



JON SHAW FOUNDATION

SUPPORTING Young people with Epilepsy. PROMOTING Awareness of SUDEP. IMPROVING Mental Health of Bereaved Siblings.

Jon Shaw Foundation – charity number 1189073

December 2023 Newsletter

New Recipients

Since our September newsletter, we have donated 28 monitors (including, Embrace 2, SAMi-3 kits, and Pulse Companion). We have also donated 11 safety pillows to young people living with epilepsy. We have also been able to organise and fund bereavement counselling for two young men. We love to hear from families and it is lovely for our supporters to read about the importance of the contribution they have made and the impact it is having on families who need us.



This is Mayson, his epilepsy stems from a brain injury he suffered when he was 15 months old. We received the Medpage mp5v2 monitor and it has been a great help so far. It has put us at ease at night time as we will be alerted to any seizure activity and we can view the monitor from anywhere on our phones. It has given us hope that one day Mayson will be able to go back into his own room.

This is Sayujya who has complex epilepsy, mum has been sleeping with her to keep her safe. The camera has made a huge difference to their lives as it detects seizures so quickly Sayujya is able to be in her own room without someone there and explore what it means to be an independent teenager.



This is Jacob, he has complex medical conditions and has seizures daytime and night time. With the SAMi Cam. I am notified if there is activity during the night so he will be able to start sleeping in his own room again like his sibling. I can not thank you enough for giving Jacob some independence.



This is Abigail, she has a very rare genetic condition pgap1, type one diabetes and myoclonic jerks, but has a smile on her face daily and is a very determined little girl. She has not had a full night's settled sleep since 6 months old, she is now 7. As never got to the bottom of night time issues. We are really hoping that SAMi 3 will give us the answers we need. So thank you all very, very much for your very kind donation of the epilepsy monitor.



This is Finnley, he is 4 years old, his seizures place him at a high risk of SUDEP we have been so relieved to receive the alarm which alerts us to a change in his heart rate. The peace of mind it has given our whole family is immeasurable, now my husband and I can finally sleep knowing we have a backup.

Jon Shaw Foundation Headlines

New Recipients

Fundraising reports

Support Group

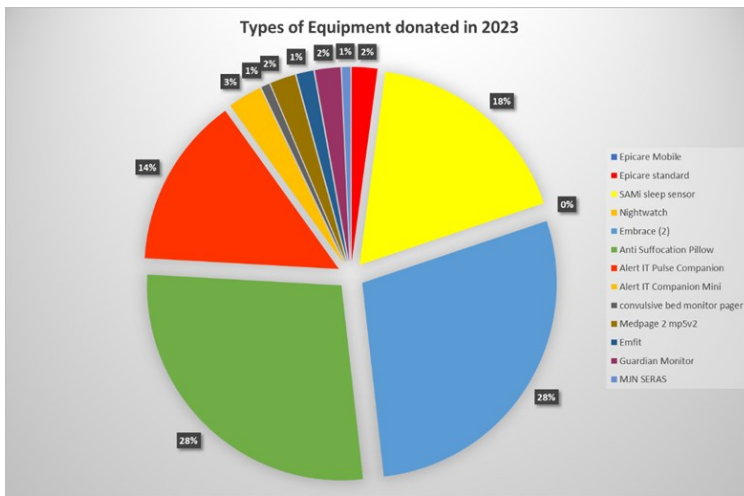
New sponsor

Thank you

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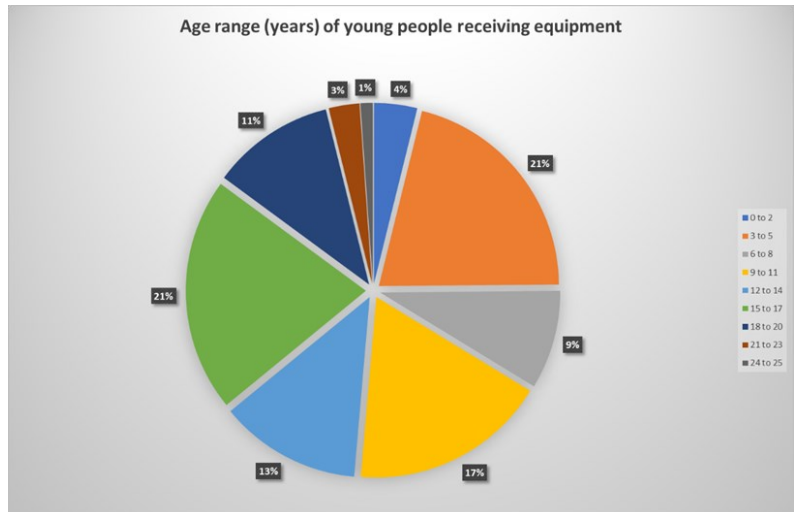
Message from Wendy Shaw—Founder of Jon Shaw Foundation



