



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 2022 Newsletter

Supporting Young People

Since our last Newsletter in September we have donated 16 alarms/monitors and 3 safety pillows to support young people living with epilepsy and their families. We still have a number of families waiting for the Nightwatch to become available, unfortunately these monitors will not be imported to the UK until at least the middle of 2023. As soon as they are, we will buy a number of units so that we can get them to our families quickly. Can I remind you that you can access a discount of 22% on safety pillows if you order through our website. www.jonshawfoundation.org/support-we-offer. We have been able extend support for one of our bereaved siblings, we had some amazing feedback from the counsellor about how well the young girl was progressing. It was felt that she would benefit from further sessions We and fortunately we were able to fund these.

Families Supporting JSF

It is lovely when families give us feedback as well as letting people know what difference we are making, it also helps us to improve our support for other families. We really enjoy receiving photographs of the young people we help too. We have been promised some more which we will share on social media. A special thank you comes when families continue to support us through fundraising. Some of our families subscribe to our weekly lottery, and one family, Martin, his mum Margarita Aija, and grandma Ljubov have been busy making Christmas Gingerbread and selling it to raise funds for us for a second year. I was lucky enough to get some and I can honestly say it is the best I have ever tasted. They raised an amazing £210, which is almost the cost of an embrace monitor. Well done all of you.

Martin, Margarita and Ljubov and their Christmas Gingerbread



Jon Shaw Foundation Headlines

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Message from the Founder

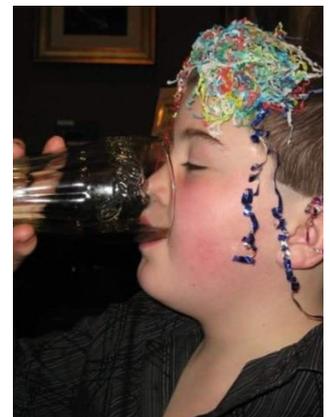
JSF Siblings & Friends Facebook Page.

Black Tie and Sparkle 2022

Meeting Santa / Quiz night

Christmas Lights

Thank you.



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Message from Wendy Shaw—Founder of Jon Shaw Foundation



What a year we have had, we have extended our reach across the UK as far as the channel Islands, supporting families from Guernsey and Isle of White. Every week we are asked to provide equipment to at least one family and in most cases we are able to provide full funding. We are working with more suppliers and discussing best deals, we have also been working with a supplier in the USA, they provide monitoring equipment including cameras which aren't available from any UK suppliers. I am hoping to discuss our charity with the CEO at some point in the New Year.

I have represented JSF at a number of meetings and discussions, including the All Party Parliamentary Group for Epilepsy where we discuss key issues being faced by families living with epilepsy, improving care and medication. We also attended the board meeting of the National Institute for Health and Care Excellence (NICE) where the priorities for improvements

to care of those living with epilepsy were discussed.

I was invited, as Chair of JSF, to a Community tea by local MP Kieran Mullan, here I had the opportunity to learn how other volunteer groups are helping the community and promote the support we offer to the epilepsy and bereaved communities.

I would like to welcome David Jackson, he has agreed to become a Trustee responsible for researching and developing General Data Protection Regulations (GDPR) for Charities.

I would like to thank the many local businesses who have supported our charity over 2022, we have had many donations to our raffles and fundraisers and hope we can rely upon their support again in 2023. More details of our supporters are published at the end of the Newsletter.

Finally on behalf of the Trustees, I would like to wish you all a happy, safe and healthy New Year.

JSF Siblings and Friends Facebook Page



<https://www.facebook.com/groups/1031318454424905/>

Hannah Holt and Matthew Shaw, two of our Trustees have an understanding of loss of siblings and good friends. Both are keen to build our support for young people. If you know anyone who has lost a sibling or friend and would benefit from meeting other young people tell them about the Facebook group.

Plans are being finalised for our regular Coffee Mornings at Wishing Well, Millhouse Bistro in Nantwich and the first social which will be paintballing, details will follow shortly on the Facebook group (link above).

