

Sturge Weber UK Newsletter - September - December 2024

As the year draws to a close, we are excited to update you on the incredible work and progress made by Sturge Weber UK over the past few months. From new campaigns to exciting grants and initiatives, here's what we've been working on:

Launching the Stronger Together Campaign

During the end 2024 the trustees have been working on launching our [Stronger Together Campaign](#), aimed at raising awareness and fostering a sense of unity within the Sturge Weber UK community. So what is the Campaign ?

The [Stronger Together Campaign](#) is all about uniting the Sturge Weber UK (SWUK) community to make a lasting impact. By raising **at least £200 per year**, every member can help us fund vital research, provide essential support to families, help fund the family weekend and minimise cost to attendees, and raise awareness of Sturge-Weber syndrome.

With everyone's contribution—whether big or small—we can achieve remarkable things. Together, we are **Stronger Together**.

How You Can Help Raise £200

Here are six simple and effective ways to hit your £200 goal and support our mission:

1. Shop and Give for Free

Turn your everyday shopping into donations without spending an extra penny!

- **Easyfundraising:** Shop with your favorite retailers online, and they'll donate a percentage of your spend to Sturge Weber UK.
[Sign Up for Easyfundraising](#)
- **Give as you Live:** Raise funds by shopping online at thousands of stores. Simply sign up and start giving as you shop.
[Join Give as You Live](#)

2. Donate Instead of Sending Cards

- Make celebrations more meaningful with **Don't Send Me a Card**. Instead of sending traditional cards, send e-cards and donate the money you'd spend to Sturge Weber UK.
- [Send an E-Card Today](#)

3. Monthly Giving

Make a regular, meaningful contribution to SWUK by setting up a monthly donation. It's an easy way to spread your giving throughout the year.

Example:

- A monthly gift of just £17 adds up to over £200 annually.

Your monthly donations provide SWUK with a reliable income stream to fund research, grants, and family support services.

Set Up Monthly Giving

4. Facebook Fundraising

Use your social media to make a difference!

- Celebrate your birthday, anniversary, or a milestone by creating a fundraiser on Facebook.
- Share your story with friends and encourage them to contribute.

Start a Facebook Fundraiser

5. Donate via PayPal

Make a quick and secure donation to Sturge Weber UK through PayPal. It's fast, easy, and impactful.

[Donate via PayPal](#)

6. Fundraise Your Way

Get creative and organize your own fundraiser! There are countless ways to get involved:

- Host a bake sale or coffee morning.
- Take on a sponsored challenge like a walk, run, or cycle.
- Organise a sponsored walk, run, or cycle.
- Celebrate special occasions (birthdays, anniversaries) by asking for donations instead of gifts.
- Hold a quiz night, auction, or talent show.

Need ideas or resources? Download our fundraising pack to get started.

[Get Your Fundraising Pack](#)

7. Active in April

Join our annual **Active in April** challenge and get moving for a great cause!

How to Participate:

- Choose your activity—walk, run, cycle, or get creative!
- Set your target, such as walking 10,000 steps daily or cycling 50 miles in April.
- Create a fundraising page and ask for sponsorship from friends, family, and colleagues.

Every step, mile, or movement you make will help us get closer to our goals.

8. Match Funding

Double your fundraising impact! Many employers offer **match funding** programs to support their employees' charitable efforts.

How It Works:

- Ask your employer if they have a match funding scheme.
- They can match the money you raise through your fundraising efforts, instantly doubling your total!

Not sure how to ask your employer? Contact us, and we can provide a letter or information to help.

9. Engage Corporate Sponsors

Encourage local businesses to support Sturge Weber UK as part of their Corporate Social Responsibility (CSR) efforts.

Ways to Get Businesses Involved:

- Ask businesses to sponsor your fundraising event or activity.
- Invite them to join SWUK as a **corporate partner** or donate directly.
- Highlight their support on your social media or event materials.

Are you a business owner? Contact us to explore sponsorship opportunities with SWUK!

Learn About Corporate Partnerships

Your Impact: What £200 Can Do

Every £200 you raise helps us:

- **Fund vital research** into better treatments and therapies for Sturge-Weber syndrome.
- **Provide grants** to families for essential therapies and specialist equipment.
- **Deliver education and awareness programs** to improve diagnosis and care.
- **Offer emotional and practical support** to families navigating life with Sturge-Weber syndrome.

With everyone raising £200, we could reach an incredible **£50,000 in one year**. Imagine the difference we could make together!

How to Get Started

1. Pick one or more fundraising methods that suit you.
2. Set a goal to raise at least £200.
3. Share your progress and story with friends, family, and colleagues to rally their support.

Join the Stronger Together Campaign Now!

Need Help?

We're here to support you every step of the way. Get in touch for:

- Branded materials like posters, leaflets, and social media graphics.
- Ideas and advice for planning your fundraiser.
- Information on match funding and corporate sponsorship.

