

December 2023 January and February 2024 Update

30 years of being a registered Charity in England and Wales

The 27th of January 2024 was the day we celebrated 30 years being completed of us being a registered Charity in England and Wales. This is a fabulous achievement for the charity, and I would like to take this opportunity to thank new and old members and Trustees for all their support in achieving this.

Cody

It was with a very heavy heart we had to share on 22nd January 2024 the sad news that Cody had passed away at the age of 26. She will be sadly missed by all our members and our love and thoughts are sent to Mel, Gary, and family at this sad time.

Trustee Meetings

The Trustees had a face-to-face meeting in January at the Double Tree by Hilton. During this meeting we were joined by Nicola and undertook training. The result of this was we established that our Make a Difference Grant scheme process needed to be reviewed. As a result of this meeting the Make a Difference Grant was temporarily closed.

Discussions during training were :

Q - Who we are?

A- Support, Empowering, Family Weekend, Grants, Research, Medical Professionals, Signposting, Training Volunteers, Upskilling all, Collaboration and Referrals

Q - What do we do?

A - Advocacy, Empowering, Knowledge and Community

Q - Future/long term ideas

A - Sibling support, Parent/Carer Professional Day (Every 2 years), Sibling Weekend, Paid member of staff, Increase Public Awareness, Patronage (Famous) and Christmas Party

Q – Who do we support

A – Families although more focus needs to be on everything we do being for the person with a diagnosis of Sturge Weber being supported make every thing we do be person centred to members who have a diagnosis.

Following on from this training it was agreed that the Trustees will be using public page to announce things and the members only page would be just that. A safe environment for our members to ask questions and share experiences.

Mother's Day Competition

Mother's Day is just around the corner, to show our appreciation for our mums we are going to add names in to a hat and pick one lucky winner who will then receive a Ringston's Tea Hamper.

Family Weekend

As you are aware the Family Weekend booking forms are live on the website. [Family Weekend 2024 Application Form - Sturge Weber UK](#)

You can get your booking forms in now and the deposit is not due until 8th March 2024. If you are wanting to attend and need more time to settle the deposit, please do not let this stop you booking. Send your booking form in and speak to Trustees to see if we can help work around your situation.

The Family Weekend booking is well underway. We will be joined on Saturday afternoon by SIBS who will be doing a sibling's workshop and on Sunday by Contact who will be talking on:

Transition - Supporting children get ready for a new school year. Can be delivered suitable for all ages, or specifically for children from nursery to school age. This workshop can also be delivered for transition into adult services.

Educational support for school age children with additional needs in England Understand what support is available for your school aged child in educational settings (in England). Understand SEND provision and Education, Health, and Care (EHC) plans.

Money Matters An overview of benefits, DLA, Carers Allowance, grants available, discounts on utilities, leisure, discounts for carers. Accessing services for support with financial applications. Local information and helplines. Dispelling myths around benefits. Also covers Covid 19-related financial updates.

AGM

The AGM forms part of the Family Weekend and will be run on Saturday 25th May 2024 at 3pm. The Annual General Meeting (AGM) is an important event for Sturge Weber UK. It

provides an opportunity for you our members to gather, review Sturge Weber UK's activities, discuss key issues, and make decisions on important matters. During this year's AGM the position of Chair, Secretary and Treasurer are also up for election/re-election. Attached with this newsletter is:-

1. Notice of AGM
2. Notification of election or re-election of Chair
3. Job Description of Chair
4. Notification of election or re-election of Secretary
5. Job Description of Secretary
6. Notification of election or re-election of Treasurer
7. Job Description of Treasurer

Please keep an eye out for the Agenda and AGM Pack which will be sent to members 21 days prior to the AGM. Please take the time to read these and raise any questions on them prior to the AGM.

The AGM is also open to member who are not in attendance and if you wish to join via Zoom please email support@sturgeweber.org.uk to register your interest.

Please do not hesitate to contact the Trustees if you have any questions about the attached documentation.

New Treasurer

We announced in January that Antonia had stepped down from her role as Treasurer in December. I would like to thank Antonia for her support and time donated over many years to the charity. We are looking out for a new treasurer and attach the Treasurer job description and trustee application form.

New website

The new website is well under way, and we will be showcasing this to the members in attendance at the Family Weekend and it will go live after the AGM.

We need up to date pictures for the website and would appreciate members sending these in with consent for them to be used on the website, leaflets and social media. Thank you to the members who have already done this your support is appreciated.