Charity Christmas Black Tie Ball

Once again we had a wonderful evening at our ball at Crewe Hall, Cheshire. Everyone donned their sparkles, brushed off the tuxedos, and looked fantastic. We were lucky enough to have some really lovely prizes for our Grand Draw which helped raise our total amount. The Golden Ticket proved popular again with some really stiff competition to win, also boosting our fundraising. I would like to thank Martin and Emma Pitchforth, who joined us from Yorkshire. Sadly they became involved with JSF after their lovely son, Ollie passed in July aged only 11. I thought they were really brave supporting us and allowing me to mention them and their family in the opening speech. Thank you to Pat O'Brien who manned the card reader again during the evening (I run away from this particular technology). Thank you to Sarah Parker

for coordinating the arrangements and the team on the night for looking after us. We are just waiting for £1200 pledged for the Golden Envelope but including that, we raised an astonishing £8275.75, this amount will enable us to help many more young people. I have to give a special thanks to The Gilligan Family for their extreme generosity and special thanks also to our friend Nick Mitchell who once again offered us outstanding support and generosity to make the night a success. I am humbled by the support we get from individuals like these. Thank you to David Jackson who couldn't make it this year but donated £500 towards seats and prizes. I must also thank those who won, prizes and donated them straight back, Steve Holt who won the lucky ticket prize and donated his £50 winnings. David and Dorothy Jones donated the £300 raised when they auctioned the Crewe Alex Shirt. Amazing people, amazing. Thank you to Alex who took all the photos during the



The kids enjoyed Christmas Fun and got to meet Santa

As a thank you for the support from local families, Jackie Stubbs at The White Lion helped us to hold an afternoon of fun for the little ones. They were able to try their hand at crafts with Gill, and lots entered the "decorate a tree" competition, won by Page. They could have their faces painted eat candyfloss and popcorn, cakes and nibbles and of course for the younger ones there was a chance to have a chat with Santa. The youngsters seemed to enjoy themselves, we were all exhausted but they had fun which is the main thing. The same evening we held a Christmas quiz, just for fun and to get into the Festive spirit, all teams won a bottle of Prosecco, which were all donated by The White Lion, thank you again Jackie for your continuing support.





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Christmas Lights display supporting Jon Shaw Foundation

A huge thank you to Maria Conno, a resident on Merlin Way Crewe. She enjoys decorating her garden for Christmas, to bring pleasure and festive spirit to families in the local area and beyond. This year after speaking with Roz and Billie she decided to ask for donations on behalf of Jon Shaw Foundation. She had a collection bottle and set up a crowdfunding page. She was also interviewed by the local press and Radio Stoke where she very kindly promoted awareness of our charity. Her lights display was switched on between 5pm and 8pm nightly and over the few weeks they were lit she managed to raise a total of £84.75, enough to buy two safety pillows. Well done Maria, much appreciated.



Thank you for all your support

There are so many businesses and individuals to thank this year, I hope not to forget anyone. First, thank you to a great friend of JSF, **Roz Marsland** who, with the help of Billie, organized the Christmas Hamper Raffle, It was a fabulous luxury hamper, then she went on to contact what seemed like hundreds of local businesses, requesting donations for the prize draw. If it hadn't been for the efforts of Roz, we wouldn't have been able to offer most of the prizes. We all appreciate the hard work you do for JSF. Thank you to **Billie**, who designed our 2022 Christmas Card, featuring Jonnie Robin. Thank you to Sam Bebbington and **Crewe & Nantwich Round Table** who donated £1200 towards the support of young people. Thank you to **Steph of Flossies Weddings** who, donated money for the table decorations at our Christmas ball.

There were many businesses who contributed to our Christmas hamper and Grand Prize draw, thanks go to:-

COOP on Parkers Road, **Cheerbrook Farm Shop**, Tesco Extra Crewe, **Grants Butchers**, Dorothy Clive Gardens, **Snugburys**, Bears Paw Warmingham, **Cod'n'All chippy**, Sandy Lane Tea rooms, **Furry Faces**, Panama Hatty's **Hickory's Smokehouse**, **Crewe and Wilmslow**, Ginger & Pickles, **Bloom & Wild**, Rydale Pharmacy, **Bluebell Florist**, Bridgemere Garden Centre, **Firebird Photography**, Farmfoods, Crewe, **Jackie, The White Lion**, Mrs. Darlington's, **Lowes Farm Shop**, Mornflake, **Bulls Head Mottram**, Rex Cinema Wilmslow, **Michelle, Beyoutiful Sandbach**, Man City (Paul) **Crewe Alex**, The Gilligan family, **Nick Mitchell**.

Ways you can help us

We rely totally on donations fundraising events and a number of online avenues. Some of the online methods are listed on the right. The weekly lottery is growing, you can sign up using the link, it costs £1 per week, you can win a weekly cash prize, or the One Lottery group jackpot of £25,000 or regular bonus prizes. You can earn money by shopping on Amazon Smile and selecting Jon Shaw Foundation as your charity, or shopping online with your favourite retailers through the Easyfundraising App. Both so simple and free to use.



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