WOLFRAM SYNDROME UK
Inform, Support, CURE

Welcome to the Winter newsletter.

Hello everyone,

It’s been a full and lively autumn for us, with our face-to-face conference followed by two virtual global events. For anyone who wasn’t able to join in, presentations from across all three gatherings are now available on the WSUK website, and you’ll find the details a little further on in this newsletter.

As we settle into the winter months and begin looking towards the promise of a new year - with the first signs of spring not too far ahead - we hope this festive season brings a sense of comfort and hope.

In this edition, we’re pleased to share updates from recent fundraising activities, along with stories from our wonderful community. If you’ve been involved in any fundraising or taken part in something you feel might inspire others, please do let us know. We genuinely enjoy hearing from you and sharing your news.

We would also like to extend our warmest congratulations to our Adult Support Co-ordinator, Phillippa, who married her husband Kev on 1st October. We wish them every happiness as they begin this new chapter together.

However you choose to celebrate, we hope you enjoy a peaceful and joyful holiday season, and we send our very best wishes for good health and happiness as we welcome 2026.

If you'd like to contribute content for future newsletters, feel free to send your news 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

Conference Round Up

Our September conference was wonderfully well attended, with a number of new families joining us for the first time. It was lovely to see everyone meeting, sharing experiences, and chatting with clinicians and the WSUK team. We were delighted to receive such positive feedback from the day – thank you to all who took the time to share your thoughts.

Most of the presentations were successfully recorded, although we did experience a few sound issues with three of them. Fortunately, one parent kindly recorded their son’s talk from the Young Panellists session, and we were able to obtain an audio recording from the other young speaker afterwards. These, along with two other presentations, are now available to watch on the conference page of the WSUK website.

A heartfelt thank you to everyone who presented, hosted a workshop, or helped organise the day – it truly was a team effort.

📅 **Save the Date:** Saturday 26th September 2026

More details about next year’s conference will be shared in the New Year and added to the website as they become available.

WSUK & The Snow Foundation Global Online Conferences

In October and November, we were delighted to be joined by members of the WS community, their families, researchers and clinicians for two virtual global events. It was wonderful to have so many people taking part from around the world.

Recordings of the presentations are now available to watch on the WSUK website for anyone who wasn't able to join live.

Our thanks go to all the researchers who contributed, and to everyone who joined us online - your support and participation are always much appreciated.

WS Global Awareness Day (WSGAD) and Walk a Week for Wolfram

To mark **Wolfram Syndrome Global Awareness Day** on 1st October, we were thrilled to launch a powerful new video bringing together voices from across our global community.

The response has been incredible, and it’s been wonderful to see so many people sharing and supporting it online.

A huge thank you to all the patients, families, doctors, and scientists who took part and shared their stories with such honesty and heart. Your courage and commitment continue to inspire us every day.

We’ll be sharing more interviews and stories throughout the giving season and into 2026 – so do keep an eye out for them!

🎥 **Watch the Wolfram Awareness videos here:**
wolframsyndrome.co.uk/media-interviews

And if you’ve been inspired to get involved, take a look at the **Walk a Week for Wolfram** challenge in our **Fundraising News** section below – a brilliant way to raise awareness and make a difference. Although this year’s event has now finished, we’ll be running it again next year – but there’s nothing to stop you organising something similar in the meantime!

WOLFRAM SYNDROME
GLOBAL AWARENESS DAY

New Support Group for Young People with Wolfram Syndrome

We’re pleased to share the re-launch of a peer-led Facebook support group for young people (**ages 16–30**) living with Wolfram Syndrome - **The Wolf Pack.**

The group offers a safe and welcoming space to simply be yourself, connect with others who truly understand, and share experiences, laughter and support.

The Wolf Pack is led by people with WS, so every conversation comes from lived experience. One enthusiastic volunteer from the UK has already stepped forward to help lead the group, and we’re now looking for another volunteer co-leader (aged 16–30) to help the community grow.

If you’d like to join the group or find out more about becoming a volunteer co-leader, please get in touch with Pat Gibilisco at pat@thesnowfoundation.org

Let’s continue building something meaningful - together.

WSUK Funded Research Projects

WSUK have contributed funds to three research projects over the last 2 years. We hope to open a new funding call in the New Year.

Other Research Updates

TREATWOLFRAM

TREATWolfram Trial

Dear friends, with this update I am sending you a summary of the results that we have so far. I hope this is helpful, and look forward to sending you more updates as we get them.

