

Marie's June, July & August Update 2024

I hope all our members are having a wonderful summer and all happy, healthy, and are well. Here's an update into what the Trustees have been doing during June, July, and August: –

Family Weekend

The Hilton at Coventry have advised us that they are unable to secure our booking for 2nd to 5th May 2025 Family Weekend. As a result of this we are in the process of looking into another hotel which is based in Leicester which can meet the dates we require.

Carolyn and Marie will be attending the hotel in November to go through planning the next Family Weekend and ensuring that we are happy that they can meet the high standards we have for our members who attend and that the rooms satisfy what we know our families need.

They have 25 interconnecting rooms but also have 52 rooms which have two double beds in which would accommodate a family of 4. The hotel has a swimming pool and gym. Picture below of what they can offer.

We are hoping that after visiting the hotel we will be able to announce the confirmed date of the next Family Weekend and the location and that booking forms are live! Watch this space.

We welcome feedback from members as to how they want the family weekend to run. If you have any suggestions or are prepared to join a group of volunteers who are happy to help plan the weekend please get in touch.



Volunteers and Charity Champions

A piece of work was undertaken by Nicola Colenso at the Family Weekend to support the Trustees as we need more volunteers. Dan Grimes is awesome, but I think he is lonely and others could support him.

I would like to thank all members who completed an expression of interest form at the Family Weekend.

Looking at the expressions of interest we have received we have two groups of volunteers.

We are very excited to announce that we will be setting up a group of Charity Champions who will be members of our charity who have a diagnosis of Sturge Weber Syndrome and who live with it daily. The wealth of knowledge and experience that they have can do nothing but support the growth of the charity and focus on a huge part of what we as a charity stand for which is supporting our members who have a diagnosis of Sturge Weber Syndrome.

The other group of volunteers are parents, carers, family and friends of our members diagnosed with Sturge Weber Syndrome.

We welcome more applications for volunteers. Please visit the website if you are interested in applying.

For those that have expressed an interest! We will be in touch. There is lots of work we are doing in the background to create the right framework and job descriptions for our new two groups of volunteers.

We will be in touch to have a chat about what it is you want from volunteering for Sturge Weber UK soon.

The Trustees are really excited at this new development for the charity and thank Nicola for her support in drumming up the new group of volunteers which will mean our charity grows from strength to strength.

Trustee Meetings

The Trustees had a meeting 10th July 2024. It was a pleasure to welcome our new secretary Mike Grimes to the meeting. It is always nice to see the team of Trustees growing and see the team going from strength to strength. I would also like to thank Carolyn Burns for moving from the role she has held for years as Secretary of Sturge Weber UK to Treasurer.

The next Trustees meeting is on Wednesday 6th November. If you would like to raise anything for the Trustees to discuss, please email it through to support@sturgeweber.org.uk.

Fundraising and Thank You

Marc Divers and Team – for completing the 3 Peak Challenge



Becky Bount – 3 Peak Challenge 5th October 2024

Natasha - Wedding Donations

All those who donated to the raffle at the family weekend.

Sturge Weber Awareness Day 27th June 2024

It was lovely to read our members share stories on Sturge Weber Awareness Day. Well done Nicola Colenso for your tireless work sharing awareness internationally.

Well Done and get well soon

Amba Smith – for working on Same but Different with Jono Lancaster and featuring on ITV News #Awareness

Harper Matthews – for successfully starting school with a big smile on her face

Nikita Matthews and all the members who have supported her - in fighting for Harper's EHCP

Beth Wright – for winning the Amazon voucher from the Family Weekend

Well done on GCSE/A levels

To all our members congratulations on any exam results you may have received over the summer. We are proud of you all. Keep being the best version of you, you can be !

September Good Lucks

Good luck to all our members who are starting nursery, school or moving school or college. We are proud of you all.

Finally, an introduction and message from Mike Grimes

All about me

Hi everyone. By way of introduction, I am Mike Grimes, the new SW UK Secretary. I am invested in SW UK because as a SW UK Dad, I have seen the first-hand effects of what good support looks like - and I want other members to benefit from it too.

My eldest son has SW, and with him being in his early 20s, our wider family have been impacted by the condition since 2002, so I believe in the importance of being part of an organisation that can deliver meaningful support whether it be through grants, mutual support or through greater awareness.

I am inspired by our members, particularly those young adults who have shown us so much through their perseverance, their bravery and their strength of character.

I hope to add value to the team in any way that I can, and if any parents or carers would ever wish to chat, I will do my best to help you out where I can.

Did you know ?

Driving Lessons

Up to 40 hours of free [driving lessons](#) could be available for people claiming Personal Independence Payment (PIP) and [Disability Living Allowance](#) (DLA). Disability charity Motability is offering a Driving Lessons Grant Programme for people receiving higher or enhanced rates of benefits.

Up to 40 hours of lessons with an [instructor](#) are available, although beneficiaries will still have to pay for the [theory](#) and practical driving tests themselves.

The grant will cover the cost for disabled people who have a provisional licence and aim to learn to drive, while those who have a licence but require familiarisation lessons to get accustomed to newly adapted cars can benefit from the scheme too.

If you think you are eligible for a grant, please contact 0800 500 3186 and ask to apply for a Driving Lessons Grant. A case manager will be allocated to applicants to means-test applications to ensure eligibility, although this could take up to 10 weeks during busy periods.

Applicants need to also have a current lease agreement on the Motability Scheme or have a pending application for a vehicle on the Motability Scheme, with a confirmed date to receive delivery of the vehicle at some point within the next four months.

Radar Key

What is a Radar Key?

A RADAR Key is a large, silver-coloured skeleton key that opens more than 10,000 locked, disabled toilets in the UK. The RADAR key is part of the National Key Scheme (NKS), giving thousands of people with disabilities and health conditions independent access to locked public toilets around the country. The Radar Key Scheme enables these disabled toilets to be locked to prevent vandalism and misuse, while also being readily available to those who really need them.

The National Key Scheme Is Widespread

Radar toilets have been around since 1981 when the first one was opened. Now, over 400 local authorities in all parts of the country have adopted the scheme as well as many public, voluntary and commercial organisations such as shopping centres, pubs, cafés, department stores, country parks, railway and bus stations, airports, motorway service areas and sports venues. The Radar key scheme ensures that people who need to use accessible toilets don't have to ask someone else to open the door for them before they can have a wee! Because disabled people's toilets are big, private and less likely to be occupied, they are open to misuse by the public. The Radar Key Scheme enables these disabled toilets to be locked, to prevent vandalism and misuse.

Who Might Be Legitimately Using A Disabled People's Toilet?

Not all disabilities are visible or obvious to the onlooker so it is important not to be too quick to judge whether a person should or shouldn't be using the toilet for disabled people. There are a wide range of problems and conditions which may require a person to carry a RADAR key. Perhaps they cannot get up the stairs to the regular loo, they may be using a catheter, suffer from incontinence and be unable to queue or have some other, invisible ailment which requires the use of the disabled people's toilet. Anyone using a disabled people's toilet without legitimate reason should bear in mind that they may be unnecessarily preventing a disabled person from accessing vital facilities. This could lead to discomfort, distress or embarrassment.

Where to buy a RADAR key ?

Amazon - Age UK - Blue Badge Company - Argos