentle Labrador retriever cross but he also had a cheeky side.

Have you ever heard of a guide dog liking shopping? Well, Crusoe did! I remember when I was in the library with Crusoe. He was happily laying down beside me while I was sitting on a chair reading a Braille book. I had arranged to meet my Mum in Waitrose and when it was time, I got Crusoe’s lead and harness on and gave him some instructions such as forward, straight on, find left to the door out of the library. So, Crusoe found the door and was ready for more commands heading towards Waitrose. He was very happy and found the entrance into the shop straight away.

Now what did Crusoe do? I thought we were heading for the bench inside the shop as planned but Crusoe had other ideas! Instead of turning right Crusoe took me up and down the aisles! Where were we going? Finally, we came to a stop. I put my hand in front of me and I felt a bag and apologised thinking it was a member of the public. I said to Crusoe where are we - where have you taken me? And then well, this was so funny! A member of the public saw me and said “Well, at least your guide dog knows where the dog food is!” I’d never taken Crusoe to that part of the shop before so he must have sniffed it out!

This is just one lovely and funny memory of Crusoe. He was so clever and a real character! He was a great companion and I feel very privileged to have had him.



Also, for those that knew him, Toby, Shane Roberts' Guide Dog also sadly passed away during the summer. He attended many conferences over the years and Shane described him as a horse as he was so big, but a gentle giant.

Both 'boys' will be missed by all those that knew them.

Birthdays (UK and worldwide)

Happy birthday to everyone that has a birthday to celebrate during September, October and November

We hope that you all have a great day!

Happy birthday to you all!!

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