Sincerely

Timothy Barrett

TREATWOLFRAM-summary of results

Title: A Pivotal, International, Randomised, Double-blind, Efficacy and Safety trial of Sodium Valproate, in paediatric and adult patients with Wolfram syndrome. EudraCT number 2017-001215-37; ISRCTN number 10176118; ClinGov number NCT03717909

Our TREATWOLFRAM research question?
Wolfram syndrome often causes vision loss that gets worse over time, as well as diabetes (high blood sugars), deafness, bladder problems, and..... read more here.

USA Trials and Research Updates

Dear Friends,

The autumn season has come, and the colors of the leaves are changing and falling as we approach Thanksgiving, Christmas, and Hanukkah. Each week, I have the privilege of seeing patients with Wolfram syndrome in our multidisciplinary clinic at Washington University Medical Center in the USA. I also stay closely connected with many of you through phone calls, Zoom, and email, which always reminds me how strong and dedicated our community is. Many of you travel long distances from across the country and from abroad to come to our clinic. I know how much planning and effort this requires, and I am truly grateful for your commitment. Please know that we are working very hard every day, and I would like to share several updates with you.

Wolfram Syndrome Webinars Hosted by Wolfram UK and the Snow Foundation

On Saturday, October 25, I had the honor of presenting at the Wolfram Syndrome Webinar organized by Wolfram UK and the Snow Foundation. I shared updates on our work developing clinical guidelines, progress in creating... [Read in full here]

Would you like to be part of a study advocating for Continuous Glucose Monitoring and Insulin Pumps?

Study Title - A qualitative study of the feasibility of diabetes technology in Wolfram syndrome

Dear Wolfram syndrome community,

Birmingham Children's Hospital Endocrine team are conducting a research study to find out more about how we can best support our patients with Wolfram syndrome to manage their insulin-dependent diabetes. We would like to hear from patients with Wolfram syndrome and their families.

This research will contribute to an understanding of the experiences of people living with Wolfram syndrome and how they feel about managing their insulin-dependent diabetes. Understanding what helps people with Wolfram syndrome to manage their diabetes will help us to better support our patients, including advocating for glucose sensors and/or insulin pumps, if these are felt to be useful to patients.
The study will take part in two steps – you can choose to do both steps, just the first step, or none at all.

Data will be gathered via an online survey and interviews with patients over 18 years old, or with their parents if patients are under 18 years old.

Stage 1: Online survey asking questions about how you or your child finds managing your/their insulin-dependent diabetes, what challenges you/they face, what makes it easier, and how it impacts on quality of life. This survey has been designed with Wolfram Syndrome UK charity and should take less than 15 minutes to complete.

This survey will be anonymous unless you give your name and number at the end of the survey to indicate that you are happy to be contacted for stage 2.

Stage 2: Interviews with patients or parents/carers via video-call to further explore your (or your child’s) experience

of managing insulin-dependent diabetes in Wolfram syndrome and a chance to elaborate on some of your answers from the online survey.
This stage will require signed consent prior to taking part. Interviews will take part over a video call and are designed to take 30-60 minutes.

Please see the patient information sheet, link below, for further information on the study and how to get involved.

If you have any questions about the study or need any adjustments made in order to take part in the study (e.g. interview by phone rather than video), please send an email to the study email address:
wolfram.diabetes.research@gmail.com.

Thank you so much for taking the time to read,

Dr Renuka Dias and Professor Tim Barrett

To read the participant Information sheet, go to our website here.

News You Can Use

Helping Vision Impaired Children find their way

(taken from the November 2025 edition of Motability

Lifestyle magazine)

The Royal Society for Blind Children (RSBC) has received a two-year grant from the Motability Foundation, which is giving VI children, young people and their families more confidence.

The RSBC provides support from the point of diagnosis right through to when a young person turns 25 and moves to adult services.

Founded in 1838, the RSBC's roots are in education but they have since expanded to providing emotional wellbeing support for those it helps by offering activities that allow them to learn new skills, to make friends and to help reduce social isolation.

To read the article in full click here. To find out more about how the RSBC could help your child and family go to their website - rsbc.org.uk.

Priority Services Register (PSR)

Are You on the Priority Services Register? Did you know you can sign up for free?

If you answered **“no”** to both of these questions, read on - this could make a real difference.

The **Priority Services Register (PSR)** is a **free, UK-wide service** offering extra advice and practical support to those who might need it - particularly during interruptions to electricity, gas or water supplies.

The PSR helps utility companies - **including your energy suppliers and network operators** - to provide additional assistance to customers with specific communication, access or safety needs. For example, in the unlikely event of a power cut, gas leak or water supply issue, those on the register can receive tailored help and updates.

