

March, April and May 2024 Update

I hope all our members are well. For those members who's children have taken exams over the last few months I hope that they have gone well and you are now looking forward to the summer.

Mother's Day Competition

The winner of the Mother's Day Competition was Chantelle Roberts. We hope that she has enjoyed her Ringtons's Tea Hamper.

Family Weekend

The Family Weekend was held at the Hilton DoubleTree Coventry from Friday 24th May to 27th May. It was yet again a huge success. I would like to thank Carolyn, Steve, Claire, Nicola, and Danny for all their hard work in helping plan and run the weekend.

The Friday was an informal start to the weekend, allowing families to settle into the hotel, have a meal in the restaurant, and then meet other families at leisure.

On Saturday morning, we discussed with members what the Trustees have been doing and discussed the need to expand the Volunteers we have. We had lunch and welcomed all members to the weekend. Saturday afternoon, we had a speaker from Sibbs who discussed ways in which to support the siblings. The adults with Sturge Weber Syndrome were invited to attend a meeting before the AGM where I went through the AGM information in an easy-to-read format.

We held the AGM and included members who were not in attendance who opted to join via Zoom.

After the afternoon session and AGM, there was free time and we met for an evening meal where there was entertainment and a disco. A raffle was held Thank you to all who donated gifts that helped make this a success.

On Sunday Helen from Contact ran sessions on Money Matters, EHCPs and wellbeing. A copy of the presentation is attached for all to view.

SOS Care were on hand over the weekend and ran a very successful activity club. The children who attended loved this and the feedback was that it was loved by all in attendance. Thanks again to Jayne Dainty and her staff at SOS Care for their support over the weekend.

Sunday evening followed a similar format to Saturday evening. Monday morning, we had a leisurely breakfast before we all said our goodbyes.

The shop was open throughout the weekend and brought in sales of £744.00. The raffle, auction and sale of the teddy brought in £1110.00.

Thank you to all members who attended the Family Weekend. The next one is planned to take place in May 2025. Booking forms will be available via the website.

AGM

The AGM pack was again emailed to all members the week before the AGM. This worked well again as it allowed the members to read the documents before the AGM and raise any questions they may have on the paperwork. This again helped the AGM run smoothly and timely.

The AGM was a success. The next AGM will run in May 2025. Please add a note to your diary as even if you are not at the family weekend you will be invited to attend via Zoom.

A copy of the minutes of the AGM are attached for members.

I am really pleased to welcome Mike Grimes to the team who was voted in as Secretary.

Chair

During the AGM I was voted in again in as Chair for a further 3 years.

New Treasurer

Carolyn Burns put herself forward to move into the role of Treasurer. She was voted in during the AGM and will serve for a further term of 3 years.

New Secretary

Mike Grimes has been voted in as Secretary. He was voted in during the AGM and will serve a further term of 3 years

Volunteer Recruitment

During the weekend Nicola did a fantastic job of encouraging members to show an expression of interest to become volunteers for the charity. If you completed the expressions of interest, we will be in touch soon.

New website

The new website was launched by Danny Grimes at the Family Weekend. Please go to www.sturgeweber.org.uk to see all the hard work Steve has done in updating the website. This has been a very large piece of work for Steve to undertake and we hope you like the look of the new website. Please feel free to feedback on this and also let us have pictures for us to add to the website.

Leaflet

A new leaflet was also launched at the family weekend. Printed versions are available should you want some posted please email support@sturgeweber.org.uk.

A PDF of the leaflet is attached with this update.

Friends of Sturge Weber UK

Moving forward we will be adding a section to the update from the Charity Champion and other volunteers.

Active In April

Active in April was a success this year raising £3255.00 for our charity. Lots of members participated in this again.

Thank you to all our members who participated and raised money on behalf of our Make a Difference Grant Scheme.

Make A Difference Gift applications NEW PROCESS

The panel who are to meet to discuss the Make a Difference Grant applications will meet in February, June and October. Please ensure any grant application which you want to be discussed are with the Trustees by the end of the month prior to the meetings.

Cuppa and a Catch-up

Cuppa and catch up dates for 2024

Friday 27th September at 12pm – for under 5s

Sunday 20th October at 10am – for all

Sunday 15th December at 3pm – for all to catch up before Christmas

Fundraising

Massive thank you to:

Sarah Leake and friends for their 3 Peaks Challenge which raised £2127.58
Sarah Leake for the Easter Raffle
Gemma Parsons, Antonia Cowan, Lydia McCusker, Hannah Griffiths, Sophie Impey, Angelina Mills for Active in April
Fred Sutton - £200 raised
Linda donation at family weekend
Ace Kelly for doing a half Marathon which raised £720.00
Kate O'Keeffe for raising £95 on Facebook
Lissa Startin for raising £186 on Facebook
Tammy Divers for raising £219 on Facebook.

Good Luck

Marc Divers has set himself the challenge of completing the Three Peaks Challenge on 7th September 2024 in under 24 hours. Good luck Marc and thank you for thinking of our charity and raising vital funds for us.

If you would like to support Marc please go to :-

[Marc Divers is fundraising for Sturge Weber UK \(justgiving.com\)](https://www.justgiving.com/MarcDivers)