New Members-Only Section on Our Website

We're thrilled to announce the launch of a dedicated [Members-Only Section](#) on our website. This exclusive area provides access to additional resources, updates, and support tailored to your needs.

Key highlights include:

- **Family Weekend Booking Forms:** Now live! Secure your spot for this much-anticipated event through the members-only section. We look forward to welcoming our members to Leicester this year !
- **Exclusive Information:** Additional resources and guidance to support our members and their families.

Log in today to explore these exciting features!

Family Weekend 2025

Planning for our 2025 **Family Weekend** in Leicester is underway, and booking forms are now live on the members-only section of our website. We ask that booking forms be completed and returned to us by 14th February 2025. If you are having problems accessing the booking form please contact support@sturgeweber.org.uk

Aldi Port Wine Doll Campaign

Sturge Weber UK were pleased to see Aldi's range of inclusive dolls launched in October. The charity had an online campaign to ask the public to send as many dolls to us as possible, and we can confirm that we still have **40 dolls** which we are happy to send on to members. Thank you to all who supported this campaign

Also thank you to Alice Hourigan who modelled for Aldi and has raised much needed awareness of Sturge Weber Syndrome.

Back to School and College

As September rolled in, many of our members and their siblings returned to school and college. We wish you all a fantastic school year ahead and remind you that we're here to support you every step of the way.

Celebrating Success

We're delighted to share that **Sophie Impey** has successfully gained employment! Congratulations, Sophie—your achievement is an inspiration to us all.

Funding Updates

- **Benefact Group Grant:** We are pleased to announce that we've received a generous grant of **£1000** from the Benefact Group to support our ongoing initiatives.
- **Grants Applied For:** We've been working hard to apply for additional grants to ensure we can continue making a difference for our members.

Make a Difference Grant Scheme

The **Make a Difference Grant Scheme** is now open again!

Grant Categories:

Our Grant Program covers a variety of categories, including but not limited to:

Classes and activities for wellbeing

White goods

Sensory and Outdoor toys

Independent living post 21

Grant Amounts:

Grants are available in different amounts, ranging up to to £1000. The grant amount awarded will be determined based on the scope and impact of the proposed project.

Eligibility Criteria:

To be eligible for the Make a Difference Grant Program, members must meet the following criteria:

- Be a current, active member of Sturge Weber UK
- Have provided evidence of a diagnosis of Sturge Weber Syndrome
- Provide evidence of the grant required and the impact it has made.
- Agree to comply with requirements of Make a difference program.

Application Process:

1. Review Guidelines;

– Carefully review the Make a Difference Grant Guidelines to ensure your application meets the eligibility criteria.

2. Submit Application:

– Complete and submit the online grant application form by the specified deadline. Applications must include a detailed description, cost and link to items

3. Review Process:

– Our Grant Review Committee will evaluate all applications based on merit, feasibility, and alignment with our mission. The Grant panel will sit 4 times a year.

4. Notification:

– Successful applicants will be notified of their grant award. The charity will pay for the agreed item or service.

Grant Review Committee Meeting Dates:

Apply by: March 9th 2025, for decision date: April 23rd 2025.

Apply by: May 18th 2025, for decision date: July 2nd 2025.

Apply by: August 10th 2025, for decision date: September 24th 2025.

Apply by: October 12th 2025, for decision date: November 26th 2025.

Reporting Requirements:

Grant recipients must submit progress reports and a final report outlining the grant's impact. This information will be used to showcase the positive contributions of our members and inspire others.

Cuppa and Catchups 2025

Looking ahead to 2025, we're excited to continue our **Cuppa and Catchups** sessions. These virtual gatherings are a great way to connect with fellow members and share experiences in a relaxed setting. Another new feature of the members only part of the website is access to the Charity Calendar where you can see all upcoming Cuppa and Catchups !

Charity Shop Sale

Don't miss our [Charity Shop Sale](#)! It's a fantastic opportunity to find great bargains while supporting the vital work of Sturge Weber UK. Every purchase makes a difference.

Thank You to Our Fundraisers

We extend our heartfelt thanks to the incredible individuals who have raised money for Sturge Weber UK:

- **Bella Parsons** for her jewellery making and sales.
- **Marc Divers and friends** for completing their 3 Peak Challenge.
- **Becky Blount** for her 3 Peak Challenge.

Your efforts and dedication make a significant difference to our charity. Thank you!

Exciting Opportunity: Join Us as a Fundraising Trustee

We are thrilled to announce an exciting role opening up at Sturge Weber UK. We are looking for a **Fundraising Trustee** to join our team and help drive forward our mission. If you have a passion for fundraising and want to make a real difference, this could be the role for you!

For more information about the role and how to apply, please contact us at support@sturgeweber.org.uk