You can join the **PSR for free** if any of the following apply:

- You have reached **State Pension age**
- You are **disabled** or have a l**ong-term medical condition**
- You are **recovering from an injury**
- You have a **hearing or sight condition**
- You have a **mental health condition**
- You are **pregnant** or have **children under five**
- You have **extra communication needs**, such as limited English
- You rely on **medical equipment that needs a power supply**

If your **water, electricity and gas** are supplied by different companies, you'll need to **register separately** with each one.

If you **switch supplier**, remember to register again with your new provider.

If you **move home** but stay with the same company, your registration continues - just be sure to **update your details**.

The **PSR promise** is shared by all participating energy companies across England, Wales and Scotland, ensuring consistent support wherever you are.

For more information, visit:

🔗 www.thepsr.co.uk

🔗 Scope – Extra services from energy suppliers

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!

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

...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.

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.camraredisease.org/patient-passport/

Stephen Bassett Achievement Award

This award was created to celebrate someone special in the **Wolfram Syndrome (WS) community.** It recognises 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.

Nominations were submitted to the WSUK Board of Trustees, who carefully considered and voted to select this year’s recipient. We are delighted to announce that the **Bhangra Family** has been chosen as the recipient of this year’s award! Well done to them!!

Support Co-ordinator's Updates

Family Support Co-ordinators

A **warm welcome** to both new and familiar faces joining us for this edition of our Wolfram Syndrome UK newsletter. As we come to the end of another busy year, we want to extend our **heartfelt thanks** to all our families for your continued support. It has been a privilege to support you, and we are grateful for the trust that you place in us.

We would like to express our special thanks to everyone who attended our annual conference this year. We want to acknowledge Tom Darley and Jay Jenkins, who courageously represented our **Young Person's Panel** and shared their experiences of living with Wolfram Syndrome. Their honesty, strength, and insight were truly inspiring. We are always looking for new faces to join our Young Person's Panel, so if this is something you or your child may be interested in, for future conferences, please feel free to contact Georgina or Olivia.

A huge thank you also goes to all families who completed our **feedback survey**. Of the 81% of families invited to share their views, 51% responded. Your feedback is invaluable and continues to help shape our work going forward. We intend to share these results when they are available to us.

- We would also like to extend our gratitude to all the families who attended our **WS Multidisciplinary Team Clinics** - both in person and virtually - throughout the year. Your commitment ensures that our clinical services continue to support each family's individual needs.

- We are pleased to let you know that we now have a **Family Support Community WhatsApp group**. If this is something you would be interested in joining, please contact Georgina or Olivia (we do need your consent to receive updates by phone, if you haven’t agreed already). The group is admin-posting only, so you will not receive spam or large numbers of messages. Instead, it is a simple and easy way to stay updated with the latest news, important information, and opportunities available within our community.

This year saw the launch of our new fundraising initiative, **Walk a Week for Wolfram**. Thank you so much to everyone who took part, donated, or helped spread the word. Your enthusiasm and generosity have been incredible. As of writing, the total raised stands at **£5990.35.** A special mention must go to the Bhangra family, who have raised over £2500 on their own - an extraordinary achievement!

We are excited to introduce a new ongoing feature in our family support newsletter segment: **'The Wolfram Warrior Spotlight'.** Each edition we will celebrate an individual who has inspired us through their strength, resilience, or positive achievements. These spotlights are based on stories shared by parents, and we hope they will help shine a light on the incredible young people within our community. If you would like your child to be featured in the future, please contact Georgina or Olivia. In the meantime, you can follow this link to our website to read more about our inspirational people: Wolfram Syndrome UK

Our first **Wolfram Warrio**r is **Christopher Stanczak.**

Christopher is a determined and independent young man whose perseverance continues to inspire everyone around him. Over the years, he has achieved remarkable milestones -many of which exceeded the expectations of his specialist teachers. Living with Wolfram syndrome brings daily challenges, particularly with his vision, yet he approaches these obstacles with resilience, optimism, and an exceptional memory that supports his learning and enriches his experiences. His story is one of dedication, capability, and a powerful belief in what's possible.

At school, Christopher continues to excel and is currently second in his class academically. His commitment to studying, improving, and pushing his potential sets him apart, and he often expresses a desire to be "as normal as possible." His parents fully support this outlook, treating him no differently from any other child and encouraging him to participate fully in the activities he loves. Since starting secondary school, Christopher has made many friends, and teachers consistently describe him as polite, positive, and a pleasure to work with. He is known for putting others first and motivating classmates who may be struggling, reminding them confidently that there is nothing they cannot achieve.