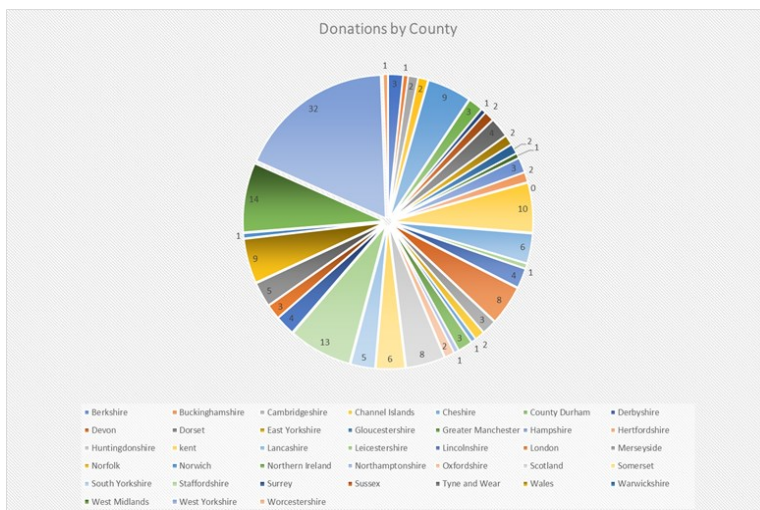
2023 was a busy year for Jon Shaw Foundation, we donated 120 monitors, and 33 safety pillows. We know that we are reaching our further, to more families than ever, and receiving referrals from a number of health authorities and other agencies around the country. It is lovely when we have feedback from some of our families and great for all our supporters to read about the equipment they have helped to fund through their events.

We have also been able to support a number of bereaved siblings and friends, we had a referral from one of our local schools for two young children

who were struggling to come to terms with the sudden death of their friend. Their struggles were having an impact on their learning, hopefully the counselling sessions we were able to fund will help them. Other referrals have arrived from North Wales and Staffordshire, these were young men who had lost, a brother to SUDEP, and a friend who lost his life to knife crime. We support bereaved siblings and close friends what ever the cause of death, illness, trauma, suicide etc.



There have been quite a few large fundraising events during the year, many of them have been organised by families and their friends. Which again is helping us to promote awareness of epilepsy and its risks, as well as our Foundation and the work we do. Local businesses have continued to support us in many ways, donating prizes, offering discounted services, sponsoring fundraising events and providing venues for our events. We are determined not to let anyone go without the support they need with either epilepsy or bereavement and with your support we are working hard to achieve that.

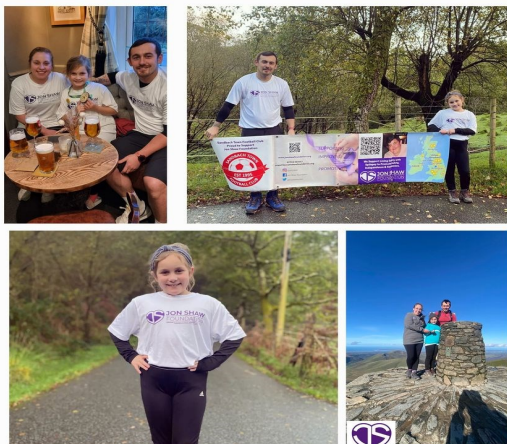


We are looking forward to what 2024 brings and would love to continue working closely with you all, we couldn't do what we do without your help. We wish you all the very best of health, wealth and happiness for 2024. Be kind to one another and treasure every single moment with your loved ones.