Online store

There is a 50% sale on all blue clothing items in the online store. Please go to [BIRTHDAY SALE COMPLETION OF 30 FULL YEARS - NOW 50% OFF BLUE SHIRTS & BLUE HOODIES \(sturgeweber-store.org.uk\)](https://sturgeweber-store.org.uk)

Give as you live/Easyfundraising

Here are several reasons why signing up for Easyfundraising can be beneficial for our charity:

- 1 Free Fundraising: Easyfundraising provides a simple and free way to raise funds for us. Supporters can raise money for our cause without any additional cost to themselves.
2. Wide Range of Retailers: The platform has partnerships with a diverse range of retailers, including popular online stores. When supporters shop through Easyfundraising, a percentage of their purchase amount is donated to us.
3. Easy to Use: The platform is user-friendly and requires minimal effort from both us and our supporters. Once set up, supporters can continue shopping as usual, and the donations will be automatically generated.
4. No Additional Costs for Supporters: Supporters can contribute to your charity without spending any extra money. The donations come from the affiliate marketing fees paid by retailers to Easyfundraising.
5. Regular Payments: Easyfundraising processes payments on a regular basis, providing a steady stream of income for our charity.
6. Online and In-Store Purchases: Easyfundraising covers both online and in-store purchases, allowing your supporters flexibility in how they choose to shop and contribute.
7. Trackable Donations: The platform provides tools to track donations, making it transparent and easy to monitor the success of your fundraising efforts.

Join our supporters by clicking on the link and signing up to raise money for us
<https://www.easyfundraising.org.uk/causes/sturge-weber-uk>

Friends of Sturge Weber UK

Do you have time to volunteer for the charity? We are looking for people to volunteer and support us at the Family Weekend. Could you help the charity and other members by volunteering? If you would like to help and volunteer, please contact support@sturgeweber.org.uk.

Active In April

Active in April is BACK! We are challenging you, your friends and family to keep active in April by walking, jogging, running skating, cycling or swimming throughout the month the miles of your choice. The challenge is set for all ages and abilities, wheelchair users are welcome to join.

Sturge Weber UK has successfully completed 30 years as a registered charity in the UK in January 2024. We are challenging 100 people to commit to raise at least £30 on our behalf during the month of April.

Why 100 people? The more people who complete this challenge the more awareness of Sturge Weber Syndrome there is.

Kind donations made from Active in April will have a direct beneficial impact on children and adults diagnosed with Sturge Weber Syndrome and all monies raised will be added to our Make a Difference Grant Scheme Pot.

Please sign up to join us in fundraising for this by clicking on the link

[Active In April 2024 - JustGiving](#)

Make A Difference Gift applications NEW PROCESS

The Make a Difference Gift scheme has been reopened.

We are inviting our members to complete a Make A Difference Gift Application. There will be 3 dates per year when a panel meet to discuss the applications received. The dates the panel will meet will follow.

The panel will be made up of a Trustee (which will change each panel meeting), Nicola Colenso, Christine Bleasdale, Ingrid Grimes, and Sarah Impey.

The criteria for the Make A Difference Gift has changed.

Criteria

1. Currently reside in UK or Ireland
2. Aged 18 or over and a registered member of Sturge Weber UK
3. Parent or legal guardian or adult with a diagnosis of Sturge Weber Syndrome
4. Evidence of diagnosis needed.
5. Letter of support for items requested maybe needed

Categories:

- 1 Classes/Activities/Wellbeing - £500
- 2 White Goods - £350
- 3 Sensory Toys/Outdoor Equipment - £500
- 4 Independent living +21-year-olds - £1000
- 5 Other - £500

Agreement/Expectations

Anyone applying for a gift will need to write an impact statement and will need to agree that they will provide 3, 6, 9, 12 and 18 month reports back to the charity on the impact the item received via the grant has had for the person with Sturge Weber Syndrome.

There is also an expectation that a news article and promotion on social media and our website will be required. In certain circumstances it may be agreed with the trustees and grant panel that this may be waived.

Cuppa and a Catch up

Cuppa and Catch up dates for 2024

Friday 15th March at 12pm – for under 5s

Sunday 28th April at 10am – for all

Friday 21st June at 12pm – for under 5s

Sunday 7th July at 10am – for all

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

Awareness raised by members

Massive shout out to everyone on the amount of awareness raised over the last 3 months.

Thank you to Lily Young for appearing on BBC One Show turning on her local hospital's Christmas Tree Lights.

Thank you to Ashton Bears for raising awareness for us by adding our logo to their open age lads' kits and collecting club fines for the season and sharing the proceeds with our charity and Multiple System Atrophy Trust.

Fundraising

Massive thank you to:

Danny Grimes for his Santa Dash

In memory of Pamela Joan New deceased

Donation from Roy Metcalfe

W H Smiths donation arranged by Sharon Appleyard

Gemma Niemiro for raising money at her Christmas Market

Jeanette Tinsley for collecting from Ms Dot Grier a donation

Don't Send Me A Card

Don't forget we have an account with Don't send me a card. The donation you make for a card to be sent comes to Sturge Weber UK.

<https://www.dontsendmeacard.com/ecards/charities/sturge-weber-uk>

If anyone has an ideas or suggestions, feel free to contact us at support@sturgeweber.org.uk