Beyond the classroom, Christopher’s drive shines just as brightly. He is an avid go-Karter who has beaten his own personal records, refusing to let vision challenges hold him back. He has memorised the entire track and even compensates for colour blindness by associating the colours he can see with those he needs to recognize - an impressive strategy that showcases both determination and creativity. Christopher also prioritises his health: he goes to the gym regularly, maintains strong fitness habits, grows his own fruits and vegetables, and chooses organic foods to care for his body. His commitment to living well, learning continuously, and lifting up others makes him a remarkable example of perseverance and possibility.

Best Wishes,
Georgina and Olivia

Georgina

Email: georginaking@wolframsyndrome.co.uk

Mobile: 07592 629813

Olivia

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 approaching the end of 2025, and what a year it has been. For me, it was a rollercoaster of emotions, from losing my dad to getting married, all alongside working with you all to offer support and to help advocate on your behalf with a range of issues as and when needed. My wedding became a month of celebrations, each unique and personal in their own way, from a cream tea to a handfasting celebration with friends and then the legal part in a registry office in Worcester. If you look at the photograph at the end of this update, you might spot someone else from the WSUK team! It was lovely to have Georgina, one of our Family Support Co-ordinators with us, she is not only a work colleague, but we have become good friends over our time working together. Following my marriage, I now have a new surname, I am GROVES not FARRANT! Thank you to all of you who sent messages.

Enough about me, and on to other things. Thank you to all those who responded to the recent adult support feedback survey. We have been reviewing the results and are considering how we can best address some of the things that were highlighted. With that, thanks to all of you who have kindly agreed to have a discussion with WSUK to help shape our future adult support. Your input will be really valuable in helping us understand what is most important to you as members of our adult community and how we, as a small national charity can best support that. These discussions will start in early 2026. Please get in touch if you would like to be included.

At the end of November, I held an informal online social for adults in the community. It was a time to chat, share what we have been doing recently, and try and build some connections within the community. You should have all received an email from me with all the details, if you have consented to be contacted about community catch ups. If you didn't and are interested in future drop ins, please contact me. I realise the time may not have suited everyone; but if you want to get in touch and let me know when would be a good time, I am always happy to receive feedback and may be able to offer an alternative date and time in future. My email is phillippagroves@wolframsyndrome.co.uk.

I have been trying to do some more exercise and walking this month, towards the Walk a Week for Wolfram fundraising challenge, which has raised a fantastic amount of money, particularly as it was the first event of its kind for WSUK. Thank you to all those who completed the challenge and to all the family, friends and supporters who kindly sponsored those taking part. Every penny counts – especially when you are a small charity.

I will be travelling to Birmingham in December, for the last adult WS clinic of the year. I hope the weather is my friend and there isn't snow on the line!!

However, you celebrate this winter, enjoy the festivities and I look forward to continuing to work with you in 2026.

Phillippa

Tel: 07752193635

Email: phillippagroves@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 always 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**.

2026 Clinic dates

23rd January
27th March
22nd May
25th July - Transition
26th September
27th 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.

2026 Clinic Dates

12th - 13th January
16th - 17th March
15th - 16th June
24th July - Transition at QEH
21st - 22nd September

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.

Bewdley Pines Golf Club Fundraiser

On 2nd August, the grandfather of one of our younger community members organised a fantastic golf day at **Bewdley Pines Golf Club**, where he serves as the Men's Captain. The event ran through to the end of September, when it officially concluded, and proved to be a great success.

Funds raised were split between two charities – **WSUK** and a charity chosen by the Ladies' Captain – and we're delighted to share that **£6,500** has been donated to WSUK!

A huge thank you to everyone involved in organising the event, and to all those who took part, sponsored a player, or made a donation. Your support means the world to us and makes a real difference to the WS community.

Big Half Marathon

On 7th September, Emma Brooks, aunt to Amy Hawkins one of our late community members, ran the Big Half in London with a close friend. Emma raised **£605.00.** Thank you so much to Emma and all those who sponsored her.

Eton Dorney Long Swim Marathon

From the same family, Emma's husband and Amy's uncle, Darren Brooks, took part in the Eton Dorney Long Swim Marathon in September. He raised a fantastic **£2629.00** for

WSUK.

Thank you so much Darren for taking part in this endurance challenge.



Walk a Week for Wolfram

Our very first **Walk a Week for Wolfram** took place throughout October as part of Global Awareness Day – and it was a great success! We even extended it into November for anyone who couldn’t take part during October.