Thank you

Wendy Shaw

Olivia conquers Ty Wyddfa for Jon Shaw



On 22 October 8 year old Olivia climbed Ty Wyddfa (Snowdon) to raise money and awareness of epilepsy, supported by her mum, Sam and dad, Mike, they smashed it in 2 hours and 25 minutes. She raised a fantastic £1671.25. Well done Olivia and team and thank you. She wrote us a beautiful letter a few weeks ago to let us know how happy she was to have raised funds to help families affected by epilepsy and bereavement. What a star she is.

Team White Lion walk from Chester to Crewe



On 8 October Jackie, Dave and a team of regulars from the White Lion Pub Warmingham Road in Crewe set off on a 27 mile walk from Chester to Crewe. They were amazing, willingly putting themselves through the pain, the blisters and more to help us reach the young people who need our support. **The team raised a total £3060!** We thank you on behalf of all the families we will help because of you.

Christmas Fair at The White Lion



We had a lovely day at the Christmas Fair, lots of wonderful stalls selling anything from cakes to candles. Special thanks to Jackie for handing the pub over to us, to Robina for baking everything for the stall and donating all takings to us, and to Roz for running the Tombola and organising and massively contributing to the beautiful Christmas Hamper. All your support has raised **(after costs) £1420.41**. Smashing job everyone.

Black Tie Charity Christmas Ball 2 December

What a fantastic night we all had, welcomed to the evening by our guest lounge singer Matt Corrigan, who performed free of charge and he was fabulous, (hope he is available for next year) The room looked great thanks in part to the lighting very generously supplied by VME UK Ltd, thank you. Thank you to the photographer Ryan Brown, J36 Photography, who gave us 2 hours of his time, Everyone looked stunning and all had a really good time. Thank you to Clive White who paid tribute to his son Jonathan, who they sadly lost to SUDEP, The family made a donation of £2830 in his memory. The night was a great success and we raised £6183 (after all costs) Bring on 7 December 2024, we will do it all again, at Cranage Hall.





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Epilepsy Support Group West Yorkshire



Our support group for families living with epilepsy will start again in the new year. Unfortunately we couldn't continue at the previous venue, however Lauren and team have been working hard to find new accommodation. They are investigating a couple of options and looking forward to welcoming everyone back to the group again. It is open to all families living with epilepsy, refreshments will be available and there will be visiting speakers throughout the year. More details will appear on our Facebook page www.facebook.com/jonshaw19 and on our website. www.jonshawfoundation.org

Our Fundraising during 2023 has been extremely successful, thanks to all the organisers, and local businesses who sponsored or donated to our events.

Chester to Crewe Walk Thank you to Mikro Coaches Crewe for providing free transport.

Christmas Fair Thank you to everyone who donated to the hampers, Nakatchas, Cheerbrook Farm Shop, COOP and many more.

Black Tie Ball Thank you to ... Arriva Traincare, Blue Planet Aquarium, Bulls Head Mottram, Christina Quine Artist, City Varieties Music Hall Leeds, Dorothy Clive Gardens, David Jackson, Tony-Drink or Draw, The Lovely Little Chocolate Company, Venture Studios, Panama Hattys, White Lion Weston, Crewe Hall, Gilligan Family, Lorraine Wilby, Nick Mitchell and anyone I have not listed (so sorry) for your support with the Grand Draw. Thanks again to VME UK Ltd, for the lighting, Matt Corrigan for your fabulous singing and to Ryan Brown for the gorgeous photographs.

New Sponsor

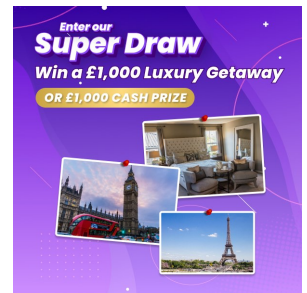
We would like to thank Cartridge People.com for their very generous support by providing us with the ink we need for our in-house printing. As you can imagine we use large amounts for our publications, correspondence and posters, and can cost quite a lot of money. Our aim is always to use our funds to directly support young people and now Cartridge People have agreed to supply our ink we don't have to allocate a budget to cover this expense. Follow the link to their website. [Cheap Printer Ink Cartridges and Toner from Cartridge People](http://www.cartridgepeople.com)



Thank you to our sponsor Mitchell Plant Repairs, who has been with us from the start, for your continued support. [Facebook](#)



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