It would be wonderful to see even more people from around the world joining in next year – so do keep an eye out for details when we launch the **2026 challenge**.

In the UK, we had eight active fundraising pages, with fantastic efforts all round. One family, brand new to the community after receiving their diagnosis over the summer, went on to become our **top fundraisers** for the event – an amazing achievement!

Altogether, a brilliant total of **£5,990.35 (including Gift Aid)** was raised. A huge well done to everyone who took part, and thank you to all who sponsored and supported them.

Let’s see if we can go even bigger next year – raising more funds, reaching more people, and encouraging others around the world to take part, whether for **WSUK** or a **local patient organisation** where you are.

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 on what you can do 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!

We Need Your Support!

We need your help to keep **WSUK** going strong. Fundraising is our main source of income – without it, we simply can’t continue supporting the community in the way we do now.

Every pound raised helps us provide vital information, events, and connections for families living with Wolfram syndrome.

👉 **Get involved. Donate. Fundraise. Spread the word.**
Together, we can make sure WSUK continues to be here for everyone who needs us.

Could You Help Too?

Would you consider making a monthly donation to WSUK? Even £2 a month - much 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 **five** friends or family members if they'd like to do the same each month- 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.

Payroll Giving – Support WSUK Tax-Free

Payroll Giving lets anyone who pays UK income tax make regular, tax-free donations straight from their pay. Each £1 you give only costs you 80p - or even less if you're a higher-rate taxpayer!

It's an easy, cost-effective way to support WSUK and helps us plan ahead with steady funding.

👉 Find out more: https://goodpaye.com/payroll-giving-schemes/?what-are-the-benefits-of-uk-salary-sacrifice

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!**

Support WSUK While You Shop!

Want to support WSUK without spending a penny extra? Now you can - simply by shopping online! It's a great way to raise funds for us while you do your Christmas shopping.

We're registered with Give as You Live and easyfundraising, two fantastic platforms that let you generate donations just by shopping at your favourite stores. Whether you're booking a holiday, renewing your insurance, or doing your weekly shop, 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 (on the images or company names).

✓ Shop as usual through the platform.

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

💡 Tip: Install the shopping reminder tool so that whenever you visit a participating retailer's website, you'll get a handy prompt to raise a donation - no need to remember manually! It’s quick, simple, and a brilliant way to support WSUK. Why not sign up today and start making a difference?


easyfundraising

You spend, retailers donate

Sign up to easyfundraising and see your favourite retailers donate to

Wolfram Syndrome UK

whenever you shop with them

Sign up and get started

WSUK Shop & Fundraising Merchandise

There is still time to purchase your **Charity Christmas cards** for this year but you will need to be quick. Stock is very limited for some designs. 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 for WSUK, and you'll find plenty of ideas on our **Fundraising Inspiration** page on the WSUK website - including raising funds by collecting used stamps.

This is a great time of year to start gathering stamps from your post! To find out more about how it works and where to send them, read the full article here.

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 **Spring newsletter**.

📅 **Deadline for submissions: 23rd February 2026**

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

A Bright Day Out for Tom!

On 29th August, Tom Darley enjoyed an illuminating day in Blackpool! His mum, Andrea, had arranged a special visit with **Laurence Llewelyn-Bowen**, the creative force behind this year's stunning illuminations. Tom was given an exclusive behind-the-scenes tour of the factory where the famous lights are made - and even got to **touch the big switch** before pop star **Olly Murs** took to the stage later that evening for the official switch-on concert.

Although Tom and Andrea were kindly offered tickets to the show, they opted for the magical factory experience instead - a perfect, sparkling memory without the crowds!

Rory’s Big Day with the Harriers

Rory Mason, from Kidderminster, had a day to remember when he led out his beloved **Kidderminster Harriers** for their match against **Macclesfield** on Saturday, 6th September.

Rory’s dad, **Tim**, had nominated him for a special VIP experience run by **Talbots Law**, who were celebrating renewing their sponsorship of the Harriers for a second season. Out of hundreds of entries, Rory was chosen by the Talbots team as their deserving winner.

On the big day, Rory enjoyed a behind-the-scenes tour, met the players, and proudly led the team onto the pitch for their 1–1 draw with Macclesfield. To make the experience even more special, the club invited Rory’s big brother **Reuben** to join him, giving Rory the confidence to enjoy every moment of his unforgettable day.

Birthdays (UK and worldwide)

Happy birthday to everyone that has a birthday to celebrate during December, January and February.

We hope that you all have a great day!

Happy birthday to you all!!

Our mailing address is:
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